Hospital discharge: 
the patient, carer and doctor perspective

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Foreword by Dr Mark Porter

BMA council chair

Going into hospital can be an uncertain, and sometimes distressing, time for patients. The NHS is under considerable pressure to cope with a rising number of hospital admissions coupled with a reduction in the number of available beds. Our ageing population places a further strain on NHS resources, with the majority of patients admitted to hospital being over the age of 65.

The involvement of patients in decisions that affect them, and the information and support available for when they leave hospital, is pivotal in preventing unplanned readmissions and providing good continuity of care. This will be even more important as the NHS goes through a period of major change, and is faced with significant pressure to use resources more efficiently.

Personal stories are a critical part of putting a patient face to a policy issue. Therefore, I am pleased to encourage you to read the BMA PLG (patient liaison group) booklet on hospital discharge, which documents fascinating true stories, told from the different perspectives of patients, carers and doctors. It is imperative these views are heard if we are to ensure the NHS is truly responsive to the needs of patients.
Foreword by Catherine Macadam
BMA patient liaison group chair

Nobody wants to be in hospital longer than they need to. But the process of leaving hospital can be complicated, involving a range of different services, and needs to be planned and managed well. The consequences of not doing this can have a negative effect on patients, their family and carers, the hospital itself and people needing hospital treatment. So it is crucial that we get it right.

The PLG is aware of growing concerns among patients about delayed or inappropriate discharges from hospital. The challenges posed by trying to co-ordinate services between hospital staff, transport providers, GPs and social care staff may be exacerbated by those involved not seeing the whole picture and not being aware of the impact that their contribution can have on other aspects of the process. This is why we feel it is important to share patient stories about good and bad experiences to try and illustrate the importance of sensitive and timely ‘joined-up-working’ to facilitate a smooth and effective transfer of care for patients leaving hospital.

With increasing pressure on NHS resources, it is very timely for the PLG to engage with this topic, and we hope that this booklet will be a valuable resource for patients, carers, doctors and others involved in the process. We also hope that it will encourage all the key players to reflect on the discharge process and how it can be improved, for everyone’s benefit.
At its meeting on 5 February 2013, the PLG agreed that it would develop a checklist to help patients identify what they could reasonably expect from the hospital discharge process.

In addition to providing a patient checklist, this booklet documents patients’, carers’ and doctors’ perspectives of hospital discharge. This is with the aim of identifying factors that can facilitate a smooth and effective transfer of care for patients leaving hospital, and to illustrate the consequences of when the process is not properly planned, co-ordinated and carried through.

**Background**

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**BMA patient liaison group**

These positive and negative stories serve as learning tool for doctors as well as being a useful online resource for patients and members of the public.
Introduction

Hospital discharge can be a challenging process for healthcare professionals, patients, family members and carers. While at least 80 per cent of patients discharged from hospital return home without any complications or ongoing care needs, some patients will require input from a number of different healthcare professionals, such as social workers, therapists and GPs (general practitioners). Patients with complex needs, such as those with multiple chronic illnesses, or over the age of 65, not least because they are more likely to have complex medical needs, including more after-care needs. Intermediate care can also include a short stay in a local residential rehabilitation unit, to help patients recover and regain their independence.

Despite these differences, the basic principles for planning for discharge apply to every patient including those who are admitted to hospital with straightforward medical investigations and treatments. The key focus is achieving ‘timely’ discharge, where a patient is transferred home, or to an appropriate level of care, as soon as they are clinically stable and fit for discharge.

It is vital that patients are not in hospital for unnecessary amounts of time, known as ‘delayed discharge’, but also that social and practical factors are taken into consideration before rapid and unsafe discharges occur, known as ‘premature discharge’ (see page 8).

Barriers to achieving timely discharge are mainly associated with patients over the age of 65, not least because they are more likely to have complex medical needs, including more after-care needs. The longstanding separation between health and social care services in the UK, and limited capacity to deal with some (or many) older patients’ multiple and complex needs, has contributed to this problem.

Patients with complex needs, such as care home or intermediate care, and their length of stay in hospital is more difficult to predict than patients with simple care needs. Intermediate care is made up of support services that help an individual to make the transition back to their home.

These are delivered by a team that can include nurses, care assistants, occupational therapists and others. Intermediate care can also include a short stay in a local residential rehabilitation unit, to help patients recover and regain their independence.

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Delayed hospital discharge is where patients are well enough to leave hospital but are not able to because alternative care arrangements or transport are not available or easily accessible. Delayed discharge can also occur when there is, for example, a long wait for a drug to be dispensed at an acute hospital’s pharmacy.

Delayed hospital discharges can occur at any stage of the discharge process and can affect inpatients of any age, including children. The majority of patients who experience delays are over the age of 65.

Staying in hospital for unnecessary amounts of time increases the risk of infection, depression, loss of independence, and inappropriate use of NHS resources. It can also lead to delays in patient admissions, inpatient transfers, and cancellations of surgical procedures.

Premature hospital discharge is where patients are discharged from hospital before they are clinically ready, and before it is clinically safe for them to be discharged. This can happen for a variety of reasons, including poor communication, assumptions that family members will look after the patient, bed shortages, or because patients leave against medical advice.

Staff members may feel pressurised to make beds available, especially as bed occupancy rates are high. Patients who are deemed ‘medically fit for discharge’ can be given little or no notice to make the necessary arrangements and adjustments for their return home, or into care.

Premature discharge is an important contributor to unplanned readmission. The likelihood of a patient being readmitted to hospital is influenced by the support they receive during hospitalisation, and at the point of going home. There is an increased risk of readmission, or using inappropriate or more costly care services, if patients are not given appropriate post-discharge advice or follow-up arrangements.
**Patient, carer and family involvement**

Patients should be able to discuss arrangements for their discharge with staff members and receive full information on their diagnosis and health and social needs. If patients are unhappy about their discharge or transfer date, they should be able to raise concerns with the hospital staff.

There can be clear benefits for some patients with complex medical and social needs in involving carers and family members. It is important that healthcare professionals ensure that the patient has given consent before their confidential health information is shared.

Although it may sometimes appear to be obvious that a patient is happy for information to be shared with family members/carers, health professionals should check this with the patient beforehand. This is particularly important where there is doubt or a risk of misunderstanding as to what information will be shared. Care should also be taken to share only information which is relevant to the discharge planning process.

It can be beneficial for patients with complex needs to share relevant information with their carers. This can ensure that they are suitably cared for after leaving hospital and are not at risk of being unable to cope.
Leaving hospital

Timely discharge can improve the safety and appropriateness of discharge from hospital, and can have a positive impact on length of stay while reducing unplanned readmissions. It is part of wider action needed to reduce the delays at all stages of the patient journey. Effectively managing the patient journey is crucial to improving patient experience of the NHS and making the best use of beds.

Each hospital will have its own policy and standard arrangements for discharging patients. The patient, carer and doctor experiences in this booklet show that effective discharge planning requires multidisciplinary and multi-agency team working to manage all aspects of the discharge process.

Patients with ongoing needs are also likely to benefit from a discharge coordinator, who can provide a single point of contact for all stages of the patient journey.\(^1\)

The length of stay in an acute hospital bed may not be enough time for patients with complex needs, who may benefit from a period of rehabilitation, either as an inpatient or in the community. This could be achieved by increased care services and, if necessary, long-term care in a care home.\(^6\)

Intermediate care, or a ‘step-down’ facility, is designed to bridge the gap from hospital to home (or to residential care). There are a number of national and local services available that enable people to live in a supported environment with appropriate care. These services can give patients and their families’ time to make decisions about their future living arrangements, facilitate timely discharge and prevent unplanned readmissions.\(^7\) Access to intermediate care services is often via a joint assessment by a social worker and a nurse/therapist.
Discharge Summaries

Dr Helena McKeown, BMA community care committee chair shares her insight into the provision of Discharge Summaries.

A Discharge Summary is a document which essentially transfers the care of the patient from the hospital to the GP. The document should be received by the GP on the day of discharge, preferably electronically. The document should be typed and all new diagnoses should be identified, including a brief summary of what has happened to the patient (avoiding abbreviations). Investigations and why medications have been started or stopped, or catheters inserted, should also be included.

A list of medications and a supply of medicines to complete short courses (or a twenty-eight day supply of on-going medication) should be provided on discharge. If the patient is best treated using a Dosette box of medications (a plastic box system for arranging daily/weekly medicines), they should be given a supply of these by the hospital pharmacy.

It should be clear if and when patients are to be followed up. If the patient has been advised to remain off work, or adjustments made to their work, they should be given a Statement of Fitness for Work or fit note. Investigations performed by the hospital need to be followed up and appropriate action taken by the hospital team.

It is good practice for hospital doctors to phone the GP when considering discharge if there are complex problems or unresolved issues to facilitate a well-planned discharge.

A patient, or a patient’s relative, may have access to information regarding what happened during the hospital admission and the medications the patient has received sooner than the GP. Patients/careers are often handed a paper ‘flimsy’ and the copy may be sent to the GP by post or perhaps delayed by an internal system, such as scanning. The discharge summary may not have been sent to the usual GP looking after the patient if there is software at the hospital that sends the discharge information to a GP who has previously been recorded as the patient’s GP.

A Discharge Summary is a clinical report prepared by a healthcare professional that outlines the patient’s history, diagnostic findings and treatment administered, as well as their condition on discharge and recommendations on continuing care.
A checklist for patients

A checklist can be an important source of information for patients to ensure there are no unanswered questions when leaving the hospital. Checklists for patients will vary depending on the severity of their illness and the level of care needed post discharge. The following checklist can be used for the majority of patients discharged from hospital:

- Do I know how I will be getting home?
- Have I provided the correct contact details, including a forwarding address for any post?
- Have I collected my hospital discharge letter for my GP, or is it sent directly to my GP?
- Do I have all the medication I need?
- Do I understand what my medication is for, how to take it, and any associated side effects?
- Do I know how to manage my condition, if I have ongoing care needs?
- Do I need a follow-up appointment?
- Do I have all my belongings, including any cash or valuables?
- Do I have contact names and numbers for organisations and services, if I require further support?
- Do I have any information leaflets about my condition, if needed?
Patient and doctors perspectives

KIM

I have suffered with depression and psychosis since childhood, with my first major episode of illness at age 16. My problems have required two hospital admissions and this discharge experience relates to my most recent admission in June 2010.

I was admitted to hospital after expressing suicidal thoughts to the crisis team staff. My condition had been declining steadily and it was agreed that a short stay might be beneficial.

As it happened, the whole experience was extremely unhelpful – for a variety of reasons – and my discharge was a difficult aspect of the experience.

I had been placed on a Section, but after lengthy discussions with myself, my mother and crisis team staff, the hospital staff agreed that I should be allowed to go home. On the morning of my discharge, I nervously approached the ward manager and asked how I should go about arranging to go home. I was told that he would arrange a taxi and that I would be notified as soon as it has arrived. Two hours later, I had to pluck up the courage to ask again. There was an apology and I was told a member of staff would be sent to order a taxi straight away. Another hour or so passed. I was waiting in the busy reception area.

The ward manager kept walking past and looking at me, but at no time did he stop to ask whether I was alright or indeed whether anyone had updated me on the arrival of the taxi.

I think I must have asked him three or four times and finally a female nurse came over to tell me that the taxi was waiting and that I was free to go. There were no discharge papers to sign, I was given no information on my discharge, no medication or advice on follow-up care, and no-one offered to give me a hand with my bag or escort me down to the taxi. I left the ward feeling anxious and confused. I was safely back at home an hour or so later. It must have been after three in the afternoon and I had waited almost an entire day.

I felt the ward manager had intentionally kept me waiting and relayed this to the senior crisis team nurse, who notified the ward manager of my concern and distress. The experience felt overwhelmingly negative. There seemed to be no clinical concern about discharging someone from an acute psychiatric ward and there was no assistance.
JOHN

My experience goes back to 22 December 2010, a very snowy day, and, with hindsight, it seems more like a farce than a true story.

The hospital was anxious to discharge me before Christmas. I had ruptured a patellar tendon in a fall on the ice on 6 December, and the repair operation had been conducted on 10 December.

The OT (occupational therapist) had visited my wife and my house, and had assessed what was needed for me to recover at home.

My first point of unease was that there was never any discussion of which of this equipment would be provided by the NHS and which my wife had to find for herself (not easy in the snowy conditions prevailing).

An ambulance was ordered for 4pm to take me home, together with a double-crew (ie four personnel) to get me up the slope into my home, and a specialist wheelchair to take me through the hospital with my fully-plastered leg raised off the ground.

When this hadn’t turned up by 6pm, the nurses rang to enquire its whereabouts and were told that no ambulance had been booked (despite the fact they had a fax acknowledging the booking). At 7pm a single ambulance driver turned up with an unsuitable wheelchair, and was turned away.
At 8:30pm or so, a suitable wheelchair arrived with two personnel, and we started the 2.5 mile journey home. With the snow and ice, this was not simple. When we arrived home, the slope that the OT had assessed as providing safe access, was sheer sheet-ice and the ambulance crew refused to take me up it (and I would have refused to go up it anyway), and wanted to take me back to A&E as being undeliverable.

A neighbour kindly came out and cleared and gritted an alternative path. But, of course, there were insufficient personnel to get me up into the house, and so a further crew had to be summoned. With some difficulty – including at one point slipping and gently ditching me into the snow – they got me indoors. There was then the problem of how to get me upstairs, which had been designated as the area I was to occupy – the toilet and beds were there. The stairs were insufficiently wide for the number of helpers needed – so I eventually dragged myself up the stairs.

We then found out that we didn’t have half the equipment we needed. Although we had the toilet surround, there was no leg hoist for me to get my injured leg into and out of bed, and at 10:30pm there was no prospect of getting one.

In summary, a 2.5 mile journey took well over five hours, involved five ambulance personnel and three ambulances, and left me unable to help myself. Never mind, the OT had said she would visit the next day... I’m still waiting...
Discharging patients is a perennial weak link in the efficient running of hospitals. I believe a larger change of culture and thinking, amongst health professionals, is necessary to overcome the barriers that now exist to facilitating timely discharges.

Kim’s experience highlights the importance of communicating with patients, keeping them up-to-date, and letting them have realistic expectations of what to expect from their discharge from hospital. Kim should have been offered far more emotional and practical support at the point of discharge and once she arrived home. It is our responsibility, as doctors, to negotiate these difficult hurdles in order to improve the patient experience and maintain their dignity and independence.

John’s story, about his experience after rupturing his patellar tendon, highlights common ‘transport’ issues in returning patients back to their natural environment. The logistical issues were compounded by the failure to provide appropriate equipment – taking into consideration the adverse weather conditions. Improved liaison and closer working between hospitals and OT/social services would have enabled a safer arrival back home with adaptations and appropriate support systems in place.

I believe we need to manage patient expectations, and integrate acute care, rehabilitation and social services to work as part of a large team towards a shared goal. This is vital if we are to facilitate more patients being able to enjoy timely, much-needed care than is presently possible with these ever-shrinking NHS resources.

Dr Radhakrishna Shanbhag
BMA staff, associate specialists and specialty doctors committee co-chair (2008-2014)
DOROTHY

My own personal experience of what I would call ‘inappropriate’ discharge was when I had undergone major orthopaedic surgery. This was carried out in a specialist hospital where surgery, nursing care and physiotherapy were all excellent; however my discharge was not. Because the surgical results had been so good, I was considered fit for discharge even though other associated issues had not been fully dealt with, such as the fact that I became post-operatively very anaemic and my medication regime was not sorted out.

I was naturally very keen to go home, and would have full family support when I got there, but I did not wish to leave the hospital without a proper medical assessment of what I could expect to happen, and how I could be assisted if things went wrong.

The house doctor even seemed offended that I should have asked and only saw me when I insisted on it! I was left in no doubt that the hospital wished to discharge me and that was it.

In the event, I did become quite ill after a few days at home and my GP was none too pleased with having to deal with the consequences.

Drawing on the above experiences, I would say that a really important thing is not to discharge patients, whatever their age or circumstances, without a proper medical assessment of what one can expect to happen, and how treatment can be seen as a seamless whole rather than fragmentary.
KEN

My experience began when, after ten days of viral enteritis, I developed severe headaches and confusion which resulted in an emergency services admission on 19 July 2012. After two days of intensive treatment I started to recover and I have no knowledge of the two days from admission. On the following Wednesday my consultant visited when it was confirmed that he felt it was meningitis, although they were waiting for the results of culture tests. A consultation took place with the consultant and neurologist on 27 July 2012 and on the Monday the neurologist felt that I could be discharged.

The discharge took place without any follow-up appointment and without any information as to where I could receive support from the various societies. The discharge form also identified the proper medical condition which I had not been made aware of during my stay in hospital.

On my return home, and lacking in advice from the hospital, I quickly discovered without hospital staff monitoring that I was far from well as there were issues with remembering certain functions. After a week, and becoming frustrated by my inability to appear normal and still suffering from headaches, I decided to gain further information and contacted the Meningitis Society. After a very long discussion they agreed it was very necessary for them to come for a home visit.

I had pointed out that on the discharge note that my diagnosis was meningoencephalitis and was then advised that this was a much more serious condition in adults than meningitis. Following the home visit it was agreed that I ought to contact the Encephalitis Society who had a greater knowledge of the medical condition. I spoke to Jon the next day who has been a mine of information and support.
Junior doctors play a particularly critical role in the discharge process, as they are usually the ones to liaise with the GP and other services. Too often it is viewed as being a bureaucratic process, but a good transition makes a huge difference to the follow up of patients and continuity of care. It is essential to ensure that this is emphasised in the training of junior doctors, and that they are well equipped to understand local services and any specialty specific discharge processes.

The importance of clear communication with patients throughout the hospital discharge process cannot be overstated. It is absolutely vital that patients are kept aware of what is happening, why it is happening, and what they can expect with regards to follow up care.

Ken’s experiences highlight the importance of ensuring that patients are equipped with the knowledge they need to readjust to living independently – not only information about follow up care, but also the resources and support which exists without the health service. Signposting patients to other sources of information is a small step which can make a huge difference to a patient’s experience in leaving hospital.
SUSAN*

I had an operation in 2010 and found my stay in hospital to be a surprisingly pleasant experience. The doctors and nurses, although extremely busy, were always very considerate, polite and kind. I was assigned one nurse to my care, who explained everything clearly including what my medicines were for, how and when to take them, and the potential side effects. She also provided help with arranging transport from the hospital to my brother’s house. However when the time came for me to leave, the ambulance was delayed by four hours. It was a bit of a nuisance because everything was in place for me to leave, but the staff members were very apologetic.

LOUISE*

I developed Guillain Barre syndrome which caused extensive weakness, especially of my legs. I was looked after in the local hospital where the multidisciplinary team provided a very successful discharge back home. While awaiting a care package, I was encouraged and enabled to sit out of bed and was allowed to go out on short trips in a car with my husband which helped my recovery enormously.

*a pseudonym.
JULIE

I have had four operations over the course of the past few years and, in general, I have found the discharge procedure to be quite a slow one. To be told early/mid morning that you can go home yet still be at the hospital late afternoon is highly frustrating. The main delay is usually caused by having to wait a long time for the nurses to collect any tablets prescribed from the hospital pharmacy. On one occasion they couldn’t find anyone senior enough to sign the discharge paperwork so I had to wait for the staff to track someone down before I could eventually leave. I understand that staff have other jobs to attend to but, in my experience of hospitals, nobody seems to follow any job through from start to finish.

Surely it makes sense for staff to be properly organised and concentrate on getting the patient out of the hospital as quickly as possible as this will free up both their workload and the bed itself. The longer a patient is kept on the ward the more it costs, as they still have to be fed and watered at the hospital’s expense. Not only that, the patient is left in the dark as to what the current position is, and often wonders if they have been forgotten.

As both my parents have also been in hospital during the past year, I can also comment on their experiences. My mother had pretty much the same experience as me; one nurse would promise to fetch a new drip she needed but then would disappear. A few hours later a second nurse would appear and ask why the drip hadn’t been replaced. She would then go to get a new one only to disappear as well. My mother’s discharge was quite a lengthy process too. However, in direct contrast to the above, my father was not kept waiting for very long at all when he was discharged after his operation earlier this year, so it proves it can be done.
HELEN*

My brother-in-law had a lower leg amputation following an industrial accident last summer. He was initially taken to a specialist skin graft unit where he had access to specialist physiotherapy for amputees and care for the grafts. The difficulty was that he was ‘out of area’ and no local social services assessments could begin until he moved back ‘into area’. He pushed for this and pulled strings to organise a transfer to a local hospital after 2-3 weeks so that the process regarding assessment of their house could begin.

At this second hospital he was kept for a week and then transferred to another hospital, without notice or consultation, and was put on a ward for stroke patients. This distressed him greatly.

My sister had to take him for the one hour and 30 minute drive back to the specialist unit for dressings and reviews each week, as neither of these latter hospitals ordered in the necessary dressings. It would have been much better if he could have stayed in the specialist unit while the local accessibility assessments and discussions with social services were taking place.

The subsequent social services occupational therapy assessment revealed that their house could not be made accessible for someone likely to continue using a wheelchair on a regular basis, and that they would have to move house – possibly into a suitable Housing Association property for which they would be considered eligible.

He could have been in the hospital for months and was clearly considered to be a ‘delayed discharge’. Thanks to family support, an interim solution has been found and somewhere has been rented. The worry is whether or not, once he has been discharged, he will be able to organise the transport necessary for his ongoing rehabilitation. He is only now being measured for a prosthesis and it will take time for him to learn to walk.

*a pseudonym
Patients often tell GPs about their difficulties in being discharged from hospital. In most cases these are caused by preventable administrative or organisational factors.

Julie's story highlights an extremely common problem in the protracted process that can take place on the day of hospital discharge. In this example, a simple task of being provided with discharge drugs and a summary took from morning to evening, which meant that she unnecessarily occupied a hospital bed for several hours, which could have been available for another patient. This causes inconvenience not just to the patient, but also to relatives or carers with a responsibility to take the patient home. Such administrative inefficiencies also have a knock-on effect, such as creating delays for other patients in A&E waiting for a hospital bed. The solution is one of better internal organisation and planning within hospitals, which would be of benefit not just to the patient, but equally for the hospital which would be maximising its bed availability for other patients.

Helen's story about her brother-in-law demonstrates that hospital discharges are often dependent upon effective coordination with social care. In this example, a social services assessment prior to discharge into his home environment could not take place because he was being treated in a distant specialist hospital, which was ‘out of area’ to his local authority. Subsequently, on establishing that his house was not suitable for wheelchair access, this would ordinarily have resulted in him remaining in hospital for possibly months as a ‘delayed discharge’ while alternative housing was found, was it not for his family intervening with a private housing arrangement. It is important that such barriers in the interface between the NHS and social care are addressed and prevented, since as highlighted in this example, it can cause much unnecessary distress for both the patient and family.
JACKY

Mum had a stroke on the 10 August 2012. She was taken to an Acute Stroke Unit and my first impression was that everyone was working to targets; the deadline in the acute ward was four days. Once the four days were up, she was to be moved to a rehab stroke unit in another hospital and there was a delay in discharge on that. I stayed in hospital for twelve hours waiting for transport, and it caused a huge amount of distress for myself and my mother. Mum was saying ‘I thought we were going, I thought we were going’ and she became very anxious. At 7.30pm I asked the staff nurse whether her discharge was going to happen, and she said ‘no... it will happen in the morning now.’

I was called the next day, and they told me to arrive at the hospital for 11am. They eventually moved her at 7.45pm. She’s a very elderly lady, paralysed down one side of the body, and she was shunted to the other hospital.

We got there at 8.30pm. The stress for everybody because of the transfer was unbelievable. They kept saying ‘oh it’s transport; you have to wait your turn.’ The staff members were pressurised to free the bed because she didn’t require this specialist service anymore after four days.

We then got her into the specialist stroke rehab unit. Again we were told, because of the nature of mum’s stroke, they have a six week target.

Everything was chaotic once the six weeks were up. Everyone got involved, from social services, discharge nurse to ward sister. I met the nurse liaison a couple of days after the six weeks were up, when they were putting in the motions of discharging her.

The delay in discharge was trying to get everyone together and arrange for her to be moved out of her borough — to my borough — so she could live with me. My mum’s borough was paying for the care
but my borough was providing it, and the lack of coordination was unbelievable. She was sitting in a bed and she didn’t need to be there anymore. She was there for two weeks longer than she should have been, purely because of the lack of coordination. Eventually on the day she was discharged, the transport arrived three hours late.

The day before she was discharged, I was expecting a checklist. The staff nurse was supposed to sit down with me, but she was run ragged and ended up getting my mum’s drugs mixed up with another patient’s drugs.

The GP was very good, he called on the night that she arrived back home, and came to see her the next day to explain the reality of her situation.

On reflection, someone like the discharge nurse should be the conduit for all this: ‘this is what you can expect, this is what you need to do and this is what you need to take out of this hospital’. But after you leave the hospital, it is not their responsibility. So who do you contact?

The best person who helped once she was discharged was the liaison officer at the Stroke Association. This role is linked with the stroke rehab unit at the hospital. She helped us understand mum’s condition and outlined the support we could get such as attendance allowance, carers allowance and other support such as opticians, hairdressers, chiropodists, physiotherapists, speech therapists, district nurses, and incontinence support. Without her, my job as a carer would have extremely difficult. She helped me put in place the support my mum needed and understand my rights as a carer. I think this should have happened before she was discharged into my care.
CATHERINE

Having established that there was nothing further that could be done for my mum apart from palliative care, and with her unconscious and not expected to regain consciousness, we were working with the hospital to transfer her back to the care home. They were very keen to look after her with help from the community palliative care team and district nurses. A bed was ordered and dispatched, and an ambulance was booked. While we were waiting to be told when she would be moved, it transpired that, because my mum’s room was on the first floor and there was no room available on the ground floor at the care home, the ambulance service was refusing to take her beyond the threshold of the care home. Neither would they allow the care home staff to take her upstairs using their stretcher. Apparently, if she had been going to a private home, this would not have been the case and the ambulance crew would have been able to take her up the stairs.

We were told that unless we were prepared to pay for a private ambulance, she would have to stay in hospital. In the end the situation was resolved by the “bed manager” who agreed that the hospital would pay for the private ambulance in order to free up the bed that she would otherwise be ‘blocking’.

The transfer then went ahead and all was well. Her last days were spent peacefully at the care home where she could be kept company by various members of the family.
The very distressing story of Catherine’s mother’s discharge for her expected death at her place of choice might best be considered by a ‘significant event audit’ involving all professionals and agencies. This could identify how a failure of joined up care occurred and provide the opportunity for shared learning.

A more senior person should have been contacted to share the possible risks with the patient and relative, seek their agreement for the GP to take the responsibility, and ask the staff to help move Catherine’s mother. A retrospective analysis would identify whether the discharge should have been identified before the discharge and suitable risk sharing explained and agreed with the patients and the carer.

Targets seem to be having unintended adverse effects, removing common sense, care and compassion that are needed during the days and the hours that are not associated with a target deadline. In Jacky’s experience, the uncertainty of waiting for ‘transport’ is not caring and should be managed from the top of the hospital and ambulance transport services as unacceptably inhumane. We have a duty not to harm our patients; however, making them wait many hours, without knowing when they are going to leave, clearly creates anxiety and may harm our patients. Discharge could be improved by more of our community staff going into the hospital before discharge takes place, such as a stroke liaison nurse.

The very distressing story of Catherine’s mother’s discharge for her expected death at her place of choice might best be considered by a ‘significant event audit’ involving all professionals and agencies. This could identify how a failure of joined up care occurred and provide the opportunity for shared learning. In my opinion, this failed the ‘was this in the best interest of the patient?’ test and if I had been there I would have tried to inject some common sense in the ‘best interest’ of Catherine’s mother and been prepared to defend my actions if challenged later.
BARBARA

My father, an 89 year old widower who lived alone and led an independent life, was diagnosed with chronic liver disease. Four years later his condition had deteriorated and he was admitted to our local community hospital having ‘gone off his legs’. Whilst there he had a haematemesis (vomited blood) and was transferred to a larger acute hospital via A&E.

He was admitted that evening to the emergency admission and discharge unit – a very busy interim unit for assessing patients. I returned the next morning and found him in a comatose state. No one on this busy unit had realised he had slipped into unconsciousness.

Following a neurological examination I was told, in view of his medical history and his current condition, there was little more they could do for him. I felt very strongly that I didn’t want him to die on a busy ward in a big hospital, so I requested that he be discharged back to our local community hospital via ambulance.

I was included in a discussion with the ward consultant, the nurse practitioner, a member of the ambulance crew and a ward nurse, and it was agreed that my father could be discharged out of hospital back to our local community hospital to die.

I felt that the hospital staff understood what I was feeling and allowed me (in the absence of my father unable to make that decision himself) to have him transferred. He died a few days later in a comfortable single room in our community hospital with compassionate nursing staff caring for him and with his family at his bedside. I felt this was the best possible outcome for my father and was very grateful to the staff of the acute hospital to have made this possible.
MICHAEL*

My wife had terminal cancer and was admitted to hospital because of a rapid decline in mobility and problems with symptom control. The latter was achieved with use of a syringe driver but her mobility remained very poor so that she was unable to climb stairs. She made it very clear that she wanted to go home to die but our house was very small with no bathroom downstairs. I felt that I wouldn’t be able to care for her adequately if she was sleeping downstairs. The multidisciplinary team, which included a social worker, worked rapidly to ensure an accelerated discharge; a local health charity paid for the installation and rental for a stair lift which, with regular carers, enabled my wife to live very comfortably in the last six weeks of her life at home.

* a pseudonym

PAT*

My uncle, a 75 year old man, had a stroke and was sent the nearest hospital which was 28 miles from his home. The hospital team was planning to send him to a nursing home as they felt he and his partner, who had severe mental health problems (bipolar, although quite stable at times) wouldn’t manage. My uncle very much wanted to go home and so did his partner, but she was refusing any help. It was difficult because his partner was relying on poor public transport to see him as she didn’t drive.

He was transferred to the community hospital where, because the local multidisciplinary team knew him and his partner, they understood the potential difficulties but were willing to try to get him home. His partner was allowed to be involved in his care in the community hospital; she was taught how to transfer and care for him, facilitated by the physiotherapists, OTs and nurses. Successful discharge occurred after a planning meeting and home assessment visits, with his bed being ‘kept open’ for two days following discharge in case of disaster. He remained at home for four years with the support of district nurses, as he had a long-term catheter and his GP, but no extra carers, until his partner sadly died.

* a pseudonym
Further information

NHS Information for patients leaving hospital:
www.nhs.uk/NHSEngland/AboutNHSservices/NHShospitals/Pages/leaving-hospital.aspx

The British Red Cross 'Independent living' services for people when they face a crisis in their daily lives:

Age UK 'going into hospital' resource:
www.ageuk.org.uk/health-wellbeing/doctors-hospitals/hospital-discharge-arrangements/

NHS practical support for carers:
www.nhs.uk/CarersDirect/guide/practicalsupport/Pages/hospital-discharge.aspx

Carers UK 'planning the discharge process' resource:

' Hospital to Home' resource pack for all professional sectors that have a role in hospital discharge for older people:
housinglin.org.uk/hospital2home_pack/

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References


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