

Carers' experiences of hospital discharge

Discharge to Assess model



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Summary

The Discharge to Assess approach was developed and implemented in some areas pre-COVID-19, but the pandemic made this the predominant model along with guidance issued first in April 2020 and refreshed in August 2020.

Carers UK had been concerned that both sets of guidance did not refer to or include carers' rights under the Care Act 2014. This was despite Carers UK being consulted on the first guidance in April 2020; none of our advice about the law in relation to carers or on safe care protecting carer's health and wellbeing was taken on board.

The guidance omitted any reference to carers rights and that carers should be asked whether they were willing and able to care under the Care Act 2014. It also missed that carers should have been assessed under the 2014 Act if they were about to provide care and on the appearance of need. If an assessment is carried out, the guidance should have referred to the fact that sufficient services are required to be in place to ensure that the patient is safe to be discharged under the Community Care (Delayed Discharges, etc) Act 2003 and the Care Act 2014 – these last provisions are being repealed by the Health and Care Bill currently passing through Parliament. Our research finds that the law did not seem to be followed in a large number of cases.

This research reveals the devastating toll on carers where it is clear that they have been left with unacceptable levels of caring responsibilities which are unsafe in some situations. This has placed intolerable stress upon carers and has had negative outcomes for people needing care and support.

A very clear thread from carers' experiences shows that carers have not been involved, consulted or given the right information in order to care safely and well. If carers are considered to be partners in care, then, like health and care professionals, they need access to relevant information to help them support a person needing care safely.

Whilst there have been examples of good practice and praise from carers, we found a number of areas of consistent concern:

- Patients, in some cases, were provided with very low levels of care but needed much more. This questions whether they should have been placed on a higher pathway and given an adequate level of support.
- Carers were not consulted about or involved in discharge.
- Consideration was not always given to a patient's ability to remember or recall important information putting the patient's and, at times, the carer's health at risk.
- Some carers were given no or little information on a person's condition and yet were expected to provide significant amounts of care.
- Carers were left to care without sufficient support, placing them at risk.
- Carers were left without contacts if there was a problem.
- Patients were clearly not safe to be discharged and their health was put at risk, with insufficient support.
- Carers' expert knowledge about complex conditions was not respected or utilised.
- Carers were not considered partners in care.
- Carers' stories suggested that nutritional needs were not always being met.

Rebecca's story

Rebecca, 42, cares for her father, 73, who has a rare condition called late-onset cerebellar ataxia. It is slowly progressive and was not diagnosed straight away but affects his ability to walk and communicate and his coordination skills are affected. Rebecca cares full-time for her father, visiting him every day in his home and supporting him to remain as independent as possible.

"In March, 2021 Dad had a prostate operation which was carried out at a local private hospital, where he stayed for two days. When he found out he was being discharged he was told that someone would contact me to ask me to pick him up. I didn't hear anything. In the end, I spoke to Dad on his mobile and we agreed that I should probably just go and get him as I was unable to make contact with the hospital.

"When I collected him I couldn't get into the building despite repeatedly ringing the buzzer. I was stood outside for about 20 minutes and considering I'd had no contact from anyone I got quite anxious. Someone finally came to the door and a healthcare professional brought Dad out in a wheelchair and took him to my car.

"I wasn't told anything about how Dad's operation went or given any information about his aftercare. Dad isn't very good at passing on relevant information or listening properly to instructions and can be forgetful. I asked him several times if there was anything he had to do when home – he said there wasn't.

"It later transpired that Dad was supposed to be wearing anti-blood clot compression socks 24 hours per day for two weeks after the operation. He hadn't been doing this, and I only found out because he was bored one day and decided to take out a leaflet the hospital had given him.



"If only I had been recognised as his carer and been given the information as well, we would have known what to do from the start. I was completely omitted from the discharge process and received no communication which made the experience more challenging than it needed to be".

What is the Discharge to Assess guidance? What does it involve?

The Discharge to Assess guidance looks at discharging a patient from hospital and deciding what pathway to put them on.

Pathway 0 - involves no support, informal care from support agencies, or the continuation of a care package that was already underway before the hospital stay.

Pathway 1 - involves additional support at home to enable someone to return home with new, additional or a restarted package of support from health and/or social care. This includes people requiring intensive support or 24-hour care at home. The guidance states that the principle of Home First should apply allowing people to recover, reable or die at home.

Pathway 2 - the guidance states that this should include recovery, rehabilitation, assessment, care planning or short-term intensive support in a 24-hour bed-based setting, ideally before returning home.

Pathway 3 - the guidance states that this is for people who require bed-based 24-hour care: includes people discharged to a care home for the first time (likely to be a maximum of 1% of people discharged) plus existing care home residents returning to their care setting (for national data monitoring purposes, returning care home residents will count towards the 50% figure for Pathway 0).

Those discharged to a care home for the first time will have such complex needs that they are likely to require 24-hour bed-based care on an ongoing basis following an assessment of their long-term care needs.

The Discharge to Assess policy does not require a Care Act 2014 assessment to be made before discharge but can happen once the patient is in the community.¹

¹ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/999443/hospital-discharge-and-community-support-policy-and-operating-model.pdf

When we asked and how

Carers UK ran a survey in March 2021 asking carers' for a range of their experiences including at the point of hospital discharge. 2,850 carers responded overall, with 1,950 from England. These results refer to England only. Those who responded tended to be providing very significant amounts of care. They should, therefore, have been more easily identifiable and should be clearly getting a carer's assessment or review. Respondents ages ranged from 18 to over 80. They were caring mostly for parents, spouses or adult sons/daughters. This group of carers were mostly looking after older people - 78% of people cared for were aged 65 and above including 14% caring for people aged over 90.

The results

A quarter (25%) of respondents have experienced hospital discharge for the person they care for, since March 2020. This is a very high percentage of carers experiencing hospital discharge.

Of those experiencing hospital discharge since March 2020:

- **Over half of carers providing significant care were not involved in decisions about discharge.** 56% of respondents disagreed (20% disagreed while 36% strongly disagreed) when asked if they were involved in the decisions about the discharge from hospital and what care and treatment they [the person they care for] needed. Only one third agreed they had been involved (22% agreed and 8% strongly agreed).
- **Most carers were not assessed.** 82% of respondents disagreed or strongly disagreed when asked if they had received a Carer's Assessment. Only one in ten appear to have been assessed (11% agreed or strongly agreed).
- **The majority of carers were not asked whether they were willing and able to care (7 out of 10).** 68% disagreed or strongly disagreed when asked if they were asked about their willingness and ability to care at discharge. Only one in five, (21%) agreed or strongly agreed.
- **Two thirds did not feel listened to about their willingness and ability to care.** 66% disagreed or strongly disagreed when asked if they felt listened to about their ability and willingness to care at discharge. Only one in six felt listened to (16% agreed or strongly agreed).
- **The majority of carers were not given enough information and advice to care safely and well.** Six out of ten (61%) disagreed or strongly disagreed when asked if they were provided with enough information and advice to be able to care safely and well at discharge. Only one in five were given enough information and advice (19% agreed or strongly agreed).
- **Most carers said insufficient support was provided to protect the health and wellbeing of either the patient or their own health.** Six out of ten (60%) disagreed or strongly disagreed when asked if they received sufficient services to protect the health and wellbeing of the person they cared for as well as their own health at discharge.

Dorothy's experience of hospital discharge

Dorothy, age 63, cares full-time for her husband Melvin, 74, who was diagnosed with a rare brain disease more than ten years ago. Melvin's condition means he is immobile and it affects his ability to communicate, and Dorothy supports him with all aspects of daily life including helping Melvin to move around.

"In February 2021 Melvin had a fall at home, fracturing his hip and pelvis and was admitted to hospital. He stayed there for seven weeks and, due to COVID-19 restrictions in place, I was unable to visit during that time, receiving just one call from a doctor.

"When Melvin was discharged in mid-March I had no warning. I was told that Melvin was able to walk a little, and was fit to come home. I found out that he had been transferred to five different wards during his time in hospital but I wasn't updated on his progress or involved when it was decided he would be discharged.

"Because I hadn't been able to visit I had no idea how much Melvin's condition had deteriorated over the seven weeks - I was shocked when he arrived home. Melvin's weight had dropped from 65kg to 51kg and he could barely walk. An assessment was carried out when he arrived and it was immediately clear that he had been discharged too early. Melvin told me he had complained of sickness and diarrhoea on the day of discharge but this was not recorded on notes and the decision remained that he would go home. The day he was discharged the emergency rapid response team came in to support me and continued to do so three times a day for eleven days until Melvin was finally admitted to a specialist rehab unit. He stayed there for five months afterwards.

"I later found out that Melvin had been diagnosed with two new conditions while in hospital but these were nowhere to be found on his discharge notes.

"I had nobody to talk to and felt completely left in the dark. I was not consulted about Melvin's care and clearly it had not been safe to discharge him - he shouldn't have come straight home. I was not given any information or advice about the kind of care he would need going forward.



"As his wife of 47 years and his main carer for the last ten years, I am the only person who knows all the complexities of his condition. His brain disease alone, never mind the added complications of his fractured hip and pelvis, means that the way that he is handled, mobilised and assisted are all extremely complex and have to be done in a specific way. Normally, I am there with him to explain these things to the medical professionals but because of COVID-19 hospital restrictions I was not allowed to accompany him. I felt that all control had been taken away from me and I was powerless to protect him.

"We were just supposed to hand over his care to the hospital staff in the hope that they had the specialist skills that he needed. Because there was no communication, his health and condition rapidly deteriorated. Both Melvin and I are now suffering with post-traumatic stress and even now, to this day, we are dealing with the aftermath of our experience".

The Health and Care Bill removes important safeguards for carers

The Health and Care Bill currently before Parliament repeals the Community Care (Delayed Discharges, etc.) Bill 2003 and the corresponding element, Section 78, in the Care Act 2014. This legislation includes an important safeguard for carers which requires a judgement to be made about whether, in terms of the carer's assessment, support needs to be provided in order to ensure that the patient is safe to be discharged. This duty is placed on social care, but also requires health services to be involved and to make the same consideration.

Although the Care Act 2014 places a duty on local authorities to assess carers on the appearance of need if they provide or are about to provide care, this does not include the strength of the test above. The Care Act 2014 is not sufficient to compensate for the removal of this test and carers' rights that are being repealed.

Geraldine's experience of hospital discharge

Geraldine and her sister Angela care for their mum, 90, who is blind and needs support in older age. She has high blood pressure and is at risk of falling. Geraldine and her sister support their mother in her own home, with support from care workers who visit three times a day.

"One Saturday in August 2020 we were visiting a farm shop and my sister and I noticed that Mum wasn't eating; she didn't seem with us and something wasn't quite right. The paramedics were called - we thought she had a urinary tract infection (UTI) but they were more concerned that her heart rate was dropping. She was taken to hospital without us and they found she had low sodium levels and a UTI.

"Mum was kept in hospital for three weeks to deal with the infection. We weren't able to visit so kept in touch over the phone. During that time she was very distressed and recently becoming blind, nothing was familiar to her.

"We were informed that she would need a pacemaker - then the advice changed and the doctors talked about Mum receiving respite care and an intense physio package. All of a sudden, the discharge coordinator said that Mum was coming home. We felt the option of respite care and intensive rehab was disregarded as it would have to be financed by our local NHS trust. We stressed that Mum, who is normally lucid, wasn't right, to which the discharge coordinator insinuated that we didn't want to care for her. She said further tests for the pacemaker would be carried out once she was home. Under duress we agreed that Mum would come home.

"The discharge coordinator then revealed to us that because Mum had been in hospital for more than two weeks, her care package was no longer in place. She suggested that she stay in hospital but Mum was so distressed by this point, she needed to come home.

"A rapid response team came in to support my sister and I while I went through the trauma of trying to find an alternative provider. This was only put in place 24 hours after discharge. We were misled about Mum's condition on discharge - we were told she was "back at her baseline" but she was now doubly incontinent.



"It took three of us to put her to bed the first night and about 20 weeks to get her back to her old self physically, although she has never regained the small bit of independence she had prior to being admitted. Despite concerns about Mum's sodium levels the hospital did not address this issue, it was our GP that prescribed her sodium tablets which seem to be keeping her relatively stable.

"Mum has had six visits to hospital now and every discharge has been problematic for us. Nothing is joined up and the first time we were left floundering. We weren't given any advice or information, we didn't know about support services - we were always left with the words "someone is going to contact you." We are constantly chasing things up, whether it be follow-up appointments or medications that haven't been sent out on two of her most recent discharges. She was encouraged to sign a DNAR (do not attempt resuscitation) without discussion with us; discharged with mild cognitive impairment but deemed cognitively fit to make the decision to implement a DNAR. We seriously worry that if my Mum didn't have us to fight for her she would not be here now".

What is Carers UK calling for?

The most recent guidance² issued by NHS England includes references to carers' rights after Carers UK raised significant concerns.

The updated guidance³ now includes the following references to carers "important considerations for all pathways": *"Before discharge a determination must be made about the status and views of any carers who provide care, including that they are willing and able to do so. Discharge to assess arrangements do not change the entitlement for an unpaid carer to a carer's assessment where they are not able to care, and/or need help. A carer's assessment can be completed after discharge, but should be undertaken before caring responsibilities begin if this is a new caring duty or if there are increased care needs. If the assessment needs to take place prior to discharge it should be organised in a timely manner so as not to delay discharge from hospital."*

Consideration must be given to identify where there are any children or young people in the household with caring responsibilities or may have some at the point of discharge. Children and young people may then be entitled to a young carer's needs assessment or benefit from a referral to a young carers service."

Whilst this reference is an improvement, it does not compensate for the removal of the provisions in primary legislation. This guidance also comes nearly 18 months after this operating model has been in place which has now become common practice – effectively missing out carers.

The guidance continues to leave carers out in key areas. None of the specific responsibilities prescribed for different health teams eg acute trusts, hospital discharge teams, etc reference carers, making teams responsible for their welfare and ensuring that carers have sufficient support. The only reference to family or carers in this list is taking the patient home. The list stipulates that local authorities have a responsibility for assessing carers needs but health also need responsibility for carers.

Carers UK believes that safeguards must be built into primary legislation to ensure that this poor practice is not embedded longer term. We are suggesting that similar provisions need to be made which ensure that the patient is safe to discharge.

Our recommendations are as follows:

Legislative:

- Safeguards must be put in place in the Health and Care Bill to ensure that the patient is safe to discharge and that carers' health and wellbeing is not put at risk.
- The Health and Care Bill should be amended to include a duty on the NHS to have regard to carers and to promote their health and wellbeing to ensure that approaches do not overlook their needs.
- The Health and Care Bill should require Integrated Care Boards to have a responsibility to follow-up on people who have been discharged into the community.

Funding:

- A continuation of funding to support hospital discharge is urgently needed.
- Social care reform must include sufficient investment to ensure that carers and the people they support have enough care.

Strategic:

- NHSX should ensure that the Data and Digital Strategies have robust and clear mechanisms for carers.
- The guidance on hospital discharge should be updated and improved.
- The Executive Lead for hospital discharge needs to be given a specific responsibility for carers.

² <https://www.gov.uk/government/publications/hospital-discharge-service-policy-and-operating-model/hospital-discharge-service-policy-and-operating-model>

³ <https://www.gov.uk/government/publications/hospital-discharge-service-policy-and-operating-model/hospital-discharge-service-policy-and-operating-model>

Procedural:

- All teams involved in discharge must have a responsibility for carers and this must be explicit in guidance.
- Training on carers, carers' assessments should be mandatory for all health and social care staff involved in hospital discharge. This should also include the direct perspectives of carers who have experienced hospital discharge.
- Every Trust, local authority and ICS should review their discharge information, procedures and policies to check that they include carers at key points and that they are compliant with carers' rights. This should be audited annually to ensure that standards are maintained. Any internal review of patients' experiences needs to ensure that this includes carers.
- Carers' support and specific workers are necessary at the point of discharge from hospital and should have strong links to community health and care services, and the voluntary sector, particularly carers' support services.
- Good practice states that carers should be involved before admission to hospital. This needs to be put into practice routinely.
- Clear responsibilities for follow-up appointments and check-ins.
- Robust information sharing and permissions should be in place so that no carer is left to care with inadequate and incomplete information.
- Every carer should have a contact so that they can get further advice, information or support if there are any issues.
- Carers should be clearly identified and flagged on the patient's record, with permissions actively sought prior to or during admission.

Quality, Experience and Data Collection

- Routine data collection should separately include carers' experiences of hospital and hospital discharge as part of quality and health inequalities measures – appraised by the Care Quality Commission.
- The Care Quality Commission should ensure that inspections of acute trusts have key lines of enquiry which relate directly to carers' experiences.
- Quality markers for acute trusts should be introduced to support good practice beyond what is required.

We had heard a lot about the success of the Discharge to Assess model, but had not seen a great deal of evidence of carers' experiences outside of the work completed by Healthwatch and British Red Cross in October 2020 reviewing first wave experiences.⁴ The research found 19% of patients and carers felt unprepared for discharge. One third (35%) were not given a contact about who could provide advice, despite this being part of the guidance. We thought we would build on that work nearly nine months later and should ask carers what their experiences have been.

Carers UK: September 2021

⁴ 509 people's stories of leaving hospital during COVID-19, Healthwatch and British Red Cross, October 2020 <https://www.healthwatch.co.uk/report/2020-10-27/590-peoples-stories-leaving-hospital-during-covid-19>



Across the UK today 6.5 million people are carers - supporting a loved one who is older, disabled or seriously ill.

Caring will touch each and every one of us in our lifetime, whether we become a carer or need care ourselves. Whilst caring can be a rewarding experience, it can also impact on a person's health, finances and relationships.

Carers UK is here to listen, to give carers expert information and tailored advice. We champion the rights of carers and support them in finding new ways to manage at home, at work, or in their community.

We're here to make life better for carers.

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