

Carers' experience of hospital discharge

Final report – April 2022

healthwatch
Warwickshire

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Executive summary

Healthwatch Warwickshire was commissioned by NHS England and Improvement (NHSE&I) to listen to the Carers experiences of the discharge process and feed into a larger national project that involved other Local Healthwatch.

We were privileged to hear from so many local people about their experiences of the discharge process. This work signified a real desire from participants to tell us about when it had worked well and what could be improved for the benefit of others.

The key findings from the interviews were shared with key stakeholders at a focus group where we discussed what challenges had been identified and what actions were needed to address them.

The interviews and focus group illustrated a real need to improve communication and understanding of Carers; their role, needs, and importantly, how best to support them.

It was evident from our work with key stakeholders like the NHS, Local Authority, and organisations like Carers Trust that there is a real desire to get things right for people in Coventry and Warwickshire. It was clear, although no new challenges or surprises were presented to stakeholders through the interviews with Carers, there was still a lot that could be done to support and help Carers in their vital role.

Healthwatch Warwickshire spoke to 23 carers about their recent experience of hospital discharge. This is what they told us was important:

- Ensuring that the **Carer is well informed** about the patient - when the patient is expected to be discharged, what needs to happen before discharge, what training or skills the Carer might need in order to be confident in providing ongoing care, and where that is not the case, that the carer does not feel judged or inadequate.
- Creating **trusted spaces** for the Carer to have honest conversations about their own ability to care for the patient and signposting them for support when needed.
- Not **assuming** that the person can, or is willing to provide, the care that is needed.
- Removing **bias**, or assumptions based on age or culture of the Carer or patient.

Next steps

Working with the NHS and local organisations, we have identified areas of improvement. Key areas are:

- A need for a single point of contact within the hospital for the Carer
- Two-way communication tools need to be developed for professionals and Carers, so patients' needs are met, and the Carer is aware of what is happening. Any tools developed will need proper consideration and consultation with Carers due to complex needs and issues around accessibility.
- Patient records need to be updated across the health and care system to ensure that Carers are not given conflicting advice.
- Working with Carers to develop training for professionals to ensure they are equipped to talk to Carers as equal partners, and challenge issues around assumptions and bias.
- Working in partnership across the statutory and voluntary sector to create a culture of learning and sharing best practice to ensure good outcomes for patients and Carers. This would allow the discharge process to be reviewed, and include the needs of the Carer and professionals.



“It’s so hard when assumptions come from medical professionals, we also need support and respite and the resources to help, we want access to it. Don’t assume we are caring out of the goodness of our hearts”



- Quote taken from a carer

Interviews with Carers

How we identified Carers

We used a variety of methods to recruit people to take part in the interviews. We used our own communication and engagement methods and worked closely with key stakeholders, such as the Carers Trust, to identify eligible participants. 38 people expressed an interest in taking part.

In total, we interviewed 23 people about their experience as a Carer during the hospital discharge process within the previous 6 months. We used the semi-structured interview guide provided by NHSE&I. Each interview was conducted by a member of staff or a trained volunteer. Each interviewee had the choice on the format of the interview:

- 3 interviews took place in person
- 18 interviews were via online platforms (e.g., Teams, Zoom)
- 2 interviews were on the telephone.

Consent was ascertained at each stage of the discussions to ensure that the person being interviewed was aware of what was happening and how their interview would be used as part of the project.

To thank interviewees for their time, a £25 retail voucher was offered, which was accepted by all participants.

Demographics of participants

Not everyone answered the demographic questions given as part of the interview guide, but we broadly matched the demographic profile for Warwickshire.

Our youngest interviewee was 22 years old and our oldest was over 80 years old. We broadly matched local age demographics for Warwickshire, having greater numbers of 50–59 year-olds than any other age group.

As anticipated, we had a lower number of males wishing to be interviewed (8) compared to females (15).

21 people chose to tell us about their ethnicity.

Percentage %	Asian/Asian British	Black/African/ Caribbean/Black British	White
Warwickshire Data*	4.6	0.8	92.7
Carer interviewees	9.5	5	85.5

*Not all ethnic categories are included in the Warwickshire Data

Out of 21 people, nine identified themselves as having a disability – out of which four said they were ‘Limited a lot’.

Out of 20 people, eight identified as having a long-term condition – with three of these people saying it affected their mobility; two said it was a mental health condition; the remaining three had various other conditions.

In Warwickshire, there are three main geographic locations, often referred to as ‘Places’; Rugby, South Warwickshire, and Warwickshire North – within which two hospitals are located (George Eliot Hospital NHS Trust and South Warwickshire Foundation Trust). The Integrated Care System also covers Coventry, where University Hospital Coventry and Warwickshire is frequently used by Warwickshire residents. We had good representation from across the County, with more participants from Warwickshire North than any other area. Given previous difficulties to make contact with people in this area it was a good outcome.

Key findings – interviews with Carers

When we analysed the findings from the 23 interviews that took place, several key issues were identified as important to Carers. These are:

Carer recognition

Carers felt their role was not always acknowledged or recognised when dealing with services, this often resulted in poor communication between the Carer and the healthcare provider.

Carers told us that their role was often assumed, usually due to their relationship with the person e.g., parent or child. This was particularly challenging when the person had not yet recognised themselves as a Carer and were being asked to/presumed to be comfortable with dealing with medical interventions and personal care of that individual – leading to feelings of guilt if this was not the case. Participants told us that they would like to have a non-judgemental conversation with professionals in a trusted space to discuss their concerns and find solutions.

Carers frequently told us that there seemed to be a lack of understanding about the complexities of their home-life, especially when they had multiple caring responsibilities.



“I have a 2-year-old as well as being a full time Carer for my dad. I don’t think the hospital realises when they discharge my dad, I also have a 2-year-old to sort out as well as my dad”



- Quote taken from a carer

Touchpoints

The most prevalent theme, which often determined the experience of the Carer was around touchpoints with services; primarily, communication between the Carer and the service or provider they were dealing with. Involving the Carer in understanding what is happening to the person they care for, and not relying on the patient to relay information, was crucial to overcoming some of the challenges identified. As illustrated by the quote below:



“They just assumed that because Dad has a phone he would tell me what was happening. Dad would get confused and forget things because of his medication so I wouldn’t always know what was happening”



- Quote taken from a carer

Interviewees understood the pressures that staff were under due to the pandemic but often needed reassurance about what was happening to their loved one, and what the next steps would be. This was crucial when Carers wanted to be informed about planning for the discharge of the person they cared for. It was cited frequently that family and carers were given little or no notice of discharge and the things that needed to be in place.

There were examples of when it went well, and this was down to teams working together across health and care services, and the effectiveness and kindness of staff (often remembered very clearly even after 6 months).

Providing ongoing care and support

Interviewees told us that they felt ill-equipped to deal with the ongoing care and support for the person they cared for once they had been discharged:

- They did not understand how to use equipment and medicines provided
- They wanted professionals to understand the sensitivities of providing personal care and where to go if they could not manage
- Carers wanted to know where to go if they did not know something or if they needed support for their own health and wellbeing



““I felt bad for wanting to say “I don’t want to be injecting my dad in his stomach. I am his daughter”. I was told if I can’t do it dad would have to do it. My dad can’t see”

- Quote taken from a carer



Patient records

Interviews with Carers highlighted a need for there to be a way of adding to patient records, to store information about the patient such as dietary, cultural, and medical needs.

Several interviewees told us about issues with prescriptions not being ready for discharge but also a wider issue of updating GP records quickly ensure any issues post-discharge are resolved quickly and without confusion.

Records need to be updated to ensure that Carers are not given conflicting advice. This stretched from health services into care services. It would reassure the Carer to know that the person they care for is understood.



““As it was during Covid I was really worried about her catching Covid whilst she was in hospital. The nurses were great and helped do her hair (mum takes great pride in her appearance) and helped her get dressed into her PJs”

- Quote taken from a carer



What steps could professionals take to improve Carers experience?

The discharge process could be improved with these simple steps:

- Ensure that the Carer is **well informed** about when the patient will be discharged. In a lot of our interviews, it was evident that notice of the patient being discharged was often unexpected and caused undue worry or stress. Communicating to the Carer expectations around discharge is crucial to ensuring the needs of the patient and Carer are met.
- **Provide training** to the Carer on how to provide ongoing care for the person they care for. This may include making the person comfortable with changing catheter bags, administering medication, or doing injections. It could also include reference guides or short videos on how to use equipment or how to lift safely.
- **Take time** to understand the personal circumstances of the patient. Never presume who is the Carer.
- **Ensure that medication needed is available for discharge.** Sometimes this had been cited as not being available or ready at time of discharge, which has resulted in delays or confusion. In one case a person was discharged without medication, and as it was the weekend the Carer was unable to get the matter resolved. The GP had not been informed of changes to medication.
- **Listen** to the Carer and ask the right questions. One interviewee told us about an experience of not being listened to by a community nurse, and receiving conflicting advice.
- **Reassure** the Carer that the person they care for is being looked after.

Focus groups

Key organisations involved in the discharge process

As part of the project brief, we were asked to organise an online focus group with key organisations, to share the findings from the interviews. We identified and invited organisations from across health and social care. These included NHS, local authority, primary care (GP) as well as Carer support organisations and the voluntary sector. Each organisation was sent information about the purpose of the focus group in advance, explaining the aim of improving Carer experience of the discharge process.

The following organisations attended:

- Commissioner of All Carers – Local Authority
- Social Care Commissioner – Local Authority
- Chair of the Health and Wellbeing Board – Local Authority
- South Warwickshire Foundation Trust – Acute Hospital
- University Hospital Coventry and Warwickshire – Acute Hospital
- George Eliot Hospital – Acute Hospital
- Carers Trust – Carer support service
- WCAVA – Voluntary community sector

There were also three representatives from NHSE in attendance, and a representative from Healthwatch Cornwall who was observing. In total there were 18 delegates present.

We accepted apologies from Coventry and Warwickshire Partnership Trust and the GP Federation. Both asked to be informed of the discussions moving forward. West Midlands Ambulance Service and a representative from Pharmacy Service did not respond to emails inviting them to be part of the discussion.

Analysis – Focus group

The focus group with key stakeholders was structured to share the key findings from the interviews, and to share a 10-minute video of a Carer. In the video, Carer 'M' shared her experience of when her loved one was discharged from hospital. She explained the impact the discharge process had on her, mentally and emotionally, which then made it harder for her to care for her loved one.

Delegates were then placed in two breakout rooms where discussions took place around identifying key areas of challenge and actions to overcome those challenges to improve Carer experience. The key challenges identified were:

- **Ensuring appropriate reviews and safeguards are in place** and built into the discharge process. The Carer video shown to key stakeholders illustrated when this had not been followed and had been instrumental in the Carers overall experience.
- Making sure that **Carers are equal partners** in the discharge process, ensuring that assumptions are not made by professionals.
- A need for a **single point of contact** for the Carer so they can find out what is happening to their cared-for person at hospital and be given reassurance.
- Ensure **accurate records are kept/created on admission** about the patient so the Carer does not have to repeat their story, and professionals are aware of the patient (and Carers') needs.

Underpinning all these challenges is a need for communication challenges to be addressed throughout the discharge process.

Suggestions from breakout rooms

The discussions in the breakout rooms illustrated that there were already several initiatives being used or trialled to overcome the challenges listed above. The groups listed the following suggestions:

- Carers Trust (Heart of England) suggested a 'hospital discharge person' on wards who could begin to communicate with people on the ward and their Carers about what they could expect from discharge and what the process was (Single Point of Contact), ensuring expectations and needs are met.
- Consider moving the discharge process further upstream so it was dealt with over a longer period of time. This would manage the expectations of what a good discharge would look like for that particular family, patient, and Carers, from their perspective - tackling some of the assumptions made by professionals.
- All recognised the importance of individual acts of kindness and effectiveness of staff, and how this improved the experience of Carers.
- Staff awareness training to try and ensure that carers are viewed as equal partners in the discharge process. Work with Carers to produce training for professionals to raise awareness of needs and tackle assumptions.
- One hospital is trialling a communication board to share essential information on patients with carers, to find out what communication channel is best for Carers, such as emails instead of calls, if that suited the Carer better.
- Comfort Calls are being carried out by one hospital in which patients are contacted before admission and after they are discharged to identify what support they need.

- Create a dedicated telephone switchboard number for the carer to get updates on the patient.
- Arranging a time for the carer to call to reduce 'not knowing' stress.
- There is already a medication helpline in one hospital that people can phone to find out about new medications that have been given out.
- Discussion on discharge summary letters and how personalised they are and how they could address some of the issues raised by Carer 'M' in the video.
- Recognition that hospital resources are already fully overstretched and that the voluntary sector is key to underpinning support for families and Carers, with a desire to explore roles such as 'Carer Champions'.

The groups agreed that it was important to continue work with Healthwatch Warwickshire on hospital discharge work ensuring that patient and Carer voice is considered in development of strategy, or initiatives of discharge work.

Evaluation and analysis of focus groups.

Did the focus group meet stakeholder expectations?

Following the focus group, an evaluation form was sent out to all stakeholders who attended, to which we received 6 responses. All 6 delegates said their expectations were met.

Were stakeholders surprised by the interview findings?

The feedback from carers was not surprising to stakeholders. The breakout rooms ensured that stakeholders were aware and shared the initiatives that were already being trialled to address some of the challenges around communication. A need to understand best practice from these initiatives is key moving forward.

How will the Carers' interviews inform practice?

Ensure that the Carer is **well informed** about when the patient will be discharged. In a lot of our interviews, it was evident that notice of the patient being discharged was often unexpected and caused undue worry or stress.

Communicating to the Carer the expectations around discharge is crucial to ensuring the needs of the patient and Carer are met.

There are a number of initiatives such as a Communication Board in which professionals and the Carer can see updated information about the patient. This could include dietary requirements, and the last time they had their medication.

Provide **training** to the Carer on how to provide ongoing care for the person they care for. This may include making the person comfortable with changing catheter bags, administering medication, or doing injections. It could also include reference guides or short videos on how to use equipment or how to lift safely.

Take time to understand the personal circumstances of the patient. Never presume who is the Carer. Create training packages with Carers for professionals to create a wider understanding of needs, and tackle assumptions.

Ensure that **medication** needed is available for discharge. Sometimes this had been cited as not being available or ready at time of discharge, which resulted in delays or confusion. In one case a person was discharged without medication, and as it was the weekend the Carer was unable to get the matter resolved, the GP had not been informed of changes to medication.

One hospital is trialling a dedicated medication helpline which carers can access post discharge.

Listen to the Carer and ask the right questions. An interviewee told us about an experience of not being listened to by a community nurse and getting conflicting advice about how to change their cared-for persons dressing.

Reassure the Carer that the person they care for is being looked after.

Carers Trust have dedicated Carer Support Officers in hospital settings which can act as a Single Point of Contact. This could be rolled out Countywide.

One key area that would make a difference for Carers is **recognition** and concern about their role as a Carer.

What does 'good' discharge look like for the Carer?

The interviews have illustrated that each Carer is an individual, and understanding their specific needs is an important factor in ensuring that the discharge process runs smoothly.

The findings show that communicating and liaising with the Carer (whilst the person they care for is in hospital) is key to achieving a good outcome, as well as communicating and setting clear expectations around when the patient might be discharged.

Another vital aspect is having honest discussions about the care needed and whether the Carer can provide that level of care, and if not – where they can go for support.

There is a need to:

There is a need to:

- Ensure that the Carer is **well informed** about
 - the patient
 - what care they are receiving
 - when the patient is expected to be discharged
 - what needs to happen before discharge
 - what training or skills the Carer might need to be confident in providing ongoing care, and where that is not suitable, not passing judgement.

- **Creating trusted spaces** for the Carer to have honest conversations about their own ability to care for the patient and signposting them for support when needed.
- Approaching each Carer as an individual – not assuming that the person can, or is willing to, provide the care that is needed.
- Creating a **culture that removes bias, or assumptions** based on age or culture of the Carer or patient.

It was evident in the positive interviews that took place that discharge works well when there is a multi-faceted approach to the patient and Carer being involved and understanding what is happening. Above all, it was apparent in our interviews that the impact of one kind and helpful person had a massive impact on the experience of the Carer.

How can Carer experience inform quality of discharge alongside other measures?

Working with the Carer means the Carer understands what is happening to their cared-for person and can plan ahead, in terms of their caring role. They also do not have to spend time chasing up answers to questions.

Working with organisations that gather independent feedback from Carers allows services and providers to identify best practice and where improvements can be made to improve Carer experience.

Co-produce training programs with Carers and professionals to ensure expectations and needs are met.

What can be done to make this happen?

Clear open and honest communication between Carers and professionals and working together to ensure expectations are met. There is a need to avoid making assumptions that a carer is medically trained or comfortable in carrying out more complex/personal caring duties. This could be addressed through open dialogue as well as training and awareness raising sessions for professionals.

How can this learning be shared with staff groups?

Instrumental to the learning from this work is a commitment from key stakeholders and Healthwatch Warwickshire to ensure that the report and interviews inform the work, not only of decision makers but that it is shared with staff groups from across the health and care services and providers; as well as raising awareness of the challenges identified and the actions needed to address them.

What is the best way to raise the profile of unpaid Carers?

There is a need to involve Carers' voices at all levels of health and social care. This must be done appropriately and with consideration on how views sought will be used to inform decision making, not as a 'tick box' or after-thought to plans.

It is widely understood that most people will have some caring responsibility in their lifetime and just as likely that people may experience mental health or wellbeing concerns. This means there is a wider need to discuss unpaid Carers in the workplace and in all health and care settings.

It therefore becomes increasingly important for people to understand what it means to be a Carer and the legal protections it offers. Carers should be considered with impact assessments, policies, service delivery and training.

Focus group – Next steps

Where should our follow-up work focus?

The interviews with Carers who had a positive experience illustrated when the discharge process worked well, the Carer had been involved and there had been clear communication and understanding on both parts about what was needed. The focus group with key stakeholders told us that there are a number of initiatives being trialled by hospitals to improve communication with Carers (such as a communication board) and using support services to act as a single point of contact. Healthwatch Warwickshire can help support these initiatives, helping to gather and encourage Carer feedback, ensuring that other services learn about best practice, ensuring equitable access across Warwickshire.

The solutions offered during the focus groups centred largely around what hospitals are doing to address these challenges but there is a need to approach follow-up work across the health and care services. An all-age Carers strategy is being developed across Coventry and Warwickshire and the voice of the Carer should be included and considered at every point of its development.

What can/ should be done differently? Are there any “easy wins”?

The development of an all-age Carers Strategy should provide a shared vision, with clear aims and objectives, which fits in with the Integrated Care System (Coventry and Warwickshire). Organisations, both statutory and voluntary, need to be focused on sharing and learning from best practice. Healthwatch Warwickshire is an independent organisation which focuses on patient voice and experience and can help in facilitating this discussion impartially, ensuring that regular and planned Carer feedback is being used to improve service and delivery.

There is a need for a follow-up focus group to be developed following the NHS England and Improvement national report to ensure that key stakeholders are following up on the challenges identified as part of this work. The focus group should involve key stakeholders who were missing – namely the GP federation, Mental Health services, Ambulance, and pharmacy. These wider stakeholders are pivotal to ensuring the discharge process runs smoothly from start to finish.

How can we measure success? What improvements should we set ourselves in the next six months/ 12 months/ 24 months?

All stakeholders present at the focus group had a real willingness to improve Carer experience. We need to ensure that in the development of the new

Integrated Care System in Coventry and Warwickshire, there are clear aims and objectives that include not only patient voice – but patient and Carer voice. The development of the Integrated Care System is based on an understanding that health and care, and third sector organisations need to work in partnership to tackle the challenges faced and ensure better outcomes for people.

Within 6 months –

Share the findings from this report with the public, participants, and key stakeholders. Ensuring that the findings from this report are used to improve outcomes for people who engage with health and care services.

There is a need to have further engagement with organisations and agree, where possible, what improvements can be made within their organisations. There is a need to create a forum and identify where organisations can work together and identify best practice which can be shared and implemented to the benefit of the public. Terms of reference and objectives would need to be agreed and set to ensure that real change can be expected. Having an independent, patient-focused organisation such as Healthwatch facilitate these discussions and bring this work together would be ideal.

Advocate for Carer focused work across the system. Involve carers when it comes to all services. This should be a thread that runs throughout all areas of work.

12 to 24 months –

Healthwatch Warwickshire will review the work undertaken in this report 12 months on and work with key stakeholders to understand what has changed as a result to this work. Where initiatives were identified or trialled, understand the benefits to the Carer (through continued engagement and working with Carers) and how and when best practice would be rolled out across the Integrated Care System in Coventry and Warwickshire. Once this has been analysed, report back to the Carers and the public to tell them of the results and any further support they could expect going forward.

The development and implementation of the all-age Carers Strategy for Coventry and Warwickshire can be used to measure how the needs of Carers are being addressed and how the voice of the Carer is being included at all levels of health and care provision.

The implementation of the new Health and Care Bill is expected to include safeguards to Carers rights (anticipated July 2022) and could be used to understand how the needs of Carers are being addressed and the expectation that health and care professionals consider Carers in their decision-making process – this should directly affect outcomes for discharge, but will have to be measured.

Thanks

We would like to offer our thanks and gratitude to all the people who offered and took part in our interviews. We were privileged to hear about your experiences and will endeavour to use them for the benefit and improvement of services for your loved ones and yourselves in your caring roles. Special thanks to the Carer who shared their experience by video for the focus group session.

Thank you to all the key stakeholders who took part in the focus groups, for your contribution and expertise. We look forward to working with you in the future to hear about how you are improving outcomes for patients and Carers using the feedback we have provided.

We offer thanks to NHS England and Improvement for the opportunity to be involved in the project and to our colleagues in the Healthwatch Network for your helpful cooperation and support.



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