

Involvement of carers in acute secondary care patient discharge

**Report of engagement activity
January – April 2022**

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Abbreviations

D2A	Discharge to Assess
LPA	Lasting Power of Attorney
MPOA	Medical Power of Attorney
NHS	National Health Service
UHS	University Hospital Southampton NHS Foundation Trust
VLE	Virtual Learning Environment

1 Executive summary

Our 'carers involvement in discharge processes' project was designed to investigate how carers are currently brought in during the planning of discharge, assess how carers would ultimately like to be involved, and then action how we can move forward to achieve the most pressing aims set by carers.

From January to March 2022, UHS invited carers of patients under the care of the Trust to inform the Experience of Care Team of how they are presently, and how they would like to be, involved in planning discharges from the trust for patients under their care. This was promoted with posters around the hospital building, as well as through electronic communications, social media and a dedicated section on the UHS website.

A second survey was launched to allow for Trust staff to anonymously share their experiences of engaging with carers prior to discharge, as well as express their views on carer involvement in planning for discharges.

The Experience of Care Team also conducted one-to-one and group meetings with carers that volunteered to speak to the team to discuss their experiences in greater depth, and therefore allow us to gain a greater insight into carer involvement in discharge processes.

From this initial research, we learnt that communication and involvement were key themes that carers wanted addressing in order to be improved. This formed the foundation of our Carers Listening Lunch at the start of April 2022 where we invited carers that were signed up through UHS communications, as well as carers in the community, to attend and share their experiences.

Our engagement opportunities presented key themes and learning points that we needed to address:

- Greater advocacy for our patients and carers, including a singular point of contact where questions can be asked
- More questions to be asked of the carer, including whether they are able and willing to care for the patient and what their support needs are
- Improvement of the existing training for staff on carers, including greater promotion of the training packages available
- Identification of carers and their wellbeing by healthcare services

Following a detailed review of the feedback given to us through the surveys, the one-to-one meetings and the Carers Listening Lunch, we synthesised the learning that we had obtained so far in the process in order to draw conclusions on what we had obtained. This then formed our next steps moving forward, which we will adopt as a carers strategy.

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The Experience of Care Team of UHSFT would like to take this opportunity to thank all the individual carers and staff members that supported and engaged with the project in some way.

We are particularly grateful to individuals that assisted us by completion of the surveys, and to those who engaged with our team and had their say as part of our focus groups or one-to-one meetings, to allow us to better understand their experiences.

We would further like to thank all those who assisted with the promotion of our project, through sharing the online surveys or engagement opportunities through social media accounts, website updates and any other means.

2 Methodology

For patients who are medically fit to return home, the D2A (Discharge to Assess) process supports Trusts in deciding appropriate pathways for patients which can lead to faster discharge. Following evaluations by Healthwatch and Carers UK, it was found that this process isn't working everywhere and in response we decided to explore carer involvement in discharge further. Our main objective was to review how carers are involved in patient discharge, as well as how they are supported in their caring role and how communication can be improved between the Trust, carers and partner organisations.

We were able to recruit a part-time carer engagement officer using the money sourced via this bid who initiated the project at the end of December 2021.

Our project focused heavily around the views and experiences of carers, with a staff review running alongside. We decided to use a variety of methods to obtain this feedback, which included:

- Surveys – both patient/carer and staff survey
- One to one interviews
- Public event – Carers Listening Lunch in partnership with Carers in Southampton.
- Partner meetings with Complex Discharge Team, Carers in Southampton, Solent NHS Trust, Southampton City Council and Southern Health NHS Foundation Trust.

The primary method for obtaining feedback from carers was using an anonymous survey containing approximately 50 questions. This was shared with our carers registered through the Hidden Disability (Sunflower Lanyard) Scheme hosted by the Patient Support Hub. A total of 331 carers were contacted (191 via email and 140 by letter with paper survey). We also contacted 59 charities and organisations with services in Hampshire. We shared the project details and why we were looking to expand engagement of the project. From the 59 charities contacted, only two responded informing us they had distributed the survey amongst carers registered with their services. Finally, we used Trust and team social media platforms to promote the survey, which included Facebook, Twitter and Instagram.

Through engagement with Carers in Southampton and our Complex Discharge Team we agreed to hold a carers listening lunch to encourage open conversations with carers and patients. A total of 19 carers and patients were in attendance. Key aims of the event was to explore two key themes; involvement and communication. Four questions were posed to the audience to discuss in small groups.

1. What are the useful questions for carers to be asked? When should these be asked?
2. What information is useful for carers to have prior to patient discharge?
3. What does a 'gold standard' experience look like?
4. How much carer involvement would be ideal in patient discharge?

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Our staff survey contained 13 questions, which was promoted to via online internal platform, Workplace, as well as weekly Staff newsletter. Our advertisement was viewed 672 times via the Trust social media channels and the survey was completed 24 times, suggesting a 3.57% completion rate. Within this number of staff it does include administrative staff, some of which may have decided it was not appropriate for them to respond to the survey.

3 Key project findings

The engagement work we have conducted has successfully delivered the findings of a carer and staff survey, one-to-one interviews with carers, and a Carers Listening Lunch, whilst the Patient Support Hub have been developing quick actions that help carers with immediate support. The outcome of these opportunities were measured by obtaining new information that was yet to be discussed with the Experience of Care Team, as well as whether new ideas and feedback was given to allow us to develop our response to the report. Upon reflection, we were pleased at the way the timeline of events we had originally planned was well adhered to, allowing us sufficient opportunity between engagement events to review what was said and plan appropriate and meaningful questions based off of the evidence of the previous opportunity for the next.

Since the start of the pandemic, the Patient Support Hub have been offering carers and patients the chance to self-refer to their hidden disability scheme, collecting information about the carer and/or patient and producing personalised sunflower lanyards to act as an identifier for staff to ask anyone wearing one of these lanyards *'how can I help you today? Do you need any assistance?'*. Following the launch of this scheme, 409 carers and 405 patients have registered, helping to raise awareness around the Trust and in the wider community. These cards prevent the need for repeated challenging conversations for patients and carers and define how staff can help them to best meet their needs.

A quote from a carer signed up to our scheme: *'However, I can say that being a member of the Sunflower Lanyard Scheme has made a huge difference to both myself and my wife [...] since it has allowed me to accompany her and support her on hospital appointments (both consultations and treatments) during Covid restrictions.'*

In addition, the Patient Support Hub are in the process of developing a carers passport, linking with carers Southampton etc, to ensure carers are assessed and receiving support from services linking with support groups run by the trust. The carers lead role will become a point of contact, with regular calls to the carers of current inpatients by the Patient Support Hub to ensure carer wellbeing and offer help and assistance (if needed) from our volunteers and other services. The Patient Support Hub will also offer an open desk to support the Citizens Advice Bureau, Carers in Southampton etc. to have an on-site presence and encourage conversations. Whilst also working with the Occupational Health team to highlight staff carers and give them the support they need, allowing work with employee relations to improve support for staff carers in the trust (flexible holidays etc), carers support and counselling services focused on preparing the carer towards end of life.

Our carers strategy details three carer objectives; identifying carers, access to resources and support in a timely manner and working collaboratively with partner and carers. Our review of the data and information gained through our surveys,

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interviews and event verifies that further actions need to be undertaken to improve the experience for carers.

The introduction of a carers lead role once more will offer a single point of contact for all carers with any questions about their cared for either in hospital or in the community, as well as acting as a vector to signpost carers to services in the community run by local charities and organisations. Our engagement opportunities also suggested that whilst carers appreciate having the sunflower lanyards from the Patient Support Hub, there are questions over updates and how valid the cards are, highlighting the need to review what support is listed for carers and what more we can do to assist carers around the hospital.

From our engagement activities with carers and staff, we were able to ask questions about how carers have viewed their experiences and what feedback they had to offer about these, as well as looking into what they have found frustrating with the discharge process and what obstacles carers had faced during the planning stages. We could then compare the answers submitted by carers to those from staff members at the Trust to see where they are clear areas from staff and carers where we need to improve.

We were pleased to find that of the 331 carers contacted with regards to the survey, 61 (18%) responded by survey completion or email. From this, we found:

- Three-quarters of our patients had a 'successful discharge'
- Over half of respondents (57%) 'agree' or 'strongly agree' that they were able to balance their needs with the needs of their patient
- Almost all of the respondents (98%) say it is 'important' or 'very important' that carers are identified through health services
- Over half of respondents (51%) that wanted an in-person meeting with the healthcare team prior to patient discharge were able to meet face-to-face
- Less than one-third (31%) 'agree' or 'strongly agree' that they were supported during the discharge planning stages
- Only 32% of respondents 'agree' or 'strongly agree' that the needs of the carer were considered during the planning of discharge

Our staff survey confirmed that further staff engagement is necessary in improving carer experience. We received responses from staff across a wide range of departments, and the key highlights include:

- 39% of staff believe carers are 'always' or 'very often' involved in decisions when the patient is discharged
- Over half of respondents believe the carer is 'always' or 'very often' involved in decisions for the patient, and carers are contacted prior to patient discharge in order to discuss the needs of the patient.
- 43% of staff believe the carer is 'always' or 'very often' made aware of any changes to the level of support that the patient will receive at home prior to discharge

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- Only 4% of staff recall that they have completed the carer aware training available via the VLE
- 22% of staff believe the carer is 'always' or 'very often' signposted to key and relevant services to minimise caring disruption

Three carers agreed to be interviewed which gave us detailed insight into their experiences, which have been included in detail in Appendices A to C. From these interviews, some of the more common findings are that:

- There is the need for more communication between departments and between hospital and carer – lots of mixed messaging and inconsistency depending on who is spoken to
- Clinical setting needs to become more accessible for the general public, updating information about the staff on the ward and who everyone is (i.e. uniform colours, what their role is, etc)
- There is a lack of consideration of the needs of the carer and their ability to care, something that needs to be addressed to maximise the level of care for the patient upon discharge
- An increasing need for awareness of community projects and charities that are able to offer assistance and help to carers in need, with the aim of reducing the struggles faced by carers
- Carers desire the ability to be able to 'take a break', and this is something that should be bridged by healthcare staff to ensure that carers are aware they can step away if that is desired

Carers informed us that communication between clinical staff and the carer has been poor, and in some cases non-existent. Communication can come from arranging discharge processes to informing a registered carer what actions are being taken and updates about the wellbeing of the cared for – this is particularly more important when some carers are registered as LPA or MPOA, meaning that they have a significantly larger role to play in the medical decisions of the patient.

The fact that communication is such a significant part of the conversations that we've had surrounding patient discharge and carer involvement, regrettably most of it being in a negative light, shows that it is something that the carers who have patients under the Trust feel strongly about.

We decided to delve deeper into this theme at our listening lunch, focusing primarily on the themes of communication and involvement that had been recurring in the majority of responses in the survey and the interviews. Full details about the responses obtained at the event are available in Appendix D; however, key findings are included below:

- Carers should be asked if they have the ability to provide, and to continue to provide, care to the patient, and whether they are willing to still do so
- Greater detail about the discharge process should be provided and made accessible in different ways, including electronically and hard copies, without significant amounts of medical jargon to aid in understanding

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- There is the need for a single point of contact for carers to be able to contact via a dedicated phone line in order to have their questions answered
- Maximise the opportunity for patient-centred holistic care to ensure all the needs are met
- Carers should be involved at a level that they wish to be, rather than presumed to want to be fully involved, and these conversations need to be had prior to patient discharge to ensure the wellbeing of all parties involved.

The findings that we have obtained from the surveys, interviews and workshop ensure that we can focus on developing a carers strategy for implementation over the next three years that can improve involvement in discharge planning. In addition to this, the work that the Patient Support Hub are completing goes to great lengths to introduce a sense of holistic care to both patients and carers at the Trust, promoting ways of carers being identified and improving the signposting to services in the community.

It is clear that some of the quick actions already being taken by the Patient Support Hub are effective in helping and assisting carers, with over 400 carers actively signing up to the scheme since the start of the pandemic. The impact of the work we undertake in response to the report will be measured as part of the 2025 review on carers strategy, potentially in a survey similar to that used for the start of this project, where we will look to see an increase in carer satisfaction and accomplishment of some of the points raised by carers during this study.

We were pleased that the engagement events were run and concluded in accordance with our initial timeline, and that we were able to find additional time to host our in-person Carers Listening Lunch. This ensured that there was sufficient time to review the findings of one piece of engagement work before beginning the next, guaranteeing that as we went into each new engagement opportunity, the questions we asked and the findings we were looking for were in line with what carers had previously suggested.

With the carers strategy that we will introduce up to the end of 2025, the aim is that we will improve involvement for all carers that have patients under the care of UHS, regardless of whether it is an emergency admission or if it is an elective planned admission. In line with the expected changes that are currently passing through Parliament at the time of writing in the Health and Care Bill, we will introduce guidance and measures to ensure that carers are involved in discussions in advance of patient discharge.

4 Review synthesis

With an estimated 52,500 carers living in Southampton alone, there was an appreciation going into the project that the findings of our report would have significant impacts across our catchment^[1,2,3]. Considering the widespread implications of our study, we wanted to focus on the impact of Covid-19, carers involvement and their preferences in discharge.

When we initiated the project, we expected to see that issues with carers involvement were present, with a range of themes and topics contributing to the issues. Our preliminary research prior to engagement opportunities suggested that communication was one of the main issues; however, we didn't expect that communication would be such a prominent issue that carers want addressed. In addition, it was a surprise to see such a low completion rate for the carer aware training available on the VLE, something that will be pushed as a result of this study.

Alongside the existing work of the Patient Support Hub and both the carer and the patient strategy, this report will help to improve the quality of discharge experienced, specifically those that have carers. Our patients, with their consent, will have their carers involved from the earliest opportunity, ideally in the first 12 hours following admission. This target would ensure that we are engaging with the carer at the start of the patient's care to not only increase the efficiency of discharge, but also to ensure that the carer is kept involved if the cared for is admitted to the hospital as an inpatient and to establish a point of contact.

New guidance will be introduced to ensure that a member of the hospital team will speak to the patient, or next of kin where appropriate, to enquire about a carer being involved in the patient's care and whether the carer should be contacted. In addition, we will include a section on talking to carers as part of the training package for staff to ensure that the questions that are asked are appropriate and relevant, but also to guarantee that staff are taking the correct information away from their conversations and taking account of the concerns and knowledge of carers.

From this project, we have gained a great understanding of what good involvement for carers looks like during the processes of patient discharge. We have seen that carers would like to be asked more about their cared for, as well as asked about their ability and willingness to continue their caring role. In addition, carers have suggested it is important to be able to offer additional support from healthcare services to ensure that the carer is being well looked after and can maintain their livelihoods whilst caring.

This project has indicated that, as a Trust, we have taken steps forward in bridging any issues with inequalities and diversity. For instance, the profound impact of the sunflower lanyard scheme on the awareness of carers and patients with hidden disabilities, and the feedback that we have heard from carers, has shown that the effects have been significant. However, the learning has also highlighted that we

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must continue to work to do more and giving carers the ability to confidently advocate for the patient is one area we are going to implement with our carers lead. As well as the sunflower lanyard, the Patient Support Hub looks to introduce patient and carer passports, creating one document to hand to healthcare professionals that gives all the essential information upon admission. This will then be extended to 'crisis planning', to ensure that there is a plan in place for the cared for in the event that the carer is admitted to hospital.

The findings that we have gained from this report will be shared locally with our Hampshire and Isle of Wight Carers Network meeting, where we will be able to share details of our findings with local trusts and carers groups to promote this further. With the report being submitted to the wider NHS England team, we hope that our learning will be more widely available and distributed to acute secondary care trusts across the country to help benefit patients and their carers.

5 Next steps

Our next steps focus on four main areas – staff involvement, communication, carer involvement and patient involvement. As part of our plan to action improvements following the learning of this project, we have put together a three-year action plan to December 2025, where a further report will be conducted to review the progress made towards our actions. Our main targets are as follows:

Staff Involvement

- Develop training package for staff – to include carer aware training (already available but to be promoted or made a requirement), support for staff in how to involve carers and reasonable adjustments
- Look to develop an element for NHS Professionals training for individuals working in clinical settings, such as Healthcare Assistants

Communication

- Patient Support Hub to develop carers passport which will allow carers to provide details of the support they and the person they care for require.
- Carers lead to undertake review of all carers registered with UHS to offer support and advice
- Point of contact for carers to call with regards to any questions or concerns that carers have and signposting services.

Carer Involvement

- Introduction of renewed guidance for discharge, including questions about carer capacity and willingness to care for the patient
- Renew awareness of the sunflower lanyard scheme amongst staff and carers, highlighting the importance of the scheme
- Develop links with community partner organisations to enhance relationships and cross service working
- Production of a carer passport that informs healthcare staff about the carer's role and how they help the patient

Patient Involvement

- Consultation with the patient upon admission on whether they have a carer, and their preference for care following hospital discharge where required
- Increase conversations between staff members and patient to ensure maximum transparency is available
- Development of a patient passport to have one document that conveys all important information to healthcare staff without the need to ask

Each year, at a time set out in the carers strategy, a review of the strategy will be conducted to determine whether the points with an expired deadline have been completed, or whether a greater emphasis is needed on being able to achieve the part.

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By December 2025, a review paper on the carers strategy should be published assessing whether the parts have been achieved. This will be measured in three stages: whether the part is yet to be implemented/currently being implemented, whether the part has been fully implemented but no clear results have been obtained yet, and whether the part has successfully made the change it was intending to. A survey of carers, much like the one conducted for this report, should also be conducted as part of the 2025 report to gain an understanding of how the changes we have made impacts carers. We would also be keen to discuss the progress made by December 2025 with our carers, potentially with the use of one-to-one meetings and a Carers Listening Lunch, to see how the changes we make will benefit them in their caring roles.

Upon publication of the December 2025 report, it will be shared through our social media channels, staff networks and on the UHS website to ensure that it is promoted to as wide of an audience as possible. We will assess the benefits of the work we have implemented as part of the strategy and discuss how best we can move forward to continue to make inroads to improve carer experience in patient discharge.

6 Reflection

Since the pandemic, this has been the first involvement project we have been able to meet face to face with patients and the public. Over the last two years we have found that the public has become fatigued with virtual involvement but this allowed us to build relationships and increase our membership. Carers were engaged and having the opportunity to be at the centre of discussions was well received. Following our listening lunch we found that four carers swapped contact details to support each other in their carers role.

Partners in attendance also found the event beneficial and allowed them to learn and engage about other services not previously aware of.

The results of this piece of work will be far reaching as our Complex Discharge Team will also be using the information collected to form their strategy and the Trust's Quality Priorities.

7 References

¹ *Health and Care Bill*. HL Bill 2021-22 132.

² Carers UK. *Facts & figures*. Available from: <https://www.carersuk.org/news-and-campaigns/press-releases/facts-and-figures> [Accessed 01 February 2022].

³ Hampshire County Council. *Population statistics*. Available from: <https://www.hants.gov.uk/landplanningandenvironment/facts-figures/population> [Accessed 01 February 2022].

⁴ Southampton City Council. *Southampton Strategic Assessment: Population size and structure*. Southampton City Council, 2021.

⁵ *Health and Care Bill*. HL Bill 2021-22 145.

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Appendix A: One-to-one meeting with Carer A

How involved was the carer whilst the cared for was in hospital?

Carer A described how they were the transport for the patient during admission and the primary discharge, describing it as an “absolute nightmare” due to the circumstances surrounding the patient. The cared for was detailed as having no strength to get through the main entrance due to their condition, struggled with their mobility, and struggled with retention of heat. One of the major issues Carer A outlined was the lack of access to wheelchairs, and the distance that the wheelchairs are from the nearest car park. This would result in one of two scenarios: the patient was dropped-off at the drop-off point, wheeled inside and left so that the carer could return the car to the car park and make their way into the hospital; or the patient would wait in the car whilst the carer went to get a wheelchair, bring it back to the car and then take the patient to the main entrance.

When the patient was undergoing investigations, Carer A described the importance of their attendance with the patient. The cared for was often anxious at the thought of having to go for a test without knowing what specifically was being investigated, and the carer described how they became the eyes, ears and mobility for the patient due to a sensory overload with all that was going on. The carer further commented on the need to be aware of where the bathrooms are and how to access these.

Carer A was very complementary of the guide volunteers that were “strategically placed” around the site, saying that the help they provided was “invaluable”. At UHSFT, volunteers have been deployed under the title of ‘Guides’. These volunteers are positioned around the Trust in order to help navigate patients, carers and their families to the correct location for their appointment. In addition to the guides, and in response to the outbreak of the SARS-CoV-2 pandemic and the visiting restrictions that were in place, the Patient Support Hub was responsible for setting up a companion service. Like the guides, they can take people around the hospital to the correct location but are also ‘booked’ to be with the patient for the duration of their outpatient appointment, albeit without entering the appointment themselves. From discussions, both with Carer A and in telephone conversations, both guides and companions have provided a critical service to patients and their carers in response to the pandemic.

When the cared for was admitted into hospital, the carer took on a lot of the responsibilities for caring for the patient on the ward. Carer A described that they had no medical skills but considering the pressures on the nursing staff and the time limits they had, the carer would help with general comfort care, such as plumping pillows, changing bed linen or getting certain items. The carer commented that “all the nursing team have time to do is administer medication”, and whilst the carer puts their help down as giving 100% support, love and care, it is important to note that some of these responsibilities should’ve been completed by Trust staff. Despite the pressures of the pandemic experience, more needs to be done to give nursing staff

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time to care for their patients and their needs, rather than being time-restricted to only administer medication.

Discharge involvement

Discharge for the cared for in the first case study was heavily driven by the patient's desire to get back home, although Carer A remarked about a lack of clarity in the process. Neither the patient, nor the carer, was told what the process of discharge from hospital was, and what to expect whilst arrangements were finalised. It was not clear what updates would be provided, when these updates would come, what medication would be needed and more generally what the processes around discharging a patient were; however, Carer A did comment on a consensus being reached over when to discharge the patient, allowing for a time and date to be selected that would mean a wider range of services would be available.

Despite a lack of communication over the processes surrounding discharge, Carer A praised the consultant for the clarity provided to the carer and the patient's family over the circumstances the patient was experiencing. The carer described how they asked the consultant to relay information to the family that had just arrived from overseas and described how it was "very helpful" for the consultant to discuss this one-to-one with the family. However, the carer did comment on the "paper exercise" feel of the discussions, where the consultant would make a comment, and then it would be passed through several channels rather than being direct.

Issues became apparent when the carer was discussing their experiences of discharge from UHSFT, describing their belief that statistics had a role to play in how the cared for was discharged. Carer A described how, when the patient was ready to be discharged, they were moved to a "broom cupboard" with a table for the nurse to lean on and two chairs. They described how it was extremely warm and cramped, with no space for belongings and the impression that they had to get off of the ward as they needed the beds for other patients. There was also a lack of communication with regards to the drugs that the cared for required, with the carer waiting three hours to receive painkillers from the pharmacy. After a discussion with the discharge team, the patient was allowed to leave hospital with the carer staying to collect the prescription, but this introduced more hurdles due to the arrangements of transporting the patient to their discharge address. Carer A described the event as introducing "too many hurdles, making life too difficult", highlighting the need to streamline the discharge processes.

Personal consideration

When Carer A was asked about the accommodation and consideration of their personal needs in their caring capacity, they mentioned that they were asked who they were and their relationship to the patient, but there was no additional consideration of needs or support. The carer also added that they were unaware that community support was available, and that awareness about this wasn't raised until after their caring responsibilities had changed.

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However, commendation was paid to the cleaners who would engage and interact with the carer to make them feel more welcome in the hospital environment, as well as the courteous touches of being offered a hot cup of tea, which helped improve the times they were sat in hospital.

Recommended improvements

Throughout the case study, various recommendations were made by Carer A. The most prevalent was the need to improve communication between hospital and carer in order to provide continuity of care, as well as to provide information about what is going on. Carer A also mentioned about additional forewarning of what is going to happen and when it will happen, allowing for the appropriate adjustments to be made to ease the transition for the patient.

Carer A also mentioned about having the ability to take a break from their caring responsibilities or being able to go outside with the patient. The carer commented on the difficulty of being able to manage pushing a wheelchair with a hot drink and other personal belongings, suggesting that a simple clip-on cup holder for the wheelchair could be good to help. Carer A further mentioned that a quiet place to go and sit to have a conversation with the cared for, or even just for a moment of reflection, would be greatly appreciated.

One final key improvement Carer A discussed was about the need for improving the way conversations are conducted. They mentioned that they felt uncomfortable about sharing personal details in a space so public, such as the name and address, as well as contact number and other personal information. Carer A remarked that sharing this in public made it feel like anyone could have been listening to the conversation, and therefore wanted to put forward a suggestion to improve the awareness surrounding conversations and personal information.

Other discussions

Carer A mentioned that staffing information on the wards needs reviewing and updating more regularly, as the carer found themselves approaching ward staff to ask to speak to a certain staff member, only to be told they don't work here. The carer also mentioned the need to provide additional information about the uniform colours to family and carers, as well as the patient. These details would help to ensure the carer or family member know who best to talk to in the event that they are needed.

Carer A further discussed a second discharge from UHSFT to Countess Mountbatten Hospice. There was no discussion between the hospital trust and the carer about a discharge to CMB, and it was the consultant that said a hospice would be a better place for the patient than the hospital, with the carer remarking that it was as if the "hospital had come to its cycle in terms of what could be done, and therefore the comfort and availability of what could be done would be in the patient's favour". When the patient arrived at CMB, the carer recalls how they had none of the paperwork that should've come with the cared for, and that they were in severe pain and had painkillers that couldn't be administered due to a lack of medical records.

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Carer A commented that many apologies were made for this, but it doesn't change the fact the patient had to endure what they had to endure.

One of the final points of discussion we had with Carer A was with regards to their application for a blue-badge permit. The carer received the permit after three weeks, however the patient sadly passed away just one week later. The carer questioned why something like a permit took three weeks to be arranged, commenting that they "have to live with the fact that [they] tried but [they] didn't go well enough", before adding that they loved being a carer but "don't give [them] all of these barriers when the most human thing is to offer support".

Appendix B: One-to-one meeting with Carer B

How involved was the carer whilst the cared for was in hospital?

For continuity around the timeline of events, discharge involvement has been included in the same way as the carer was involved in patient care decisions.

During the interview, Carer B detailed multiple instances of when the patient was discharged from UHSFT and was happy to expand on their experiences of this.

When the patient was first admitted to UHSFT in June that year, the carer and their family were advised that they wouldn't be allowed to visit the patient on the ward, although UHSFT had ensured that virtual visiting was in place to facilitate and substitute the ability to come in-person. However, Carer B mentioned that this was never offered to neither the carer nor the family, and that they eventually got a disposable phone to the patient to be able to call, only after long periods of not being able to get in touch. The carer mentioned how they felt detached and uninvolved in the processes surrounding this admission, receiving only a phone call on the morning of discharge to inform the carer that the cared for was leaving hospital. Carer B did, however, refer during the meeting to the Patient Property Pod (part of the Patient Support Hub), remarking about how useful it was to be able to have a set place to drop off property and have it taken to the wards.

Following the June admission, the patient was readmitted in July for a separate reason and was discharged out of UHSFT to Royal South Hants for rehabilitation purposes until August of that year. In contrast to the June admission, Carer B said that they were able to visit the cared for at RSH (although this was still restricted in some manner), as well as mentioning that they felt more involved and included in the process. The carer did mention that they would've preferred a greater degree of flexibility surrounding when they were able to go to RSH but appreciated that restrictions meant it was more difficult than hoped.

The cared for was again admitted to UHSFT in August, and whilst this was only a short admission, highlighted a major incident. The carer remarked, once again, that they were not involved in any of the processes surrounding the patient's care nor their discharge. However, this lack of involvement was made significantly worse when the patient was discharged back to an empty address. The carer shared how they had gone away for a day and received a phone call from the cared for when the transport had arrived to take them home; they were an hour away, and they were concerned that the patient would be left alone with Alzheimer's Disease and the inability to walk (fracture). When the carer made contact with the ward regarding this, the carer mentioned how they were not informed of the discharge, to be told by the staff that they informed the patient that they were going home. Carer B was disappointed that they were not kept up to date with what was happening as the Next of Kin, particularly given the patient's Alzheimer's Disease diagnosis.

Involvement of carers in acute secondary care patient discharge

Carer B was asked about the transport from the hospital to home regarding the August discharge, and the carer remarked that the driver was “exemplary”. When the driver had arrived at the address, having realised it was empty and the patient was left outside, the driver contacted the social care team, found out the combination for the key safe and took the patient in through the house. The driver stayed with the patient to ensure their wellbeing, and when the carer arrived, informed Carer B that this wasn’t the first time the ward has done this and advised the carer to contact the Patient Advice and Liaison Service. However, given that the patient was readmitted a short time later to the same ward, the carer wished to not contact the PALS service, believing it was “too late to say anything”.

The final admission for the patient was December of that year, when the doctor called the carer saying they were “not sure whether we should be treating” the patient. The doctor then said they were going to discuss it with the senior, to be later told that the team will “help you treat at home”. The carer was not called back by the doctor, although the wishes of the patient were respected, and the patient was discharged home to pass away.

Personal consideration

Carer B mentioned that they could recall any conversation with staff members about their needs and consideration about their role. The carer mentioned how they held Financial Power of Attorney for the patient but not Medical, although they mentioned they were setting up MPOA at the time of the patient’s death. They believed that they would be kept up to date as the NOK, although this never came to fruition. Had the carer of been kept more involved, or at least updated, then the carer believes that incidents like the discharge to an empty house would never have happened, whilst allowing for other personal considerations of the needs of the carer to be taken into account.

However, when the patient was in RSH, Carer B mentioned how they felt as though they were being kept up to date and informed with what was going on, although the personal consideration wasn’t much of a factor. The carer referenced how staff members at RSH had a conversation with them about the care package that would be put in place following the rehabilitation discharged, and the carer appreciated this.

On a personal note, Carer B mentioned that they felt their personal life was heavily impacted by their caring role. They discussed how they were a very social person, but this was ended when they took on their responsibilities; this included having to shield with the patient for 15-weeks, although they did say they felt like they missed very little due to SARS-CoV-2 restrictions. The carer did mention how they had registered with the Carers Association and got useful sources for help, as well as being advised by the GP that the carer could register for attendance allowance.

The carer further spoke about how the GP came and visited the patient towards the end of life and escalated a referral to the End-of-Life team. The carer mentioned that they wished they were informed about the EOL team from CMB earlier, as they really helped and supported the carer.

Involvement of carers in acute secondary care patient discharge

Recommended improvements

The main improvement suggested from the conversation with Carer B is the need to improve communication. The carer mentioned that, as a carer, they need more involvement and awareness of what's happening and what they need to prepare for (i.e. discharge of patient back home). The carer mentioned how they weren't given much information about what to expect and felt like the staff weren't telling the carer the full picture, almost as if "they didn't know how to say it". The carer commended the conversations that they had with the consultancy team, saying that they were "exemplary", but again reinforcing the fact that it felt as though they didn't know what to say. It was only when the carer noticed a letter on the patient's medical record saying that the patient was nearing the end of their life, although the carer believed that this would be months when it turned out to be days.

The carer mentioned that once they knew "there was an end point", they felt "more tolerant" and "made the most of everything" that they could at the time. Carer B mentioned that they were proactive in all the arrangements, including the GP visit and the subsequent EOL team referral by the GP, to ensure that the last few days of life were enjoyable.

In addition to improving communication, the carer wished to mention about signposting to support and assistance services outside of the hospital. They felt that making them aware of these services sooner could've helped make the process surrounding the end of life easier, but also referencing how they would've been supportive throughout their caring role.

Appendix C: One-to-one meeting with Carer C

How involved was the carer whilst the cared for was in hospital?

Carer C, who holds Lasting Power of Attorney for the cared for, mentioned that they were unable to help in the care of the patient during their admissions to UHSFT, describing it as being “completely uninvolved”. Despite holding LPA and being registered as a carer through the Sunflower Lanyard Scheme hosted by the Patient Support Hub, the carer said that the only update they got was “[they’re] comfortable, [they’re] stable”, and was never updated as to what was happening nor what tests they were conducting. Carer C mentioned that because the patient was compos mentis and able to make decisions in their own capacity, the LPA felt as though it wasn’t considered. However, the cared for was unable to remember everything that was being said, and couldn’t remember names, who they were and where they were working. In addition, the carer commented on the fact that a significant diagnosis wasn’t shared with either the cared for or the carer, and their discovery was through a discharge letter. The carer shared that it is “not the role of a carer” to have to share that level of news with the cared for, and that it was “not appropriate”.

The nursing staff were “second to none”, according to Carer C, saying that they couldn’t fault them at all. However, when the cared for was still in hospital, the carer remarked how there had been no medical post-operation follow-up of the procedure that they carried out, with the carer adding that the “doctor said they didn’t have to see [the patient] post-operation”. They were also advised by a clinician to follow a recovery plan that involved a set of exercises and plans to help ease any discomfort, although the recovery plan meant that the cared for couldn’t perform what needed to be done by themselves. When the patient returned to the clinic a few weeks post-discharge, the clinic told the cared for that they didn’t need to perform the exercises, and that it wasn’t relevant to the patient’s recovery. This misalignment of the strategy proposed by the clinician at discharge and the comments made at the clinic post-discharge meant that the patient believed that they had to do exercises that were later deemed to be irrelevant to her recovery.

However, when asked what they found most valuable about the discharge processes, the carer said that “nothing was valuable”, further saying that the “service was really poor” and describing it as “awful” and “appalling”. The carer’s survey response goes on to add that this “is not the standard of care I would expect from UHS” with regards to discharge planning.

Personal consideration

Carer C said that there was no consideration for the carer’s needs during the whole process from admission to discharge, and that there was a lack of communication at all stages of the process.

The carer did also add that they haven’t “felt the need” to use services in the community, such as those run by charities.

Involvement of carers in acute secondary care patient discharge

Recommended improvements

One of the key improvement areas that came up with Carer C was the need for improved communication. As previously mentioned, the discovery of the significant diagnosis by reading a discharge summary was, in the words of the carer, “not appropriate” and “not the role of a carer”. Carer C also believed it was important to improve communication between departments and teams within the hospital, saying that phone numbers which were given wouldn’t connect and that paperwork “didn’t get passed on”, suggesting a lack of working together. The carer also believed that communication between clinical team and the cared for is important to ensure that there is clarity in the patient’s understanding, but also to ensure that the cared for has the opportunity to ask any questions that may arise.

Carer C also mentioned that there is the need for discharge to “be bespoke to each individual”, as different people experience different levels of impact from both being in a caring role and becoming cared for. The carer mentioned that there is a clear element of responsibility that they adopted when they became a carer for the cared for, and that there is the need for the hospital process to be “seamless from admission to discharge”.

Additionally, the carer spoke out their experiences with the community nurse team. The patient required regular change in dressing, which happened to fall on a long weekend with bank holidays. The community nurse team said someone would be out over the bank holiday period, but Carer C mentioned that no one ever turned up, and as a result, the carer took it upon themselves to replace the dressing. With skeleton telephone staff during that period, the carer said it was a case of “three sides to get round a square” due to the lack of help they had access to. The carer argues that there should be a simpler system for access to community nurses, with a “significant improvement” needed to their out-of-hours service.

There also need to be increased awareness about the role of LPA and a discussion of the care that the patient needs with the LPA, given that this never happened and there was a significant lack of communication between the hospital teams and the carer. This considered, there is a need to better improve the involvement of carers in the decisions made around preparing a patient for discharge and the actual discharge process itself.

Appendix D: Details of feedback received and comments from Experience of Care Team

Question: What are the useful questions to carers to be asked? When should these be asked?

Feedback

Questions should be asked continuously

Questions should include information about the patient, including what the patient needs to be okay

Is the carer able to care for the patient?

Ask how the carer is, and a wellbeing check to ensure that they are okay

How have the patient and carer gotten to the hospital? i.e. opportunities for subsidising parking

Ask what information the Trust should know, i.e. likes and dislikes

Experience of Care Comments

This question will form part of our guidance for discharging patients in accordance with Lords' amendment 51A to the Health and Care ^[1,5] bill

Car parking tickets are available for carers and patients that have long appointments, and can be obtained by asking ward staff

Question: What information is useful for carers to have prior to patient discharge?

Feedback

Knowledge that experiences can vary considerably between wards, and that it should be tailored to the patients individually

Information to be communicated to carers throughout the hospital journey, and continuity of care should be evident

When calling patients to share information, calls should be clearly identifiable due to concerns surrounding spam calls

Useful to have any letters between medical professionals to get a wider understanding, but also seek assurance that carers and patient understand the information

Information about carer support networks and where additional information/assistance can be accessed / leaflets available in holders

Explanation of the discharge process to patients and carers

Provide options for how information is communicated, including electronically and in paper format

Information about which teams to contact/ward contacts in the event additional assistance is required, such as a decline in patient health

Experience of Care Comments

This will form part of our guidance for discharging patients in response to Lords' amendment 51A to the Health and Care bill ^[1,5]

We are currently working on creating a discharge pack of information alongside the Integrated Discharge Bureau and hope to have this completed soon

Involvement of carers in acute secondary care patient discharge

Question: What does a 'gold standard' experience look like?

Feedback

Informing families about what is available in the community / consideration of the family dynamic in patient discharge

Providing a discharge pack of information, including social services, benefits and where to seek support / support with the logistics of discharge

Continual patient assessment due to illness evolution / pull on resources available at the hospital to ensure a multi-disciplinary response / joined up services or a central hub

Being honest about what's available and any issues being faced (i.e. staff shortages, managing expectations, etc)

Flag patient needs and respond to them consistently

Involvement of carers in handover / make the process clearer / reduce the medical jargon usage when talking to carers and patients

Member of staff who can be dedicated to deal with carer calls at specific times of day / point of contact to ask further questions

Somewhere quiet to go following receipt of diagnosis / allow time for patient and carers to digest information

Person-centric holistic care

Experience of Care Comments

We are currently working on creating a discharge pack of information alongside the Integrated Discharge Bureau and hope to have this completed soon

At UHS, we have an Integrated Discharge Bureau that oversees discharges across the Trust, but also a Patient Support Hub if additional support is required by either the carer or the patient

This will form part of our guidance for discharging patients in response to Lords' amendment 51A to the Health and Care ^[1,5] bill

We have recruited a member of staff to join our team as the Carers Lead, and they will be able to deal with specific cases and calls

Question: How much involvement would be ideal in patient discharge?

Feedback

Carers need to be involved as little or as much as they want / carers should be kept in the loop and should be asked how much involvement they want

Involvement can be crucial for success of a care plan

Can vary from person to person, and therefore there isn't a one-size fits all response

Carers need to be heard and respected with what they know of the patient already

Appreciation for how much information can be taken in at any one point, and may need additional time

Experience of Care Comments

This will form part of our guidance for discharging patients in response to Lords' amendment 51A to the Health and Care ^[1,5] bill