

## Discharge Report

A *Deep Dive* into patients' and carers' experience of being discharged from acute hospitals in West Sussex

August 2015





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# Introduction

## Acknowledgements

Healthwatch West Sussex would like to thank:

- the patients and their relatives who were involved in the study
- the nurses, medics, staff and research team of Western Sussex Hospitals NHS Foundation Trust
- the Authorised Representatives of Healthwatch West Sussex
- Ines Garcia, Phillip Chadwell, Viv Nuttall, Chris McCrory and Chris Rainey

## What is this report about?

Healthwatch West Sussex's report *Well Enough to Go Home?* highlighted some of the issues patients faced when they were discharged from hospital. This report aims to explore in more detail patients' and carers' experiences of being discharged from hospital, including the steps taken beforehand, and what happened afterwards.

The work was commissioned by West Sussex County Council, but was carried out independently by Healthwatch West Sussex, with the agreement of Western Sussex Hospitals NHS Foundation Trust.

## What did we do?

### Data collection: Surveys

Data was collected in two stages. In the first, patients were surveyed on the day they were discharged from Worthing Hospital or St. Richard's Hospital. Surveys were carried out in the Discharge Lounges and on a broad selection of wards. This involved Authorised Representatives of Healthwatch West Sussex.

Participants were asked about the condition they had been treated for, their experience of discharge planning up to that point, and what support they expected to receive after they left hospital.

Surveying took place during June and July 2015, on twelve days at Worthing Hospital and seven at St. Richard's Hospital. In total, we spoke to 71 patients and/or their relatives. The surveys were used to identify potential topics to explore during the next stage, and for selecting suitable participants.

### Data collection: In-depth interviews

A number of patients then took part in a follow-up interview. The participants approached were those whose cases were likely to give the greatest insight – positive or negative – into hospital discharge. The cases covered a range of ages, locations and personal situations, as well as a variety of conditions, treatments and ongoing support needs.



10 in-depth interviews were conducted in person. These interviews typically lasted 50-60 minutes, exploring the patient's journey in detail. Topics included the onset of the patient's condition or problem, their time in hospital, steps taken to plan and prepare for discharge, events on the day of discharge, and the experience of receiving help and support afterwards.

A further 8 people were interviewed by telephone. These covered similar content to the in-person interviews, but focussed on a smaller number of specific areas most relevant to that case. The telephone interviews lasted between 10-40 minutes.

### Analysis and findings

The analysis used verbal transcripts of in-person interviews and detailed notes from telephone interviews. Case studies were drawn from 15 of the surveys, plus notes on trends found across the remaining surveys. A small number of conversations with hospital staff were also used, as were observations made by the researchers. In total, 37 sources were analysed.

Themes for data analysis were drawn from researcher notes made after each Stage 2 interview (these noted the significant points discussed, and reflected on other points to explore). Trends identified from Stage 1 surveys were also added. Each source was then analysed systematically, identifying and coding the extracts relevant to each theme.

Finally, the material collected for each theme was then reviewed. The findings of this report draw upon points which were mentioned in a number of sources, using the quotations and examples which illustrated each point most clearly. Where contrasting views or outcomes were evident, these discrepancies were also discussed. This allows the report to present similarities and differences in participants' experiences of hospital discharge.

In reading this report, it is important to bear in mind that its aim has been to provide an account of patients' typical experiences of hospital discharge in West Sussex. It does not consider extreme examples or worst-case scenarios; nor was the work carried out at a time of unusually high demand for local health services.

Recommendations have been made on the basis of the report's findings, and as such, can be considered to apply directly to Western Sussex Hospitals NHS Foundation Trust and the other stakeholders named in the report. However, the recommendations are worded more generally, as it is hoped that other Trusts and providers in West Sussex will also consider what they can learn from the report.

### Ethics and governance

At all stages, care was taken to conduct the research ethically. The research design was discussed with and approved by both West Sussex County Council and Western Sussex Hospitals NHS Foundation Trust. Informed consent was sought from patients at both the survey and interview stages. Participants were free to say as much or as little as they wished. It was made clear that patients' treatment would not be affected by their decision whether or not to take part.

Patients' views were not shared with hospital or medical staff. In order to protect identities, the names and genders of some participants have been changed in this report, and some other details have been redacted or are described in less specific terms.



## In hospital

It's important to begin by acknowledging that, overall, patients were pleased with the treatment they had received. Even when patients had a bad experience or things had not gone smoothly, the majority of participants acknowledged how grateful they were for their treatment, paying tribute to the staff who had cared for them.

*“The staff were excellent - right from the nurses to transport staff. I was very happy with how I'd been treated.”*

*(Ray, Digestive system infection, Worthing)*

*Rosa reported that it was ‘brilliant on Selsey Ward’ and that she had ‘nothing but praise’. She felt the same way about the theatre staff.*

*(Rosa, Knee replacement, St. Richard's)*

*“The way I was treated in hospital I can't say enough about the staff. From the meals to the nursing staff to the doctors and the physios, they were absolutely wonderful, you know? I couldn't have done without them... They know what they are doing. It is like everybody with their job, you know what you are doing. But I am quite happy with the way things went, more than happy.”*

*(Donald, Stroke, St. Richard's)*

### Lack of diagnosis

For some patients, problems occurring after they had been discharged stemmed from a failure to diagnose and treat the condition for which they had come into hospital. While this affected a minority of patients, it generally led to patients being readmitted or making little recovery in the weeks after they were discharged.

*Amy had reoccurring problems in controlling high blood pressure. She was admitted to A&E at Worthing Hospital after a blackout, monitored overnight and then discharged the next day. She was not offered any follow-up, but was told to go and see her GP. Amy had asked for investigations to be carried out, as the same problem had occurred about a month before, but was told that ‘we're not in the business of aftercare’. She felt that the hospital was ‘supremely disinterested’ in her.*

*(Amy, High blood pressure, Worthing)*

### Agnes's story

Agnes fell at home and was unable to move. The family became concerned when her condition began to deteriorate, and she was admitted to Worthing Hospital.



*“We did think she’d broken something or something was wrong, which is why we called the ambulance and she went in the ambulance. Why she stayed in hospital was because she couldn’t move, and yes, we thought there was something, but we didn’t know what in particular. But it was the way it deteriorated because the first day you really couldn’t move and you were incredibly tired, but those three steps you could get up and down between the rooms. But on the day after you just couldn’t walk at all, could you?”*  
(Daughter of Agnes, Lack of mobility, Worthing)

Agnes’ daughter felt that her Mother’s condition was not taken seriously, even at the beginning. Her impression was the assumptions were made because of Agnes’s advanced age. This was not helped by her stoic attitude and unwillingness to make a fuss, which she felt may have led medical staff to overlook the seriousness of the problem.

*“We phoned 111 and then I had to persuade them to phone 999 because they were saying she should be alright ... the fact that she couldn’t move. What I feel is that a lot of mother’s problems are because she’s [in her nineties] people take her to be a little old lady of [ninety-something] who can’t do anything.*

*“I think this is where some of the problems have arisen because mother says, ‘I’m not in pain’, but when you look on her face you can see. Well it’s a cross between pain and you can’t do it, you know, well it is a sort of pain because you physically can’t do it.”*  
(Daughter of Agnes, Lack of mobility, Worthing)

Because Agnes had previously broken a hip several years before, it appears that doctors focussed on this when attempting to diagnose the issue. As nothing showed up on the x-ray, she was discharged. The family was concerned that the root cause had not been identified. As the stay had been brief, there was little opportunity to plan help and support for after discharge.

*“Well primarily it was the x-rays, you see, that’s why they took me in to make sure that I hadn’t fractured anything and so that was done. No, I didn’t feel I was fully ... was never really prodded to say does it hurt there or does it hurt there...*

*“I just think, well it was obvious, I’d gone into to be x-rayed for my hips in case I had cracked my hips and having discovered that no I hadn’t cracked them then they said, ‘Well you can go home in the morning’.”*  
(Agnes, Lack of mobility, Worthing)



## Physiotherapy and Occupational Therapy

Many of the participants had received physiotherapy and occupational therapy<sup>1</sup>. The majority viewed this aspect of their treatment positively. Some patients had needed significant rehabilitation; their support was often extensive. As well as giving general exercises, it covered a wide range of practicalities to help them readapt to life at home. As this could be a lengthy process, patients were often grateful for the encouragement which helped them to persevere.

*“They started getting me to stand and do different things. I had to stand and sit and then I had to go to the gym, make a cup of tea and do a sandwich and that... I moaned [to] one of the ordinary physios... She said, ‘Well you have got to do it otherwise you won’t get moving again’...”*

*“You realise afterwards why they are doing it for you. But yes I was thankful... I am amazed I am where I am because I didn’t think I would be here getting about... And it is through their help... You need a good push sometimes to do these things.”*

*(Donald, Stroke, St. Richard’s)*

### Combining the insights of medics and patient

Physiotherapy and Occupational Therapy were often most effective when they combined the therapist’s expertise and knowledge of the condition with the patient’s understanding of their own needs. Several patients noted that the advice and support had been precisely tailored, and had managed to meet very specific but important needs.

*“She tested things like how I am on dressing myself. Unfortunately, buttons beat me unless they’re really big buttons, then I can grip them but small buttons I can’t, and making sure I’d got the right type of shoe because my MS means my coordination and my balance are completely shot.”*

*(Josephine, Ulcerative Colitis, Worthing)*

*“There was a physio... couldn’t please you enough. He wanted to please you and he tried all sorts of things that might help me and the different heights [of equipment].”*

*(Barbara, Leg injury, St. Richard’s)*

Equally, the therapists were able to help some patients to understand what their recovery would be like, and what would be needed during this time.

*“I am amazed with what you get in one respect... They give you this and that and it all helps. I have got a perching chair out there. They said to me, ‘Have the perching chair.’ I said, ‘Well I don’t know whether I want it.’ They said, ‘Use it. If you don’t want it later on you can take it back.’ And it is handy. They know, they know what you want.”*

*(Donald, Stroke, St. Richard’s)*

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<sup>1</sup> Although physiotherapy and occupational therapy are not synonymous, the terms are discussed together, because participants tended to conflate the two.



One patient felt that some of the practical assessments they underwent were not entirely realistic.

*Following his admission in May for a stroke, Warren was assessed by an Occupational Therapist to see if he could manage coins and whether he could make a cup of tea. He stated that there was quite a difference between managing loose change and organising shopping and between making a cup of tea and making a meal.*

*(Warren, Stroke, St. Richard's)*

A few patients felt that assumptions about their capabilities had been made on the basis of something written in their medical notes. Although participants valued a holistic approach, they felt it was important to have the opportunity to talk through their own needs fully; this did not always happen.

*"...because they've seen [written in the medical notes] 'Rheumatoid arthritis', they assume straightaway I'm incapable when I'm not, you know. They should use their own initiative sometimes... They might be taught that rheumatoid arthritis is a destructive disease... I can understand them asking me, how do you get on with your arthritis? But I think they do assume..."*

*(Elsie, Chronic Obstructive Pulmonary Disease, St. Richard's)*

Although patients were often told their recovery would be a long process, they did not necessarily receive clear advice on what this would mean in practice. This could leave them confused about how far to push themselves, and which activities might be unsafe to attempt. Several patients, who were receiving occasional home visits from a Physiotherapist, had chosen to attempt certain things which might have carried an element of risk.

*"[I would have liked] reassurance... that I was making progress... and doing the right thing. It's very hard to know how far to push yourself, because it makes you puff... [My daughter] was quite surprised that I'd been out in the kitchen, but then you learn [to] put your stronger leg up first, you learn that you put your bad leg down after when you're coming back down... You [work it out for yourself]."*

*(Agnes, Lack of mobility, Worthing)*

One patient was given some equipment from a neighbour. As with the previous case, it was notable that she had not felt able to seek advice beforehand, although it was clear that she had wished to.

*"The lady over the road... had her hip done about four months ago and she said, 'I have still got [my crutches], would you like to try them?'... I didn't think I would be able to manage with sticks because I thought, 'well sticks is not a good idea when you don't feel very confident'... I had been watching people in hospital using the sticks so I had an idea what they were doing putting the sticks in front and then the bad leg and what have you..."*



*“I find the sticks better than this trolley because it makes me stand up better. But I still feel very shaky when I am doing anything, because I am frightened of falling...”*

*“I suppose in a way it would have been nice to have had the option in hospital just to try them, I don’t know. I never sort of thought about it. Because I wasn’t getting on very well with the frame I didn’t think about getting any further I suppose...”*

*(Mary, Knee replacement, St. Richard’s)*

While some patients were given their physiotherapy and occupational therapy automatically, other patients received significantly less support, and it had been left to a GP to request this. Some patients experienced gaps in their support as the Physiotherapist was on holiday, and were not clear whether they would have had more frequent visits if this had not been the case.

Numerous participants had been readmitted to hospital, and had stayed on a different ward than previously. They were aware that the services available could differ between the wards, meaning that it was possible to miss out on the support needed. Although they understood why wards would specialise, they felt there could be more flexibility where this was needed.

*Bernard had a hip replacement at St. Richard’s, followed by physiotherapy to help him walk. He was discharged after a week, but was then readmitted with a suspected Pulmonary Embolism. During this second stay, he was treated on a different ward which did not offer the on-going physiotherapy which he required. This also had implications for his discharge. He was going to spend time recovering in a rehabilitation hospital, but it had been left to a relative, who worked for the NHS, to arrange this. They felt that, without their insider knowledge, Bernard would have fallen through the gaps.*

*(Bernard, Hip replacement, St. Richard’s)*

### Urinary and renal conditions

It was notable that at least four patients had developed urinary or kidney problems as secondary conditions during their stay in hospital. It was not possible to examine the medical reasons for this during the study, nor to determine whether the proportion of patients developing these issues was within the expected range.

However, this does highlight some of the challenges which secondary conditions can create: complicating treatment for the original illness/problem, and delaying discharge as patients can take longer to recover. These issues were not always made clear to the patient as soon as they could be, which may have further exacerbated them.



*“Because they found my kidneys are not working that well, I ended up staying in longer. They put me on a drip and that made me feel a bit unwell... They kept telling me to drink and drink and drink which I kept doing but nobody actually said that my kidneys weren’t working very well, not to start with. So I didn’t quite know why I was having all this drip and business, which made it difficult for me to sort of get in and out of bed.”*

*(Mary, Knee replacement, St. Richard’s)*

One patient had difficulty understanding some of the nurses’ accents, and found their attitude made them feel uncomfortable. This led to a reluctance to ask for help with the commode<sup>2</sup>.

*“It made me feel that I was a problem... One night they came round and I said, ‘Well not again, you have only just been’. And they were sort of mumbling away and that made me get out of bed. And of course when I got out of bed on the chair I could see my leg had leaked all in the bed and they had to strip all the bed. But I didn’t know what was happening because I didn’t understand... what they were sort of saying?”*

*(Mary, Knee replacement, St. Richard’s)*

It was observed that some relatives felt uncomfortable dealing with incontinence; managing catheters and stoma bags; or providing other forms of intimate personal care such as washing. Where these issues had not been resolved, it could lead to relatives being reluctant for the patient to be discharged into their care. Other relatives were being required to perform specific procedures, but did not appear to have been given sufficient advice or training on what was required. Given the sensitive nature of the topic, some felt unable to ask for advice, and found it difficult to discuss with the patient.

## Recommendations

1. Trusts should consider including follow-up checks in the discharge plans of patients whose primary cause of admission has not been identified, to reduce the risk of readmission.
2. Trusts should support physiotherapy and occupational therapist teams to adopt a consistent approach to post-discharge planning in line with the principles of the Care Act (e.g. promotes wellbeing, is person-centred, help prevents, reduces or delays the risk of readmission and reflects the person’s assets).
3. Trusts should review the delivery of a therapy services in non-specialist wards to ensure patients are able to receive the appropriate advice and care both whilst in hospital and after discharge.

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<sup>2</sup> It was not clear whether this may have been a factor in the onset of their urinary problem.



4. Western Sussex Hospitals NHS Foundation Trust should carry out a root cause analysis of a sample of patients who acquire urinary or kidney problems as secondary conditions during their stay in hospital, and to examine whether the proportion of patients developing these issues is within the expected range.
5. Trusts should ensure that all carers receive appropriate training and support to enable them to provide the care required by the patient after discharge.



# Preparing for discharge

## Planning for discharge

For some patients, the process of planning their discharge went smoothly. This appears to have been more likely where the admissions themselves were planned.

*Rosa had undergone a planned knee replacement operation at St. Richard's Hospital. She had previously attended a 'Joint School', which had provided information about the procedure, and discussed what would happen afterwards. Arrangements for discharge were made before admission, including delivering equipment to Rosa's home. Rosa felt she had been well-informed, and confident that she could access further help or advice if she had needed it.*

*(Rosa, Knee replacement, St. Richard's)*

Even in such a carefully planned case, there were certain issues which had not been anticipated. Although it proved possible to adapt to these, this took some persuasion from a family member.

*On the day of discharge, Rosa was assessed by the physiotherapist, who assented to the discharge. However, Rosa did not feel up to going home that day, as she felt very drowsy from some medication she had been given. She mentioned this to a ward nurse, but the plan to discharge her was not changed.*

*A member of Rosa's family then spoke to a member of ward staff, and persuaded them that Rosa should be discharged the following day. Rosa commented that she would have argued her own case had it been necessary, but fortunately, the family member was able to do this on her behalf. Rosa went home the following day, at which point she was feeling fine.*

*(Rosa, Knee replacement, St. Richard's)*

Not every patient received such a careful assessment. In Agnes's case, there was not sufficient time to do this before she was discharged. An assessment at home also did not run entirely as scheduled.

*'They were coming to assess mother and nobody turned up and then I phoned up and they said, 'It's been cancelled because she said she's fine.' And I said, 'Well she's not fine'. So they said, 'Okay tell her to stay in bed, don't get up, don't get out of bed, we'll be there at eight o'clock in the morning.'*

*'At 10 o'clock there was still nobody here, eventually somebody turned up, they didn't know anything about this assessment. So nobody has actually been to do the official assessment.'*



*“There was another [more specialised assessment]... One of them said, ‘Well somebody will be here to do it tomorrow’... I saw her the next day and she said, ‘I’ve been given the job of doing the assessment,’ and you thought, ‘well why couldn’t she have done it yesterday when she was here?’ It wasn’t her fault, she wasn’t meant to do it then, but she was given the job the next day, so in fact could’ve done the whole thing in one visit the day before than two visits two days on the trot.”*

*(Daughter of Agnes, Lack of mobility, Worthing)*

Where patients had more than one stay in hospital, it appeared that assessment was carried out on a first occasion, but not for subsequent stays. This approach may avoid duplicating effort, as a second assessment may not be needed. However, there may be a risk that needs are missed if the patient’s circumstances or condition have changed.

*Interviewer: Do you think the hospital asked you properly if you would have enough support for when you left hospital?*

*Elsie: No, you’re the only people that I’ve heard from.  
(Elsie, Chronic Obstructive Pulmonary Disease, St. Richard’s)*

An alternative explanation is that patients may not have realised that a discharge assessment was being carried out. This may be more likely if, as seems to have been the case, the process is conducted too informally. There was evidence that what patients perceived as mere conversation may actually have been staff asking questions to inform the discharge planning.

Overall, participants did not give a sense that they felt they had engaged in a formal process of planning for their discharge. The Trust should consider taking steps to formalise the process, making it clear to the patient that this is happening. This may be a case of explaining the process by which discharge is planned, indicating to the patient at the start of conversations whenever discharge planning is taking place, keeping the patient informed of any changes or decisions made, sharing the paperwork with the patient as it is completed, or giving the opportunity to ask questions or raise concerns.

In some cases, patients lacked the awareness or capacity to be involved in their discharge planning, and it was left to staff to make decisions. This planning appeared to have been carefully considered, and staff were often able to explain in detail a number of actions which had been carried out to ensure the patient’s needs would be met.

*Gwendoline, a dementia patient who had been treated for Cellulitis, was being discharged back to the Nursing Home she had come from. Within an hour of the decision being made, the Ward Nurse had taken a number of steps to prepare for discharge. She checked that the family were happy for Gwendoline to be discharged. As they were unable to provide transport, the Nurse arranged this. She confirmed that the Nursing Home were able to receive Gwendoline, and explained the on-going treatment that would be needed. She discussed with the Pharmacy and the Nursing Home whether the patient’s medication should be reviewed.*

*(Gwendoline, Cellulitis, Worthing)*



These patients could be largely unaware of what would be happening to them, despite attempts to explain this to them. Nonetheless, they appeared to feel happy with the decisions which were being taken, and were confident that they would receive the help and treatment needed. However, it appeared that one or two patients had not understood the seriousness of their prognosis.

*Elizabeth had made little progress in the weeks following a hip operation. She had been largely unaware of what was happening for the majority of that time. As she had no relatives who could be involved, the decision to discharge her to a rehabilitation hospital had been made by hospital staff. Elizabeth was happy with this decision, although she felt it had not been explained to her, and she had been given very little information about what would happen afterwards. A nurse told the researcher afterwards that Elizabeth was unlikely to ever leave the rehabilitation hospital.*

*(Elizabeth, Hip operation, Worthing)*

On at least one day, it was not possible for a certain number of patients to be discharged from one of the wards, because a package of care could not be arranged.

*The Ward Nurse told me they were unable to discharge the patients today, because there was no one to provide a package of care. Yesterday, by contrast, they had discharged eight people. The nurse said that it was fairly rare to be unable to get a package of care, but suggested it was an increasing problem with the private agencies. The ward is a relatively heavy user of packages of care.*

*(Ward Nurse)*

### Reliance on relatives

Some patients were highly reliant on a relative to make decisions about their discharge. Many were perfectly content to let this happen.

*“Well, to be honest, I haven’t had a lot to say with the doctors, because a lot of the time my son’s been with me, and he... because he is my carer... well, guardian, and so he usually explains to me...”*

*(Michael, Broken shoulder, Worthing)*

While most relatives were also happy taking this responsibility where necessary, it did cause a few problems. Some of these, such as interrupted holiday plans, may be of relatively minor significance. However, one relative felt that the needs of their business, a farm, had not been considered.

*“When I took Dad in it was [the farm show] that week... and I was away... I had said to them I would not be around to help until Monday and they sent Dad home on the Thursday with nobody really here. I mean my brother was back in and out, but they sent him home on the Thursday with nobody here, having said there would be nobody here until the Monday. I don’t know what my brother said... But that I really didn’t like the thought that I wasn’t available and I had said I wasn’t available.*



*“I felt that there should’ve been somewhere. Like last time, Dad went into [a community hospital] there should be somewhere that he could’ve gone because he couldn’t walk at all and there just wasn’t anybody here. In fact my daughter ended up staying. She wasn’t meant to be here, but she was about to help keep an eye on Grandad. But that was only some of the time.”*  
(Relative of Ernie)

## The discharge decision

### Unexpected or rushed decision

A number of participants had been surprised when the decision to discharge was made. Even when the potential date had been discussed, patients appeared to view this as highly provisional, particularly if it had been revised during their stay. It was often a doctor who had made this decision, without patients being aware it was likely. This suggests that patients may not have fully understood which factors were influencing this decision, or the rate at which they were progressing toward being ready. When decisions are made in this manner, it may also be difficult for patients to discuss any needs or concerns they might have.

*“This doctor came round. I wasn’t expecting to go home on the Wednesday, not at all. I still had my cannula in... and he said, ‘Oh, I think we’ll send you home today’. ‘Oh, okay.’ I mean who am I to argue with the doctor, you know? You get a bit intimidated with them when they sort of come at you like that, and I said, ‘well, if you say so.’ He says, ‘Yes, I think you’re well enough to go home,’ and that was it.”*

*(Elsie, Chronic Obstructive Pulmonary Disease, St. Richard’s)*

An unexpected decision could trigger a flurry of other activities as the patient prepared to leave the ward. Many patients’ experience of being discharge involved a period of being rushed, followed by a long period of waiting while medication and transport were arranged.

*“I was left very much up in the air. I was told on the Thursday evening there was a possibility of me going home the next day but right up until about an hour before they took me down to the Discharge Lounge I still didn’t know whether I was going or staying or what. Then they suddenly came around and said, ‘You’re going down to the Discharge Lounge in an hour.’ So I had to get the nurses to stuff my things into bags, ring my husband and let him know, and then I waited down in the Discharge Lounge I think for about four hours, maybe more.*

*“I had plenty to drink but nothing to eat, even though I was still there at gone what would have been supper time. It was all done up to a certain point maybe, and then all of a sudden you are, and it was all a rush.”*

*(Josephine, Ulcerative Colitis, Worthing)*

For another patient, the discharge decision involved liaison with a number of different people and organisations. It was therefore necessary for the decision to have been made in advance. This process appeared to have worked well in this case.



*“Yesterday, I agreed with the carers and... I heard today that the authorities have agreed to it. It’s a bit of council funding that’s just been agreed, I heard today, and I gathered her sister and everyone’s happy for the Monday discharge date. So, it’s actually, today, I suppose, finally agreed, confirmed.”*

*(David, Carer for Marilyn, Stroke, Worthing)*

On another occasion, a decision about discharge was dependent on the timing of scan results. It was not clear whether it had been possible to schedule the scan (and delivery of results) in order to support the smooth running of patients’ discharge.

*Warren was told around mid-morning on the day that he was being discharged. This was because the doctors had just received the results from the Neurology department at University Hospital Southampton. The Consultant said he could go home after lunch, which he’d already ordered. The ward sister came and said that they would need to move him to the Discharge Lounge. This was sudden and gave him no time to say good-bye to anyone, which he would have liked to have done. He said that he felt that the move to the Discharge Lounge was ‘a bit precipitous’.*

*(Warren, Stroke, St. Richard’s)*

### **Clear information about the decision**

Where decisions about discharge involve information from several sources, the potential is introduced for delays to occur in sharing important details, or for it to be unclear whom the decision rests with. There were incidences of confusion for both patients and hospital staff.

*Barbara: The day before, they didn’t know whether I was going home, the day before or that day, and there was nothing definite. And I suppose you can’t blame anybody for that other than it filters down, ‘We can take her...’*

*So they don’t know any more than [that]... When they come to tell me, they haven’t been told [themselves] very long. ‘Oh, you’re going home today.’*

*I said, ‘Oh, right, okay. Do you know when?’*

*‘No, we can’t tell you that.’*

*(Barbara, Leg injury, St. Richard’s)*

*“One day the doctor came round and she said, ‘You are doing very well, we think we can let you go.’ And I thought she said 20th June. And the physio said, ‘No, no, no. He wants another week on top of that.’ [The next day, the physio contradicted this, explaining] ‘I thought they wanted to send you out next week; that is too early. There is no reason why you can’t go out then.’ And then they let me out a day before...”*

*(Donald, Stroke, St. Richard’s)*



Discharge planning could be especially complicated for patients with more than one condition, as a change or delay in any one of their treatments could affect the overall timescale. This could be confusing for staff as well as for the patient.

*“That’s something that I found not only on my own case but on other patients, the discharge dates being changed all the time... They weren’t able to get a date in which the three surgeons who want to be there when I have my operation... I also had to wait for the MRI scan which they couldn’t fit in while I was in hospital. They kept trying but emergencies kept getting in the way.*

*“I think that’s where the confusion with the discharge with the staff came in... I was told that on three different occasions I was going home on a certain day and then told, ‘No way, there are no plans to discharge you yet’... I think a couple of [the Nurses] didn’t realise the seriousness of my condition. They thought that it was just the one problem that was keeping me there.”*

*(Josephine, Ulcerative Colitis, Worthing)*

Where family members are responsible for providing caring, it is important that they are consulted and kept informed during the discharge planning. One relative had not been informed that the person they cared for was being discharged, and so was not present when they arrived home.

## Inappropriate discharge

The majority of participants were happy with the decisions taken about their discharge. Some, like Donald, felt that their condition had been carefully monitored, and their needs accurately assessed.

*“They won’t let you out just like that. And I was glad about that, you know? You think I can do that. But I did find when I got home here I thought there were things that were more difficult but they watched me and they said, ‘Yes you will cope.’ And I do cope, but you have just got to take it steady, you know?”*

*(Donald, Stroke, St. Richard’s)*

However, this was not always the case. Some participants felt that the discharge happened too early. This seemed to be more likely when the patient’s symptoms had been treated but the underlying cause had not been addressed. While some patients had clear ongoing plans to deal with this, some felt they had been dismissed. Others lacked confidence that the plans were adequate, or were unclear what would be done.

*“I wasn’t very impressed with the doctor when he came round to see me on my last day. He said I’d still got a lot of infection in my right lung; and your left lung’s not that good either. But they sent me home. I had some antibiotics to come home with, but I feel that they could have done more.*



*“I wasn't 50% better. No, I felt a lot better but not 50%, not 100% better, 'cos I was still coughing a lot... I feel that they should have kept me in a bit longer to find out what else they could do. I know they need the beds and everything, I know they're awfully busy, I do understand that, but I just feel... And my daughters [who are also medically trained] said exactly the same thing, 'They sent you home too soon, they do this every time, they send you home too soon.' And that happens every time, they send you home too soon.”*

*(Elsie, Chronic Obstructive Pulmonary Disease, St. Richard's)*

## Readmission

Other patients were discharged swiftly after being treated, but were then readmitted in the following days, after their condition deteriorated or failed to improve.

*“I was in on the [day] I had the fall, and they kept me in overnight, discharged me on the Friday. The following Saturday a friend of mine [called 111] because my arm was all swollen up, black and blue, and he didn't like the look of it...”*

*“The 111 duty doctor came out and saw me... He didn't like the look of it at all, because it was so badly swollen. I couldn't even move my fingers. He said he didn't like it, so they took me in hospital on the Saturday night, and I came out on Monday. So, it was probably two nights I was there the second time.”*

*(Michael, Broken shoulder, Worthing)*

*Olive had been hospitalised with a bladder condition, but also had a number of conditions, some of which were related, others incidental. She was discharged after two days. Olive had not informed her family of this, seemingly because at the time, she felt very depressed.*

*She was readmitted two days later. A nurse told her that ‘I knew you'd be back; you didn't seem right.’ She had since stayed in hospital for a number of months, during which steps had been taken to build her up physically, and to address some of her other health conditions.*

*(Olive, Bladder condition, Worthing)*

## Conflict between patient's needs and wishes

Two particular cases demonstrated the potential challenges of getting discharge right for patients. Barbara's experience shows how conflict which can exist between what patients might want to happen and what might actually be best for them. Barbara had been left in severe pain after a leg injury. Although x-rays had been carried out, no break had been found, and the cause had not been identified. Despite this, the pain (which she described as “excruciating”) persisted.

*“I was in extreme agony, absolute... When I was lying in bed, I was fine, so if anyone came up to me and said, ‘How's your pain?’ I'd say, ‘Well, laying here it's fine.’ I couldn't move.”*

*(Barbara, Leg injury, St. Richard's)*



Barbara was a highly independent person, and found it challenging to remain in hospital. She didn't sleep well on the wards due to noise and feeling uncomfortable in the beds. She disliked having various treatments (including injections), and did not enjoy being dependent on others. She also found a number of individuals difficult to get on with. On account of this, she persuaded the medical staff to discharge her.

*"I was convincing them that I wanted to go home and I knew that I couldn't just go, they'd wash their hands of me. 'Do you think you can manage?' I said, 'Yes, I'd be better off at home,' so they said, 'we'll see what the OTs and physios say.'*

*"They both came down and they watched me walk with the frames and okayed it. I must be honest, I will be honest with you: I was a bit scared, but... I thought just a good night at home will be a tonic, and it was. Although it's been slow, I've coped."*

*(Barbara, Leg injury, St. Richard's)*

Although Barbara preferred to be at home, it appeared to be a difficult environment for her to be in. She postponed a scheduled interview by a week, because the pain had not subsided. Although she was clearly very resourceful, it appeared that Barbara had underestimated the challenges which would face her at home, and the amount of time it would take for her to recover.

*"I was pretty scared when the ambulance men went... once the door was shut, I felt 'oh, I'm a bit scared' [of the pain]... you sit down and you think, 'I feel fine'. It's when you get up and you get a bit of a shock with one foot forward and there's this terrible pain."*

*(Barbara, Leg injury, St. Richard's)*

Although Barbara had been supplied with some equipment to support her mobility, she had misled the medical staff about being well enough to use them. This led to her sleeping in an armchair for several weeks, and not managing to wash herself for a number of days.

*"And they gave me a piece of equipment [to]... lift your foot up. And I pretended it was okay, but it wasn't. That's my fault. I accept responsibility. But I thought when I got home, I thought when bedtime came I'm not going to risk this, I'm not going to do it. Firstly, it's going to be agony and an age to get into bed, and then I was frightened about would I ever get out of bed? And that chair goes flat, so I laid in that all night and I had the best night for two weeks, and I've slept in that ever since."*

*"...I was glad to get home, take all my clothes off, throw them in the wash, put a clean dressing gown on and I didn't get dressed for about four or five days. But I pottered around and I did get on better at home."*

*(Barbara, Leg injury, St. Richard's)*



In the interview, Barbara maintained that coming home was what she had wanted. It appears that medical staff had recognised this, and had made the decision to discharge her based on the patient's wishes. However, visiting the Barbara at home two weeks later, it seemed as though she had taken a risk in doing so. She also recognised that for others in her position, it may not have been the right course of action, although she did not apply the same verdict to herself.

*Barbara: [The OT and the Physiotherapist] knew I was resourceful, I think. They knew I was very independent, I'm sure they did...*

*Interviewer: Do you think you satisfied them that actually you would be able to cope?*

*Barbara: I think so, I'm not sure... I did sense that they [agreed to discharge me] 'cos they know that's what I wanted them to say.*

*Interviewer: With hindsight, do you think that was the right thing for them to have discharged someone in your position?*

*Barbara: Depends on the person. If it was an older person and I sensed that she really didn't understand how bad she was going to be, perhaps not. Possibly the answer to that would have been no.*

*(Barbara, Leg injury, St. Richard's)*

It should also be stated that the cause of Barbara's pain, which was still present three weeks later, had not been diagnosed. No medical follow-up had been put in place.

### Patients who are carers

Mary's case demonstrates the pressure which patients can feel if they have responsibility for looking after others. She had undergone a planned knee replacement operation, as osteoporosis had been causing an increasing amount of pain. Mary had put off the operation for over five years, because she is the carer for her husband, who has undiagnosed dementia. Mary was aware that he could not be left on his own, but would find it difficult to cope with staying elsewhere.

*"I feel awful because I think well if I hadn't have sent him he wouldn't have had to go through all that, but then I didn't have a choice. I just could not stand the pain any longer, I just couldn't do it. I was on the strongest painkillers I could get, you sleep half the day because you are drugged up with painkillers. They weren't doing a great deal...*

*"I kept asking and asking and asking over the years and he kept saying, 'No I am not going to stay with anybody'. But in the end my daughter came across and said, 'Mum can't be like this anymore, she is nearly on the floor. You have got to do something.'"*

*(Mary, Knee replacement, St. Richard's)*



Mary's husband stayed with their daughter while she went into hospital. Her discharge was delayed, as she developed a kidney problem. She was acutely aware of the effect this was having on her family.

*"I dropped my daughter in the deep end really. Because I thought three to four days at the most I had expected, but because of other problems it didn't work out like that. I felt rotten in hospital, I didn't feel well, whether that was because of the reaction to the [medication], whether it was because the kidneys weren't working very well I don't really know. But I just felt awful.*

*"And 'cos three days went to four, four days went to five, they were phoning me up in hospital and saying, 'Dad is doing this, Dad is doing that, Dad don't recognise us anymore'.*

*"And I said, 'But I can't do nothing, I am trapped, I am trapped here'... I didn't know what he would be like out of his comfort zone, he has never been away before, he has never been out of his comfort zone... He was totally lost. And 'cos we did wonder when he came back what was going to happen..."*

*(Mary, Knee replacement, St. Richard's)*

It seemed as though Mary's concern for her husband was a significant underlying reason in her wanting to leave hospital when she did. Despite this, Mary gave a different reason.

*"I honestly don't think that from their point of view keeping me in hospital was going to ... I just wasn't picking it up, I just wasn't ... If it is going to take me time [it's] something that I don't need to take up a hospital bed for. Because I can get physios to come in... I don't think it would have been worth me taking up a hospital bed just for that..."*

*"I suppose I would have never liked to be a problem to people... And I am thinking, 'Well it has got to be me, I am not putting in enough effort.' I can't quite see the point of being waited on in a hospital bed when all I need is the confidence to get moving."*

*(Mary, Knee replacement, St. Richard's)*

Despite this, Mary acknowledged that it would have been easier for her to recover without the responsibility of caring for her husband. This was also complicated by some non-medical issues. Mary's freezer broke down, leading her to lose a significant quantity of food. She ordered a replacement, but this also did not work. Mary had been intending to put in a claim for Attendance Allowance, to provide a cleaner. But two weeks after leaving hospital, she had not got round to doing so.



## Voluntary sector

Several participants mentioned that they had used voluntary sector organisations. They were all satisfied with the service they received.

*“The home help was done through Age UK... It was just mainly, because I used to do all the hoovering and that. But I said I’m no good at polishing, and I hated polishing, so they used to come, do the polishing and the dusting, and Hoover through. So, that eased it off, took it off of me, and I’ve just kept it ever since. But, I know I can always get extra help, if I needed it, from there... I have to pay for the Age UK lot. It’s only £8 for an hour.”*

*(Michael, Broken shoulder, Worthing)*

Only one participant mentioned receiving help to resettle back at home on the day they were discharged. Although it was observed that leaflets about this type of service were available on the wards, it usually required the ward staff to decide whether this would be useful for the patient or family. One member of staff felt that more needed to be done to ‘plug’ these services.

Another patient was given this information by a volunteer who had visited the ward. She appreciated the personal contact, and it appears that this arrangement may allow more time for the volunteer to explain what services they deliver.

*Norma was given extensive physiotherapy and occupational therapy after breaking her hip and arm. She was supplied with a range of equipment at home. She had been visited by a volunteer, who had given her leaflets about help available once she left hospital, such as ‘doing a bit of shopping for you’. It was left for the patient to decide whether this support would be any help to them. In this case, she was confident that she could access the support from home once she had returned. However, it seemed clear that she had valued the contact made with the volunteer, which had helped her to think through what she might need.*

*(Norma, Broken arm and hip, Worthing)*

## Recommendations

6. Trusts should ensure that patients and carers are involved at all stages of discharge planning, and understand that this is a formal process.
7. Trusts should review their discharge processes to ensure carers’ situations are taken into consideration, to reduce the risk of patients being discharged without the appropriate support at home.



8. Trusts should ensure that their discharge processes ensure a coordinated response for patients who are being treated for multiple conditions.
9. Trusts and voluntary organisations offering support services should ensure that patients and carers consistently receive information which allows potential users of the services to understand their benefits. This could form part of the discharge checklist.



# The day of discharge

## The Discharge Lounge

The day of discharge went smoothly for many patients.

*Jean had been treated for a chest infection. She was informed the day before that she would be going home the next day. On the day itself, the pharmacist on the ward sorted out her medication. She waited a little while on the ward, and went down to the Discharge Lounge around midday, where she had lunch. She contacted a friend to pick her up, who arrived at around the same time as her medications. She was given all the relevant paperwork, such as a letter for GP, at the same time. Her total wait in the Discharge Lounge was one hour. She felt that the whole discharge had gone very smoothly.*

*(Jean, Chest infection. St. Richard's)*

Although some patients were discharged directly from the ward, many spent some time waiting in the Discharge Lounge<sup>3</sup>. Patients who did not have to wait too long found these to be pleasant locations.

*Ray was offered food but had already eaten but did have a cup of tea. He found the Discharge Lounge to be 'tremendously comfortable'. He was not awaiting anything other than transport. He waited for approximately 1.5 hours.*

*(Ray, Digestive system infection, Worthing)*

*"We just sat there and I had a natter to the lady there, you know? And that was it. The television was on and it was relaxing. So it was just a case of waiting."*

*(Donald, Stroke, St. Richard's)*

Many patients experienced a wait of at least several hours, either for medication or transport. This could be inconvenient or uncomfortable.

*"For some people like myself, some of the seating could have been more comfortable. I get uncomfortable if I'm in my wheelchair for long periods, and that day I was in my wheelchair from nine in the morning until I got home so I was in it quite a few hours and my back was beginning to really ache but the chairs there were not really ones that my back would get comfortable in. There were quite a few people waiting in the Discharge Lounge too. They'd got the armchair type chairs, so [I was sat in] just an ordinary one."*

*(Ava, Sickness)*

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<sup>3</sup> Also referred to as the Goodwood Lounge at St. Richard's Hospital.



## Food

Most patients were offered food in the Discharge Lounge, or had eaten lunch on the ward before moving on. While the need for food is obvious, patients who were returning to an empty house were especially concerned to have eaten well.

*“While I was waiting for the ambulance, they were incredibly nice there, offered me sandwiches, coffee, yogurts, banana... But I thought if I have a meal here, I haven't got to worry about that when I get home, but when they were taking me to the other ward I said, ‘Oh, am I going to miss my meal?’ They didn't do meals in the Departure Lounge, but as many sandwiches as you wanted. I mean they couldn't have been nicer.”*

*(Barbara, Leg injury, St. Richard's)*

One participant, Josephine, was on a restricted diet due to her condition. The food in the Discharge Lounge was not suitable. Although she had brought her own packed lunch, a long wait meant she became hungry again. Josephine felt that staff should have been made aware that she also had diabetes. She suggested that other patients may have become hungry again later in the day.

*“I was worried I was going to have a hypo before I got home and the fact that I hadn't even got a biscuit that I could dunk in a cup of tea because I can dunk them and make them soggy...”*

*“I did ask if anybody had got a biscuit, one of the other ladies said, ‘I've got some.’ [The staff] just seemed to be busy all the time, seeing people in, seeing people out, so no, I didn't...”*

*“The Discharge Lounge could perhaps have a sandwich machine or something like that, somewhere where people can get something to eat if they need to. It's lovely having all the drinks on tap but there should have been some way for people to get something to eat, because one of the ladies from our ward went down before me and she was still there when I left, so she hadn't had anything to eat since before lunch.”*

*(Josephine, Ulcerative Colitis, Worthing)*

## Medication

The most common cause of delay was patients having to wait for their medication<sup>4</sup>. It was not unusual for patients to wait around four hours to receive this. Some patients found they needed to ‘make a fuss’, threatening to leave without their medication or offering to come back the next day. Several participants reported that other patients had actually become fed up of waiting and left without their medication. It was not clear whether they had been able to obtain this in another way.

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<sup>4</sup> TTO - ‘To Take Out’



*Dorothy waited in the Discharge Lounge from 11am, but was told not to arrange for her husband to collect her before 3pm. When he came to pick her up, she still didn't have her medication. She told the staff that if she couldn't have it immediately, she wanted to be discharged without it. This made the staff rush around, someone went to collect her medications and she got them straight away.*

*(Dorothy, Suspected kidney stone, St. Richard's)*

*"You just have to be a little bit patient. There was one woman waiting there, and she rang her friend to come and pick her up... She was waiting and waiting. In the end, the woman said, 'I can't wait any longer, I'm off'. So, her friend said, 'Right', and off they went."*

*(Michael, Broken shoulder, Worthing)*

### **Availability of pharmacists**

Several accounts suggested that the delays may have been due to an absence or shortage of pharmacists. One patient suggested they had been told the pharmacist had been on their lunch break. Although it is clearly important for medical staff to have breaks, in this case, the timing appeared to coincide with the busiest period in the Discharge Lounge.

*"I suppose I was ready to come out before lunchtime, but it was about two o'clock in the afternoon when I finally got out, because with the lunchtime of the dispensary, they can't... dispense drugs when the pharmacist [was not there]."*

*(Michael, Broken shoulder, Worthing)*

Other participants mentioned similar problems in receiving medication on the ward. One had to wait until around 2am for some sleeping tablets. Another was told that a backlog after the weekend was to blame.

*Diane had to wait on the ward for medication, which didn't arrive until just before 7pm. She asked a member of ward staff, who chased it up and the medication arrived quickly then. Diane thinks it was a case of it needing to be brought up to the ward. She was told by a member of ward staff that the long wait for medications was caused by the fact that patients aren't discharged on a Sunday and therefore there are a large number of people requiring them on a Monday.*

*(Diane, Heart failure, St. Richard's)*

A member of hospital staff commented that a computerised prescribing system had been introduced. This was speeding up the process, although at that time, there were still teething problems which were one reason for delays.



## Information about medication

Staff in the Discharge Lounges were seen to be active in fetching medication from the pharmacy, and verbally talking through what was required to be taken when. Patients are issued with paperwork which details this, but it seemed that people could find this confusing; it appeared that some may not have remembered and understood everything they were told by the time they got home.

Some doctors had used abbreviations which even the staff in the Discharge Lounge did not understand. One suggestion which was made was for a clearer record card to be issued, which listed all drugs, when to take them, what they are for, and details of any side effects or special conditions.

*A Nurse goes through a list of medications with a patient and their relative, showing them which box is which. They put one aside to 'check in a minute'. Some drugs appeared to have been previously taken, plus some additional medications given by the hospital. They were given two weeks' supply, so the relative asks if it will be on prescription afterwards. The nurse is unsure why only two weeks were given, as it's usually a month. Some come in a cartridge, so the nurse checks they have a pen to administer. They say they will query one drug, as the number of times to take daily is different to what's been supplied. The relative is worried about insulin - they have been supplied with 22 units, but the amount needed depends on diet. They are not sure how to get more if needed.*

*(Researcher observation, Discharge Lounge)*

## Drug allergies

Several participants were allergic to a particular drug. One was able to request an alternative which they knew from prior experience suited them. This did not appear to have been noted in their medical records. Another patient, Mary, had not been told she had suffered an allergic reaction to that drug.

*"They had shown me how to do the Heparin injections... The day that I came home they said, 'We have arranged for the district nurse to come in to do your Heparin'. And I said, 'Well I am going to do those myself'. And she said, 'Oh no they have changed it now you are on something different'. And they didn't say why..."*

*"When the nurse came out to give me the Heparin injection... I said to her, 'But why can't I do this? I learnt to do this'. She said, 'But you had a bad reaction to Heparin in the hospital'. Well I didn't know that. Nobody told me I had had a bad reaction to Heparin..."*

*"And I thought well why didn't somebody tell me because I have got the other knee to have done? And if I have got an allergy to that Heparin then I should really know because I don't want it to happen next time."*

*(Mary, Knee replacement, St. Richard's)*



## Transport

Most participants who used patient transport (arranged by the NHS) were satisfied that the journeys themselves were comfortable and ran smoothly.

*“The transport was marvellous, no trouble at all. The journey was comfortable. I was wheeled out of hospital in a wheelchair and the same at the other end.”*

*(Patricia, General sickness, St. Richard’s)*

However, many patients had long waits for their transport to arrive. Others were forced to make alternative arrangements.

*The patient was offered hospital transport, but none could be found, so they were forced to wait until later in the day for their son to collect them.*

*(Matthew, Chest and urinary infection, Worthing)*

*“It was all a rush, and then wait again, and [being] told the transport will be here between that time and that time, but on none of the occasions did it turn up for any of the other people until way after that time that it had said.*

*“[My information] said between 2:00 and 4:00 and it was well after 5:30. On one occasion when I was in, the transport people forgot me altogether, they ended up having to ring and get an ambulance from Uckfield to come and take me home.”*

*(Ava, Sickness)*

Discussions with staff indicated that transport arrangements do not always work as well as they could.

*Some patients are surprised that they can only take one bag on patient transport, as they often have more than one with them.*

*Transport organisations are given a two-hour window in which to collect their patients, but these are not always adhered to. This can cause difficulties if a patient has a package of care booked, such as a carer due at their home. In certain rural locations, bookings get pushed backwards because crews don’t want to travel out to those locations in late evening so it gets reallocated. It gives a bad impression if the estimated arrival time keeps changing, and forces staff to stay beyond the end of their shift.*

*Private crews were seen as having a better attitude and being more punctual. ‘They are willing to be flexible and even take people that they aren’t allocated to take.’*

*Worthing only has one Transport Coordinator while St. Richard’s has two, although Worthing has more patients.*

*(Discussions with staff)*



A number of patients were able to use patient transport despite having restricted mobility (such as using a wheelchair or crutches). However, one person found this problematic.

*“One thing I did find difficult, I had to transfer out of my wheelchair into an ordinary seat in the bus rather than being able stay in my wheelchair. Transferring from my bed to my wheelchair or from an armchair into my wheelchair, I’m fine because I’ve got the things to hold onto. But when you’ve just got a small seat at the side of you and your balance isn’t very good, it’s not easy to transfer over at all. The gentleman realised and he helped me, but he was trying to sort out the rest of them at the same time.”*  
(Ava, Sickness)

### Arranging private transport

Many patients arranged their own transport, usually relying on a relative to do this. While some had the flexibility to come at whatever time was needed, other patients had to wait. One patient encountered on a ward appeared to be having particular difficulty in finding someone to come and collect her. Another had to rely on a taxi, but did not arrive home until the evening.

*Diane’s daughter was unable to collect her mother as she was working so Diane decided to get a taxi home. A member of ward staff phoned up on her behalf. She was given an evening meal before leaving the hospital. She did not arrive home until 7.30pm. She felt that while this was okay in the summer, it would have been potentially hazardous if it had happened during the winter months.*

*(Diane, Heart failure, St. Richard’s)*

## Recommendations

10. Trusts should ensure that, wherever possible, patients being discharged alone have access to appropriate food (preferably a hot meal) before leaving the hospital.
11. Trusts should ensure that patients who wait for longer than a few hours in Discharge Lounges can access food. This should include patients with specific dietary needs.
12. Trusts should aim to ensure that drugs to be taken home are made available at the time of discharge, reducing the need for patients to wait for hours in the Discharge Lounge.
13. Trusts should review the information provided about medications on discharge, to ensure it is as clear as possible for patients and their carers. This should include being able to identify each medication, as well as understanding what each one is for, when and how they should be taken, and any potential side-effects.



14. Trusts should ensure that, wherever possible, patients are informed of any complications arising from their stay in hospital, such as allergic reactions to drugs.
15. Clinical Commissioning Groups should note and consider what patients and staff have shared about transport when commissioning transport services.
16. Western Sussex Hospitals NHS Foundation Trust should review the transport co-ordinator arrangements and ensure there are appropriate arrangements for both Worthing Hospital and St. Richard's Hospital.



# After discharge

## Carers

Around half the participants received some form of care after leaving hospital, providing assistance with either medical or personal needs. This is in addition to care given by relatives. The majority of participants were satisfied with the service they received, and were grateful for the provision.

Many patients received care from more than one organisation, each of which might send a number of different individuals.

*“You don’t get the same one every time... I had one this morning, she said, ‘Well, I won’t see you tonight, it’ll be one of the other nurses’. But, the one that came today... goes all over the place. First day or two, I had a lot from Crawley in the morning and at night, but there’s different ones; they just have to go round as and where they can.”*

*(Michael, Broken shoulder, Worthing)*

As one participant noted, there could be a big difference between the approaches of different carers. In particular, some failed to meet patients’ needs fully, as they did not show enough initiative to work out what was actually needed.

*“There are two types of people that come and help. Most of them have been absolutely brilliant, in fact almost to go over the top of what they’re meant to do and been really helpful.*

*“Twice nobody has turned up and I’ve phoned up and they’ve said, ‘Somebody has been and she says she’s fine’. What they don’t do is look at her. You know and see that I’m fine actually she’s not fine, she can’t get up, she can’t go to the toilet because she can’t walk.”*

*(Daughter of Agnes, Lack of mobility, Worthing)*

Michael felt that his carers were able to be consistent in the care they delivered, in part because they kept detailed notes. However, it also seems that he was able to make it clear what he needed. This may be more difficult for other patients, such as those who have dementia, who may be at risk of receiving less consistent or suitable care.

*“They make notes of what they do, and how long they’re here, and they have to book it all in when they go back... They do quite a bit of writing, and then when the next one comes tonight, she’ll look and see what she’d done this morning...”*

*“It’s like this morning, when she washed under my arm - she knew I couldn’t lift my arm up, so I just held my arm up like that so she could get the towel under there, and dry it.”*

*(Michael, Broken shoulder, Worthing)*



When providing personal care, it can be important to gain the trust of the person. Although some participants found it easy to accept unfamiliar carers, others appeared a little bemused at the wide range of individuals who were involved in their treatment. Several gave lists of the various different nationalities of their carers. In doing this, they did not give the impression of being uncomfortable with foreign carers, but some people may have found it easier to cope with one or two regular carers.

This may be particularly the case where carers are required to give intimate care. Although Michael explained that he did not feel embarrassed, the question was clearly one he had considered. Other people appeared to be more reticent about receiving this type of care.

*“Well, I don’t take notice of it. It’s their job and they’re used to it, and seen it all before, as they say, so... I mean, having been in the forces as well, so I don’t get embarrassed about things. It’s no good getting embarrassed about it, because it’s their job.”*

*(Michael, Broken shoulder, Worthing)*

The range of organisations and individuals can make it difficult to understand what role each should play, and to keep track of appointments and visits. Agnes was being looked after by her daughter after a fall. The family talked the researcher through a ring-binder which was full of letters, information booklets and record sheets. However, both they and the researcher quickly became confused as to which organisation was doing what. This was exacerbated by the similarity of some of the names of the services.

Agnes’s main wish was for a single point of contact, who could oversee the range of care services and medical treatments she was receiving.

*“I’m quite glad you’re confused because it is confusing... There doesn’t appear to have been any one person, there have been a lot of very helpful, caring people, but I don’t know how many I’ve had. I mean a dozen at least I should think.*

*“What I just personally feel was that there was no one person to say, ‘Yes we know all about your hips and what you’ve done previously’... I just feel that there should be one person who appears to be in charge of all the others.”*

*(Agnes, Lack of mobility, Worthing)*

Another patient shared a similar collection of paperwork and leaflets. Some of these were of faded photocopies of poor appearance. Others were several years’ old, predating recent changes to the NHS, and therefore gave incorrect, out-of-date information, including contact details.

The quality of information on some was also poor. Some leaflets were rather vague about what service the patient was entitled to, or what provision had been made. For this reason, a number of participants were more than a little unclear about what support they should be receiving.



The clearest forms of information were often those prepared specifically for the individual, for example, a list of physiotherapy exercises. Although these tended not to be well presented, the participants understood what they said and were able to follow them. There may be benefit to adapting generic leaflets about services, to include specific details of the provisions which the individual patient should receive.

### **An experience of care through direct payment**

David was the designated carer for his wife, Marilyn, whose mobility was gradually reducing after a stroke. Marilyn had previously received care from an organisation funded by West Sussex County Council. However, they had found this service unreliable.

*“They sometimes didn’t turn up; sometimes they were very late, and you’d wonder if they were coming... They were due, say, at eight o’ clock; half past ten, no one would turn up. Way out. All different carers would come.*

*“We couldn’t rely on it... You just couldn’t rely on them coming. I mean, one day we had a doctor’s appointment. I could get my wife out at that time to the doctor’s, and if they were three quarters of an hour, an hour late, then she wouldn’t be ready in time to see the doctor. You’d allow what you think was a reasonably safety margin, but not an hour late. So, we had to cancel a doctor’s appointment once. It’s the unreliability, mainly, that was affecting us, and you get fed up with it.”*

*(David, Carer for Marilyn, Stroke, Worthing)*

David suggested that the problem stemmed from the firm and the environment in which they operated, rather than the individual carers.

*“Most of...well, all of the carers were complaining about the firm, and the stress they’re under. Lots of them were leaving. So, they were really having trouble, and it must stem from the management, really. I gather, reading in the papers and so on, that their problems, generally, is that they’re not adequately funded.*

*“One of the things the carers were complaining about was, they weren’t paid their proper mileage. They’d have a last call, and they wouldn’t pay the mileage home. When calls were cancelled, it was the last minute and they suddenly missed that slot and missed that pay... So they’d have three quarters of an hour where they couldn’t do anything; it’s in the middle of [the day] but they weren’t paid for it...*

*“They were very short staffed, and the manager and assistant manager from Worthing [had left with stress]... One day at quarter past eight in the morning, they said, ‘Sorry, we haven’t got anyone we can send you today’. That happened more than once... I think so many carers had left, they obviously didn’t have the staff. The individual carers were okay, but it was the organisation behind them that was causing the problems.”*

*(David, Carer for Marilyn, Stroke, Worthing)*



Using the flexibility available under the direct payment mechanism, David applied to receive care through Guild Care. He was very pleased with this service.

*“I think they’re the best there is, the carers. We’ve found them very, very helpful. When you phone up, they’re friendly... One or two things don’t work perfectly; they can’t always get the times you want, and so on, but I feel we’re in good hands with them, put it that way...”*

*“The staff speak well of Guild Care. All the staff seem to muck in to put it together, and they seem a real team. You can tell - it rubs off; they’re happy when they come. The individual carers at the other one were okay, but it was the organisation behind them that was causing the problems.”*

*(David, carer for Marilyn, Stroke, Worthing)*

David uses the freedom offered under direct payment to buy this care. However, this is only possible because he is able to top up the amount received from the County Council.

*“Now, the council send a payment every four months, and I have to add to that about £70 a week extra we’d need... That’s the only way we could get into Guild Care because they weren’t taking on any more council places, they were only taking private clients...”*

*“They’re a charity, and I suppose they’ve only got a certain amount they can do, because I think they don’t get enough money to cover the costs... So, the only way I could get them was by going as a private client, and the fact, it doesn’t directly concern Guild Care that we’re being helped by the council. We’re a private client, as far as they’re concerned.”*

*(David, carer for Marilyn, Stroke, Worthing)*

Overall, David was very pleased with the service received from Guild Care. Nonetheless, he was able to suggest one improvement to the service.

*“Just the times of visits, in the evening could be improved... There’ve been just one or two quite extreme cases, where someone was going to come at quarter to seven and they came at half past five to put my wife in her nightclothes. We were still having tea.”*

*(David, carer for Marilyn, Stroke, Worthing)*

### **Patients underestimating what is required**

Some patients appeared to underestimate the amount of care they needed. This could be for a number of reasons. Some wished to retain their independence, even when this was no longer realistic. Others had not fully anticipated how difficult they would find it when they left hospital. Still others did not wish to cause a fuss, often arguing that there were other people in greater need.



*Interviewer: When people ask how you are and you say, “I’m fine”, what do you mean by that?*

*Agnes: I’m saying I’m not complaining, that’s basically what I’m saying... Some people moan, they’ll moan about anything. I mean yes, I can sort of give up and not try and get up the steps and do my exercise. I mean they emphasise that you must exercise your muscles or you will lose your muscles, so therefore well I feel you must push yourself to use those muscles.*

*Daughter: ...The biggest problem is mother always has done so much for herself and always says, “I’m fine”, well she might be fine, but you still need some help, don’t you?*

*(Agnes, Lack of mobility, Worthing)*

This suggests that merely asking patients what support they need might not be sufficient to identify what is actually needed. As identified earlier, some patients would benefit from practical help or guidance in understanding what equipment and assistance might be useful when they leave hospital. Other patients needed someone close to be persistent at persuading them to accept some extra help. This begs the question of who would perform this task for individuals who do not have someone to do this for them.

*“I’ve got a home help comes for an hour a week; she does the polishing, hoovering the bedroom and the hall and this room, and she even does my ironing for me... But, that was the only help that I had, because somebody kept moaning and moaning at me, ‘You should have somebody’. So, I said, all right, to keep them quiet, I just... It’s only for an hour, so... Plus, the fact that it’s a little bit of company for a little while.”*

*(Michael, Broken shoulder, Worthing)*

## Funding and eligibility

Only a few participants made specific mention of funding. It seems that for most, services had been arranged without them having to deal with this issue. David had applied for funding from West Sussex County Council, and found the process very straightforward.

*“[The social worker] has been in touch with the council, because my wife gets a social payment each month, but it isn’t enough to pay all the carers, so I top it up. They call it direct payment, I think. We had to open a special account, send them regular statements and all that sort of thing - that’s up and running.*

*“I’ve heard today, confirmed, they’ve agreed an improved package... It’s only taken days, it’s fallen into place quite efficiently, really...”*

*“The OT here contacted the social worker, who’s based at the hospital, and she contacted me... They’ve seen how she is; they phoned the Guild Care... to confirm the arrangements are in place. So apart from phoning Guild Care, I haven’t actually had to apply. They know what was needed and they’ve done it, more or less, really.”*

*(David, carer for Marilyn, Stroke, Worthing)*



Another participant's financial situation was shaped by their career as a farmer. Their provision for retirement was held as savings rather than a pension fund. They felt they were disadvantaged when it came to applying for funding, because means testing took these savings into account. By contrast, someone with a pension would be assessed on the income it provided, but not on the total value of the pension fund.

*“Because we own the farm, Dad has never paid into a pension fund, he’s always saved his money so the interest from the money is what he has as his pension, instead of having a pension. So therefore, because the money is in ISAs and then the interest is there to live on, they then take all that money.*

*“You’ve got a pension fund presumably... but you’ll never have to write that on a form ... because it’s locked away. Because Dad doesn’t have a pension fund, he has savings to live on the interest as his pension, because we’re self-employed farmers. Therefore all that pension fund they go ‘well you’ve got all this money, you can spend it’, which would then leave Dad with no pension.”*

*(Relative of Ernie)*

### Claiming for Attendance Allowance

Mary was considering putting in a claim for Attendance Allowance, to provide some help with cleaning. It was clear that this would be helpful for her. However, she appeared a little concerned about whether she would be eligible, and also keen to justify that it was actually needed.

*“I think probably I have been entitled to it for a long, long time. But I don’t know how to go about getting it... It is just daily things like hoovering your bedroom, changing your bed, cleaning your bathroom, just running the Hoover through. I can’t clean baths at the moment, maybe I might be able to in time to come again, I don’t know. But at the moment it is quite painful to try and lean over a bath and do that. And I have never lived in a state like it is now all my life because things have gradually gone downhill and I just can’t keep up with them, you know? So the time has come where I need a little bit of help.”*

*(Mary, Knee replacement, St. Richard’s)*

Mary had been given the relevant contact information to make a claim while she was still in hospital. However, even several weeks later, she had not got round to arranging this. She appeared a little daunted by the prospect of applying.

*“The occupational therapist... gave me a telephone number of a main office to get in touch with the attendance allowance people which I haven’t yet done... I mentioned to him about it and he said, ‘Well I can give you a general number if you would like to ring’.*



*“But here it is no good saying go to Social Services or whatever you do, I have never claimed anything so I don’t know, because I can’t get there, you know? So it is no good me trying to go down into Littlehampton and wander through and find a place that you have got to go up steps and be assessed and all this because I can’t get down there. So I never sort of got any further with that. But I will have to now phone them up and ask them if there is a possibility of anybody coming round.”*

*(Mary, Knee replacement, St. Richard’s)*

Another reason for the delay was that Mary had other domestic issues to handle. These were not easy for someone who was still recovering from an operation, had limited mobility, and was trying to care for her husband, who has dementia.

*“To be quite honest there is something going on every day. The freezer broke down, I had all that to deal with. Every day something seems to happen. So I haven’t got as far as doing things for myself that I would like to have done.*

*“...I bought a new freezer yesterday, apparently somebody came in this morning and said ‘[your husband] has turned it off’. And I have got £300 worth of [defrosted food] here...”*

*(Mary, Knee replacement, St. Richard’s)*

Rather than being given information, it may have been helpful if a referral had been made on Mary’s behalf, rather than her being left to make contact herself.

## Medical follow-up

Appointments seemed to run smoothly for most participants, although a number of people were not entirely clear what they were for. This was often complicated by having to deal with separate information for different services.

*Interviewer: Now, you told me you’ve got a breathing session booked next week. What will that involve?*

*Elsie: I’ve got no idea. It’s something to do with the respiratory, the Respiratory Nurse Clinic. What they’re going to do is something to do with the breathing, to breathe properly. I don’t know, I really don’t know. I really don’t know what it’s about.*

*(Elsie, Chronic Obstructive Pulmonary Disease, St. Richard’s)*

A number of participants lost their sense of daily routine while they were in hospital. This meant that they could become confused about what date or day of the week it was. Even once they had returned home, patients were often unable to get back into their usual routine. This all made it more difficult to keep track of appointments, particularly when they had several scheduled for different purposes. Some people became highly reliant on relatives to keep track of appointments.



*“My son’s got all the details, because he comes with me and he’s got one of these phones, it’s got calendars and all sorts, and he puts... Because he has to take me everywhere, and I don’t know what appointments he has, and so of course, I have to leave it to him to make arrangements to suit him...”*

*“Seems to have gone pretty smooth, from what I can make of it. I haven’t actually had to do anything; it’s all sort of been arranged from one lot to the other, and when I’ve seen that lot, they arrange for the next move, so to speak.”*

*(Michael, Broken shoulder, Worthing)*

Overall, it appears that patients would benefit from clearer information about their ongoing treatment, to help them understand what their appointments are for. Presenting information in a consistent format may make this easier to manage. Having all appointments listed in one place may also be helpful for some people.

It was notable that some patients had follow-up appointments which had been made by the hospital before discharge. Others only had their appointments made after seeing their GP. This may have been to allow the GP to assess whether follow-up treatment was needed, and to enable them to monitor it more closely. However, it may suggest that the discharge planning had not put into place everything which was necessary.

Some patients appeared to have received several visitors who each performed specific, brief tasks. Each one was important, but it may have been possible for one person to have carried out several or all the tasks at the same time. Another point made by one participant was that during a follow-up appointment with their consultant, they were asked how they were getting on medically but not how they were coping practically.

*“The carers come in only to wash from my knees down to my feet and do my feet... But I wash myself all my top and all my private bits and down to my knees, all my arms and everything, my face and everything and shave, clean my teeth and do everything else before they get here.”*

*(Donald, Stroke, St. Richard’s)*

Some patients received a follow-up phone call a few days after discharge, to check on their progress. This may have benefitted other patients who did not have any other form of follow-up arranged.

*“What would have been nice [would be for someone] to ring up and say ‘How are you getting on?’ That would have been quite nice, not bossy attitude and patronising, but just a nice OT [or] physio. It would have been nice, a friendly call.”*

*(Barbara, Leg injury, St. Richard’s)*

### **Delay in obtaining services**

Several patients experienced delays in receiving their follow-up treatment. They were concerned that this may have affected their recovery.



*Warren was referred to Bognor War Memorial Hospital for Speech and Language therapy after his stroke. He had been told that it would be between 4-6 weeks following discharge. After this time had elapsed, he phoned to chase the referral. He was told that the speech therapist was going on holiday, and that his therapy would start when they returned. This would be more than two months after Warren's stroke. No explanation was given for the delay.*

*(Warren, Stroke, St. Richard's)*

*"A physio came... and he helped us up the stairs and helped mother into the car which was very, very difficult. He did actually phone... to make sure that she'd got back again alright because he was concerned because we had a wheelchair as mother couldn't walk.*

*"But I just feel that there should be somebody else to help her, advise her, because he said, 'Oh yes, you'll get another physio'. Well a physio in two or three weeks' time might be too late. You need to get going as soon as you can."*

*(Daughter of Agnes, Lack of mobility, Worthing)*

## Rehabilitation hospitals

Several participants had moved to a rehabilitation hospital after discharge, in order to continue their recovery. They were all happy with their destinations, although some did not appear to have been consulted. These patients were also less clear about how their recovery might proceed, so found it more difficult to understand whether they were making good progress.

*"I saw them in the morning that I was coming unexpectedly because Zackary Merton had been suggested but I was told on Friday morning that I was to come here, I knew nothing about it but I was quite happy about it."*

*(Alfred, Hip replacement, Worthing)*

By contrast, one patient was involved in the decision about his destination, although it was largely influenced by a lack of availability of the alternative options.

*Alun underwent surgery at St. Richard's after breaking his leg. He felt he had also been 'very involved' in the decisions about his discharge; he were given a choice of destination. He chose to go to Bognor Regis War Memorial Hospital, as they could go there within a week of the operation. The other option had been receiving physiotherapy support at home, which he would ideally have preferred but did not choose because there was a wait of around three weeks.*

*(Alun, Broken leg, St. Richard's)*

Although the transition to the rehabilitation hospital went smoothly for most patients, one was not provided with an evening meal on the day of their arrival. A relative, who did not live in the area, was forced to provide something.



## Travelling to follow-up appointments

Several participants had found it expensive to travel to follow-up appointments.

*Diane required her leg to be dressed each week following an injury that was not healing well. A hospital doctor had tried to arrange a nurse to visit her to do this after discharge but was told by the surgery that they do not send nurses out to the house anymore.*

*As it was too far to walk to the surgery, Diane paid for a taxi. This has ended up costing £40 per month, and has persisted for a number of months. She did raise this with one of the nurses at the surgery but was told there was nothing they could do.*

*(Diane, Heart failure, St. Richard's)*

*Mary had follow-up appointments arranged at St. Richard's, but was finding it difficult to travel there. She tried to drive on the first occasion, but got lost, taking three hours to get home again. After that, she has taken a taxi. But for an all-day appointment, the taxi has to make two separate return trips, which costs £70 in total. She wondered why services could not be delivered at Worthing, which is closer to her home; or at Goring Hall, where she was originally seen, but which lacks the necessary facilities to perform the operation she underwent.*

*(Mary, Knee replacement, St. Richard's)*

## Equipment

Numerous patients had been given equipment to support them once they left hospital. Most were pleased with what they received, finding them helpful. A few suggested that they were not using all the items, but some did not seem to know how they could return them.

Others had to wait for equipment to be installed in their homes, such as hand rails. This led to them remaining in hospital for longer than would otherwise have been required. Information about when this would happen did not always appear to be clearly communicated to the patient and hospital in advance. This may have been one reason why some discharges appeared to be rushed.

*“The occupational therapist came around three times to see me. She decided that I needed to have one of the mattresses like they've got in hospital, the electric piece underneath that raises the top of the mattress and the knee part of the mattress, so that I can sleep propped up... She said there was no way I was going home until that was installed.”*

*(Josephine, Ulcerative Colitis, Worthing)*



## Housing and accommodation

Several participants raised concerns that a housing association had been slow to make adaptations to their home. A common feature of these conversations was the participant explaining how they did not wish to make a fuss. They felt it was important to be patient, believing there were other people in greater need. However, they had been left for many months without adaptations which were clearly necessary. Housing Associations and other organisations need to be aware of this tendency, and need to be more proactive in following up on requests of this type, particularly for residents who have serious health conditions.

*When surveyed at St. Richard's Hospital, Diane mentioned having a shower fitted. She was unable to use the bath, because she could not step into it without risk of falling. The Housing Association, Hyde Martlet, had measured up over seven months earlier, but nothing had been fitted. Diane had telephoned a few days earlier, and someone was going to look into the reason for the delay.*

*During the follow-up interview, she said that she had decided to cancel this, as she'd been strip washing for 25 years and thought she might not like the shower. She did not want any money being wasted on fitting it for her.*

*(Diane, Heart failure, St. Richard's)*

One patient with limited mobility had looked into measures to prevent neighbours from parking across her drive, but was not successful in getting it arranged.

*Sharon received physiotherapy at St. Richard's to help her regain her mobility after a stroke. The NHS had had special shoes made to assist with this process. Even before the stroke, her mobility had been limited. This problem was made more difficult as neighbours parked their cars outside her house. She felt that a no-parking zone would help. She enquired about this, but was told that 'it wasn't law; other people are allowed to use it.'*

*(Sharon, Stroke, St. Richard's)*

Another participant found it difficult to get some handrails installed, as their house was listed. They ended up having to arrange this privately. They felt it was unfair, as most people would have been entitled to have this funded.

*"They put handrails on the back door and this one here, but that was all the rails they had... That was sufficient for her to come home and they were ordering more rails.*

*"A different person... said the house is listed therefore he's not allowed to put any handrails up... They wouldn't give her any help for the stair lift... and eventually they agreed the fact that, if we put them into the wooden bit of the stairs, she could have a stair lift on that. But it mustn't touch the wall to affect the wall because the house is listed...*

*"It took over a year and then we had to do it when everybody had pulled out... A property should not be more important than the person who lives in it."*

*(Daughter of Agnes, Lack of mobility, Worthing)*



One patient, who lived in sheltered accommodation, had to deal with a water leak shortly after returning from hospital. This was challenging, as she was still in pain and had limited mobility. She had not received support from the warden, who was not present at the time.

*“I've just had a flood here from upstairs. The lady, she's just gone into hospital, I think she's got early dementia, and she left her tap on. And I've got to have the ceiling done in the kitchen and the hallway and the bathroom because the water came in. And I've got to have a new carpet in the hallway.*

*“[The warden] wasn't around, which was a bit of a nuisance, and I was... And it happened, I came out of hospital on the Wednesday and on the Thursday I was mopping up the bathroom and the kitchen and, you know, and I shouldn't have been doing that but it had to be done, you know.”*

*(Elsie, Chronic Obstructive Pulmonary Disease, St. Richard's)*

One person was homeless at the time they were discharged from hospital. The hospital appeared to be aware of this fact, but was unable to do anything. However, it is surprising that it was not possible for something to have been put in place.

*Charles was surveyed in the Discharge Lounge at in St. Richard's, where he had undergone an operation for a broken jaw. He was being discharged after 3-4 days. As he was homeless, Charles was unsure where he would be going. He suggested he would possibly end up on the street, or have to walk from Chichester to Bognor Regis.*

*Charles had a conversation about discharge planning while in the hospital, but had been told that the hospital could not help with arranging hostel accommodation. He did not blame the hospital for this. His plan was to see a GP for follow-up, but he did not expect to receive any further support in the meantime.*

*(Charles, Broken jaw, St. Richard's)*

### **Evelyn's story**

Evelyn was in a difficult situation regarding her care and housing, because her relationship with her husband had broken down. She had multiple health conditions which led to her being severely restricted in a number of respects. Evelyn was highly reliant on her husband to provide care for her.

*“My husband would wake me up with a cup of tea and my breakfast, I need help to get up. He'd put everything ready for me doing my [medical self-treatment]... He does all the housework, he gives me my shower and hair wash. Obviously he does all the washing, all the cleaning... He's there if I need him at night for anything, but a lot of it's done with a show of goodwill but there's a vein of reluctance... I suppose I have to rely on him probably about 90% indoors.”*

*(Evelyn)*



Evelyn's husband has deteriorating mental health. This can make him very controlling and potentially aggressive.

*"My husband suffers with [a mental health condition] bordering on dementia and he will not go for help, so they've given me a personal alarm. He's never got aggressive towards me physically but verbally he has, but his aggression towards other people is getting worse and worse, and he won't let anybody into the house so I can't have anybody come up and help me."*  
(Evelyn)

This has begun to take an emotion toll on Evelyn.

*"If I do anything, like the night before last [I needed help]. There was nothing I could do... except call him and he just went on and on and on as if I'd done it on purpose. He doesn't realise how small that makes me feel, and if I try to do anything in the house, he pushes me to one side and says, 'I'm doing it,' it makes me feel completely useless."*  
(Evelyn)

Evelyn has received good support from Social Services and the Police, who have put precautions in place in case the husband becomes violent.

*"...Social services got involved... They come to the hospital and talk to me. They're absolutely brilliant in what they've set in place. They've set a marker up with the Police so that, God forbid, if my husband did decide to become violent towards me or if I was afraid at any time, I can just ring the Police and they've got a marker on the address to send somebody up there."*  
(Evelyn)

Evelyn attempted to move out, but was prevented from doing so because she was unable to secure her own accommodation.

*"I did try to move out. I found a beautiful flat and about a week before I was going to move out, Worthing Council pulled the plug, said, 'You have a joint tenancy on your bungalow. If you move out, you're deemed to have made yourself homeless and we won't help with the rent. If you kick your husband out, you'll have broken the law, we'll prosecute you and evict you.' It was a no win situation both ways."*  
(Evelyn)

The housing association does not seem to have taken into account the potential risk which Evelyn believes she faces, because the husband's condition has not been officially diagnosed. However, this is something the husband refuses to consider.



*“[Worthing Homes] said, ‘He’s your registered carer, he’s joint tenant, he hasn’t done anything to warrant us asking him to move out.’ If he’d been physically violent towards me, it would have been different, but he hasn’t, and he hasn’t been officially diagnosing as [having a mental health condition] and borderline dementia, but that was my doctor’s opinion when he’s seen him with me.*

*“But unless he goes to the doctors willingly for a medical examination, there’s nothing that can be done there, can’t force him to go, and without an official diagnosis, Worthing Homes, as far as they’re concerned, he’s not got anything wrong with him.”*

*(Evelyn)*

## Recommendations

17. Health and Social Care providers and stakeholders should examine how they can deliver a seamless transition of care between hospital and home, involving the patient, carers and family at all stages. Written information should be given to the patient detailing their expected care requirements and how these are to be met, with contact details should problems arise.
18. Providers should review their paperwork and leaflets to check legibility, accuracy and currency of the information being provided to patients. Where possible vague standard information should be replaced with information tailored to each patient.
19. Providers should ensure that information giving details of ongoing treatment or appointments explains clearly what has been arranged and why.
20. As part of their information, advice and guidance commissioning and legal requirements under the Care Act, West Sussex County Council should undertake to look at how people living alone (e.g. without informal carers support) can access and use information and advice to prevent, reduce or delay the need for additional admissions or support.
21. Both Health and Social Care providers should ensure patients are informed that additional funding may be available to support them at home. They can be advised to seek support from Citizens Advice or Age UK to make an application.
22. Western Sussex Hospitals NHS Foundation Trust should consider whether it can extend its programme of follow-up call to include as many patients as possible, checking patients’ progress and where necessary, taking steps to reduce the risk of readmissions.
23. The West Sussex Clinical Commissioning Groups should review the commissioned pathways for patients accessing speech and language therapy as part of their stroke review.



24. Local general practices should ensure their patients have access to up-to-date information about community transport options. Staff should assist patients to understand what support is available to help them get to/from the surgery.
25. Trusts should ensure that, where appropriate, a home assessment is undertaken to identify the steps necessary to make the home safe for the patient to be discharged.
26. The Safeguarding Adults Board should review 'Evelyn's case' to see what lessons can be learnt from this example.

# healthwatch

## West Sussex

The local independent consumer champion for health and social care.

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