

Commitment to Carers – Understanding Carers’ Experiences of the Hospital Discharge Process

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Funding provided courtesy of the Commitment to Carers Programme, Experience of Care Team, NHS England. This project, managed by Care City, is part of over 40 Trust Discharge projects intended to improve our understanding and develop best practice around involving, listening to and valuing carer voices in hospital discharge processes. This work forms part of our NHS Long Term Plan deliverables.



Executive Summary

This work has been hampered by COVID-19 in two ways:

- It has not been possible to get into Whipps Cross Hospital to access carers experiencing discharge directly.
- Organisations supporting carers are strained and disrupted by the aftermath of COVID-19 and have struggled to engage as much as they would like.

This has delayed our work, but not pushed it off course. We believe we have learnt a great deal from the carers we have spoken with, and our work will continue.

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Our focus has been interviewing carers to understand their experiences of discharge, and how they might be improved. In the following report, we chronicle three of those stories in detail, to provide some reference points for the following synthesis of all the stories we have

heard. When discharge goes well, these stories can seem very simple. However, little problems in the first day or so can seriously hamper discharge, and problems can compound. We have been working to better understand this dynamic.

We believe that part of the context for this dynamic is the well-evidenced, well-intentioned view that patients should 'leave hospital as soon as they are medically optimised for discharge'. This is based on:

- COVID-19 and the need for system recovery
- Discharge evidence and practice

On the whole, this is clearly beneficial for patients. However, for some carers, whose home situation is more complex, it does seem to raise some challenges, placing an even greater premium on the quality of support they receive.

In particular, carers talked to us about a set of issues that can create risks for a successful discharge. These relate to:

- Carers and families
- Housing and finance
- Paid social care
- Concerns about exploitation

There are a set of insights in the report that follows about these challenges, and the kind of support that might make a difference.

The first principle of NHSE&I's campaign to reduce long stays in hospital is 'plan for discharge from the start'. The focus of this is setting clinical, therapeutic and functional criteria for discharge and an expected date of discharge at the earliest opportunity.

Our work suggests that the moment would also be a good moment:

- To identify carers and plan for good communication with those carers
- To think about the non-clinical criteria for a successful discharge if relevant

Once staff have connected with carers, the stories we have heard suggest there are some key things to get right. Around discharge, carers need from hospitals **communication**, **education** and **support**:



Communication

Carers need to be kept closely informed about patients' condition, location and the timeline for their discharge. They need to be part of planning for discharge and to be helped to prepare for discharge, practically and psychologically. Although the prevailing view is 'think 'Why not home? Why not today?' every day', surprises – even positive surprises – can be difficult and expensive for carers to react to quickly enough to support discharge.



Education

At the practical level, there are skills and pieces of information that carers want to learn to support the patient, and there are clearly opportunities to do more to identify these resources where they exist, fill any gaps and provide them in a user-friendly way to carers. We will continue to work on this area with Barts Health.



Support

For some, this is about connecting to wider communities and support groups – as some carers we spoke to have done. However, it can also start with a good, honest conversation with a clinician. When these conversations are at their best, they are about listening to carers' wishes and feelings but also actively coaching and negotiating with carers about what is best for the patient. This is skilled, challenging work, and this should play into the wider conversations at Barts Health about staff training and development.

There is a clear set of next steps for this work:

- Consider this report
- Continue the work
- Build in to Ticket Home work
- Connect to broader work on supporting discharge, building on NHSE&I guidance to consider discharge from the moment of admission
- Strengthen relationships to carers organisations and related third sector organisations

Method / Process

Our original project plan had two phases:

- Interview carers with experience of discharge at Whipps Cross.
- Build on what we learn from these interviews to shape a set of next steps and products, which we can co-design with a subset of the carers we have spoken with.

Due to some Covid-related challenges, we have completed the first phase of this work not the second. We have spent our time trying to access family members, friends and unpaid carers to discover what experiences they have had with the discharge process for their loved ones. We have been able to interview 14 carers with experiences of discharge and to interview 9 staff members across the NHS, social care and third sector organisations.

We believe that the work has been extremely helpful and productive, and are committed to completing the work using additional time. We will use the insights we have gathered from this work to create a set of outputs we describe below, and to feed into the wider work on discharge, including the Ticket Home work.

We have struggled to get access to carers for two reasons:

- Infection control continues to mean that access to hospitals both for relatives and friends and for researchers is very restricted.
- Carers organisations and other related third sector organisations have been hit hard by COVID-19 and its aftermath, and they might have struggled to engage with us in the kind of sustained way that might have wished.

Initially we planned to concentrate on carers who had experienced discharge from Whipps Cross. In March, the project team decided to expand our information gathering across East London to gain more insights.

We have contacted over 40 local organisations that covered the Whipps Cross Catchment area asking for support with the project, following up intensively with phone calls and using social media. Organisations that have been actively involved with the project have included:

- Teams from Whipps Cross Hospital
- Carers First (Waltham Forest)
- Carers of Barking and Dagenham
- Age UK Walthamstow
- Waltham Forest Integrated Supported Discharge Hub

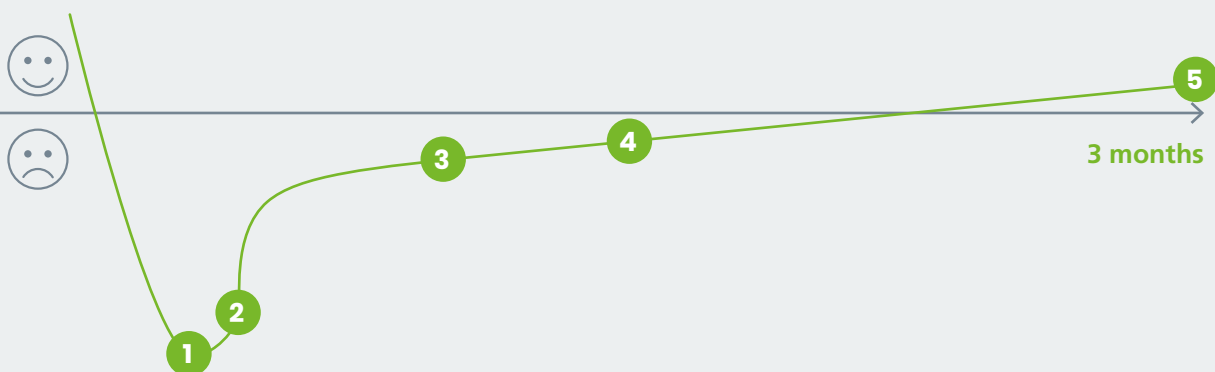
Naturally, given what we have been able to do, we are focused in this report on the stories we have heard from carers and on learning from them. The next section, on key findings, begins by relaying in detail three stories we heard from carers, which represent well many of the themes and issues we want to draw out.

Key Findings

When discharge works well, the stories are simple

Mary, 95

Very active and resilient person.



- 1** Mary falls at home and is found by her daughter. An ambulance is called and she is admitted to Whipps Cross with a hairline hip fracture.
- 2** Mary is discharged by 11 am next morning with a 5-week care package, Zimmer and pain killers. Ambulance let patient in and waited for her daughter-in-law to arrive. Shortly after, her carer arrives.
- 3** In 2014 Mary had broken her leg so she got out the exercises she was given and started to follow them.
- 4** Mary has 3 sessions of physio and is invited to attend a Falls Clinic at Whipps Cross. She receives a snack, lunch and leaflets.
- 5** Mary has recovered her full mobility. However, she has lost confidence about being alone outside, including her garden.

However, problems can easily compound

Gloria, 85

Lives alone. Uses a wheelchair, but able to walk short distances and use the toilet independently.



- 1 A fall sees Gloria admitted to Whipps Cross Hospital.
- 2 The family are told that Gloria will move to a Rehabilitation Unit when a bed is available.
- 3 Her daughter works away from home and is worried about what will happen if plans change.
- 4 Her daughter has been contacted to say Gloria is being discharged home. There is no food and the storage heaters mean that her flat will take 24 hours to warm up.
- 5 Doctor tells her daughter that they have seen Gloria walk 8m on the Ward. Her daughter says she has not done this for years and the doctor concedes they have not seen this, but say it is in Gloria's notes.
- 6 A hospital bed is delivered to Gloria's flat, but they cannot gain access as her daughter had removed the key from the safe for security. The agency is cross, but for this reason Gloria is not discharged.
- 7 Two further attempts are made to discharge Gloria. Her daughter has power of attorney and is not happy because one carer visit per day means that her Mum would have to wear incontinence pads simply due to lack of care staff.
- 8
- 9 A care package is agreed for two care staff, four times each day.
- 10 However, Gloria catches pneumonia and then cannot be discharged.
- 11 While Gloria was able to recover physically, her mental state had deteriorated and she had become confused.
- 12 Gloria is eventually discharged with the agreed care package. However, her daughter believes the extended stay in hospital has had a lasting effect on her health.

The stories can quickly become complex and difficult

Sakina, 89

Very independent woman, enjoying an active social life.



- 1** Sakina falls in the bath and is found by her neighbour. An ambulance is called and she is admitted to Whipps Cross Hospital.
- 2** Her brother says 'yes' to a hospital bed being upstairs, but he is unaware to what extent his sister's mobility has deteriorated. Sakina needs support to stand and can walk a few steps with a frame.
- 3** Her brother and his wife are told two carers will come to help her to the bed. One carer comes and cannot help. At 10.30 pm they manage 'perilously' to help Sakina upstairs.
- 4** The next day, Sakina is up and washed, and sat in a chair in an empty room with nothing to occupy her. Her brother finds a bag of pills, unopened. A local voluntary organisation phones Integrated Care to ask for support about moving the bed downstairs as being confined upstairs meant she was totally isolated.
- 5** A bed and Zimmer arrive for downstairs, but the bed bleeps endlessly and Sakina decides to brave the stairs.
- 6** Sakina falls and breaks her hip. She is readmitted to Whipps Cross.
- 7** Sakina receives surgery for her broken hip.
- 8** Her brother finds out Sakina has been moved to a local Care Centre.
- 9** Sakina is unable to get out of bed, has no TV and can't reach the radio. She is told by staff to use pads rather than the toilet.
- 10** Sakina is moved to a Community Rehabilitation Unit. Her family is unable to see her due to not having booked an appointment.
- 11** The family are asked to come in to discuss discharge. A meeting is agreed for for the beginning of March.
- 12** Sakina is readmitted to Whipps Cross. Her brother is not informed by either organisation that Sakina had been readmitted.
- 13** Virtual meeting with Whipps Cross. Family is astonished that an iPad is available on each ward and someone could have been available to do puzzles with Sakina.
- 14** Sakina is transferred to a care home. Family are given 30 minutes notice. She remains confused.

It is right to begin thinking about our findings by looking at carers' stories of discharge as they have been told to us. As the three examples suggest, when discharge goes well, the stories are relatively simple. However, when something does not work quite so well, the story rapidly becomes more complicated. Often the initial problem is far from insurmountable – practical and short-term issues that can be fixed. However, the effects can compound and become serious. This very simple trend repeated often in the stories we heard.

It is easy to conclude from stories like these that *life is just messy* and improvement is difficult. However, we have been thinking hard about why we have seen this kind of pattern in the stories carers have told us, and what might be done about it.

First, we are conscious of two elements of the current context for these stories:

- COVID-19 and Recovery
- Discharge evidence and practice

In relation to COVID-19 and NHS Recovery, it is more important than ever to support timely discharge for patients. Being in hospital carries an extra risk of COVID-19 infection. At the same time, there is greater pressure on the system from patient demand, and significant determination to clear the elective backlog.

At the same time, it is in patients' interests to be discharged as soon as possible.

“ The discharge to assess model is built on evidence that the most effective way to support people is to ensure they are discharged safely when they are clinically ready, with timely and appropriate recovery support if needed. An assessment of longer-term or end of life care needs should take place once they have reached a point of recovery, where it is possible to make an accurate assessment of their longer-term needs. ”

From Hospital discharge and community support guidance 31 March 2022

There is now very strong research to show both that the effects of being in a hospital bed on measures such as muscle mass can be measured in hours rather than days. At the same time, the background to Discharge to Assess is that – in general – if we assess patients at home, we will see capabilities and resources that enable independence that were not visible in hospital.

For the average person, discharging them as soon as they are clinically ready is in their interest and in everybody's interest. However, what about those people who are not very average – whose lives are more complex? For these people, the supports and safeguards that go alongside discharging when clinically ready are particularly important.

We believe that our work has:

- Helped to highlight some helpful examples of the kinds of social complexity that generate greater risks for discharge, which are often associated with having a carer.
- Suggested some possible responses, to manage these risks and support patients and their carers.

Thinking about carers, social complexity and risks to discharge, the stories we have heard have helped us to understand the range of issues carers may have to be dealing with:



Carers and families

- Carers know the person they care for better than anyone, and are rightly at the heart of decisions about their care. However, a significant stay in hospital can rapidly change the needs and capabilities of loved ones. Around hospital discharge, therefore, carers have to participate in conversations about next steps while learning about and processing potentially life-changing shifts. This is difficult for both hospital and carer, because the carer needs to be listened to and helped to understand the latest situation. For example, in Sakina's story, her brother needed more information about her mobility in order to advise where best to place her bed.
- Carers feel huge commitment to play a role in supporting discharge, and often anxiety about understanding what they need to do and fulfilling this role. This anxiety can very quickly turn to guilt and further destabilise the home situation without the right support. For example, we spoke to one carer whose loved one had developed a pressure sore, and who through interactions with health and care staff around this felt significant shame.
- We also spoke to carers of patients who were part of family and friendship relationships in which they were caring for others as well as being cared for. This creates complex interdependencies that can be affected by discharge decisions in ways that it is difficult for assessments to fully capture, which was a further source of risk.



Housing and finance

- When a patient is discharged, there may be a lot to fix quickly about their home. For example, they need a warm house, with hot running water and food. For some carers, getting this organised quickly enough has been a challenge. These challenges seem to be compounded where carers have less money and economic power. They cannot spend the extra money to travel or fix things urgently and they can find it hard, for example, to get time off work. In Gloria's story, for example, her daughter was stuck working away from home and could not return in time.
- Housing can also be a more long-term problem. Damp, air quality, trip hazards and so on may have contributed to the initial hospitalisation, and may pose ongoing risks to health. Crucially, while care needs are often identified in hospital, this does not mean that they were triggered by the reason for admission. Hospital is a place where people with unmet needs are spotted, but this can complicate discharge.



Paid social care

- Carers are often working in collaboration with paid social care staff to support patients on discharge from hospital. In the few weeks following discharge, the effects of the more general challenges facing home care can affect patients and carers significantly. Carers talked to us about the challenges and risks created by care staff arriving very late, staying for very little time or simply not arriving.
- One issue that carers spoke to us about, was toileting and continence pads. This was part of Gloria's story, but she was not alone in being told to use continence pads as an alternative to having support to reach the toilet, often being left for large parts of the day in this situation. Because this is so at odds with patients' and carers' sense of what dignity requires, they will likely battle to get to the toilet themselves, creating falls and other risks.



Exploitation

Exploitation is a very different kind of issue, with which both health and care staff – and patients and carers – have to deal:

- On the one hand, we heard from a carer whose family member had seen the locks in her house changed by other family members during her hospital stay. This was part of a move to resist discharge home and seek control of the property. While this is shocking, London property is so valuable that the stakes for family have never been higher.
- At the same time, in Gloria's story, health and care staff are clearly anxious about exploitation because a key has been removed from the safe, although this has been done for the best of reasons.



Conclusion – Synthesis

We have also been thinking about some possible responses, to manage these risks and support patients and their carers.

Some of the challenges relating to discharge are primarily related to what happens beyond the hospital:

- Hospitals have always been a key site for identifying unmet need, and amid austerity, rising costs and possible recession, this may become a more significant challenge for all discharges. This is a wider issue for the integrated care system.
- We also highlight in this report some possible challenges relating to reablement and homecare, which are primarily for local authorities but which have increasing impact on the ICS as a whole.

However, there is a great deal that hospitals may be able to do to support carers and patients in relation to discharge.

The first principle of NHSE&I's campaign to reduce long stays in hospital is 'plan for discharge from the start'. The focus of this is setting clinical, therapeutic and functional criteria for discharge and an expected date of discharge at the earliest opportunity.

Our work suggests that the moment would also be a good moment:

- To identify carers and plan for good communication with those carers
- Think about the non-clinical criteria for a successful discharge if relevant

Once staff have connected with carers, the stories we have heard suggest there are some key things to get right. Around discharge, carers need from hospitals **communication, education** and **support**.

Staff and carers alike have emphasised to us repeatedly that **communication** is of paramount importance. We heard from carers who felt that they had not been informed when their loved ones had moved ward or institution or when the timeline for their discharge had changed. We equally heard from carers who had not understood key features of their time in hospital. For example, in Sakina's story, the family had not understood that they could have used an iPad to video call with Sakina.

Part of the value of communication is enabling carers to prepare for and visualise discharge.

Part of the value of communication is enabling carers to prepare for and visualise discharge. Perhaps in contrast, the NHSE&I campaign says to staff, 'think 'Why not home? Why not today?' every day'. Clearly, this is well-evidenced and well-intentioned and staff will clearly understand what is meant. However, it may be

helpful to note that, for carers – when a discharge has some complexity and the hospital stay has been relatively long – having a clear indication of the day that a patient is to be discharged to give the carer time to plan, has huge benefits. Where it happens, it significantly increases the premium on the quality of communication, education and support that can associate a discharge. As a general rule, surprises – even good ones – can be tough for carers in the first 1-2 days, particularly so for less advantaged ones. And as we know, discharges can fail in a matter of minutes and hours.

Education is vitally important. At the practical level, there are skills and pieces of information that carers want to learn to support the patient, and there are clearly opportunities to do more to identify these resources where they exist, fill any gaps and provide them in a user-friendly way to carers. We will continue to work on this area with Barts Health.

At a deeper level, carers – with patients – are often also trying to quickly come to terms with life-changing events, in a way that enables them to help discharge and recuperation.

At a deeper level, carers – with patients – are often also trying to quickly come to terms with life-changing events, in a way that enables them to help discharge and recuperation. This takes **support**. For some, this is about connecting to wider communities and support groups – as some carers we spoke to have done. However, it can also start with a good, honest conversation with a clinician. When these conversations are at their best, they are about listening to carers’ wishes and feelings but also actively

coaching and negotiating with carers about what is best for the patient. This is skilled, challenging work, and this should play into the wider conversations at Barts Health about staff training and development.

Perhaps a difficult element of this support, given all the pressures on the system, is time. As the NHSE&I campaign begins by saying, ‘it’s much better for a patient’s physical and mental wellbeing to leave hospital as soon as they are medically optimised for discharge’. However, this also arguably places a greater premium on the support that goes alongside this discharge, and this support takes time.

It may also be worth Barts Health reflecting on the challenges that the very many third sector organisations relevant to carers face, and considering what more it can do strengthen relationships across this network.



Conclusions – Next Steps

The next steps for this work are clear:

- Barts Health need an opportunity to consider this report. They will be able to reflect both on some of the wider messages for the system as a whole and on some of the specific opportunities to improve carers' experiences of discharge. In particular, there are opportunities for Barts Health to consider what more they can do to give all carers at discharge the communication, education and support that they need.
- As a mission-led, community-interest company, Care City will use some of its own time to continue its work with Barts Health on this agenda, to deliver on the original ambition to translate these insights into practical tools to support communication with and education of carers.
- Care City will also work with Barts Health colleagues to make sense of these stories and findings in the wider context of the Ticket Home work. We hope to include carers very explicitly in the Ticket Home process and tools, building clearly on this report.
- More generally, as Barts Health digests and acts on advice from NHSE&I about supporting discharge – referred to above – it will want to bear in mind the insights and recommendations from this work.
- Building on this work, Barts Health may also want to share this report with the organisations we have been in touch with, and to work directly with them to monitor progress in carers' experiences of discharge.

Barts Health and Care City





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