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Purpose of this briefing

We are sharing this briefing to give you an insight into the emerging findings from our special inquiry, focusing on the experiences of older people who have been discharged from health and care settings.

In this briefing we share:
- an overview of people’s experiences and the impact on their lives;
- an exploration of ways professionals and services are trying to improve discharge; and
- discussion points that highlight questions and concerns that need further exploration

We are sharing this briefing at this stage to gather feedback on the emerging findings, and to build an appetite for change amongst policy and decision makers. We want to ensure that this inquiry helps lead to tangible and positive change for all the people affected by this issue.

Background

Over the last year we have been looking into peoples’ experiences of being discharged from health and care settings.

Our approach is different from that taken by many statutory inquiries. This inquiry has been led by people who have direct experience of being discharged from these settings. As a statutory watchdog our role is to ensure that health and social care services, and the Government, put people at the heart of their care.

Last year alone there were more than one million emergency readmissions\(^1\), a strong indication that many people are leaving hospital too soon or without the right support in place, while still recovering from an accident or illness. Local Healthwatch highlighted early on that unsafe discharge was an issue of real concern for their communities.

Emergency readmissions are thought to cost the NHS more than £2 billion every year\(^2\), however, not enough is known about the human cost. We have a duty to ensure that peoples’ experiences are heard by those who regulate, commission and deliver services, which is why we have undertaken this special inquiry.

Findings of our early evidence review identified a number of groups particularly at risk of unsafe discharge. For this inquiry, we have focused on homeless people, those with mental health conditions and older people.

\(^1\) There were 5.3 million emergency admissions in 2012/13 which cost the NHS £12.5 billion. 19\% were readmissions. For more information: National Audit Office (2013) ‘Emergency admissions to hospital: managing the demand’ http://www.nao.org.uk/wp-content/uploads/2013/10/10288-001-Emergency-admissions.pdf

\(^2\) Ibid.
Healthwatch England, together with our user-led advisory group and more than 100 local Healthwatch, has been listening to people around the country, about their experiences of discharge and the impact on their lives. We also collected evidence from the voluntary sector, providers and front line workers.

Everything we say and do is informed by our connections to people in every town, city and county in England. Local Healthwatch collect experiences from communities and facilities across England and for this inquiry visited hospitals, held user-led focus groups, public meetings, face to face meetings and conducted online surveys.

This briefing is informed by the in-depth experiences of over 1000 older people, their families and carers around the country. By working alongside older people and specialist older people’s organisations, such as Age UK and Royal Voluntary Service, we have accessed people many statutory inquiries do not. We have had rich and dynamic conversations about peoples’ experiences and their ideas for change. For example, we visited an NHS trust which set up a scheme to improve experiences for older people visiting A&E and being admitted and discharged from hospital, and shadowed a voluntary sector run ‘hospital to home’ scheme.

During the inquiry we also brought people with a personal experience of poor discharge together with providers, national policy and decision makers at a workshop, to share their stories and develop solutions in partnership.

This briefing draws on all of the insight, evidence and conversations that our network has had throughout this inquiry.

This report focusses on older people and explores the experiences of those we heard from, what we and the Government can learn from their stories and sets out recommendations for the future.

The briefing is part of our special inquiry which has also investigated the experiences of people with mental health conditions and homeless people and the findings of these groups are being shared with key stakeholders in two separate briefings.

Overview

What is the problem?
We have observed a disjointed system struggling to provide compassionate aftercare and support for a rapidly ageing population.

Older people are discharged without adequate assessments or care plans, left alone and isolated. Others are stuck in hospital waiting for assessments or for health and care arrangements to be put in place. We have heard about those near the end of their lives, discharged from hospital to die in care homes that are ill-equipped and poorly prepared to deal with palliative care needs, and others for whom delayed discharged can mean dying in hospital against their wishes.
**Why is this happening?**

Misunderstandings about entitlements, inadequate or delayed assessments and disagreements between the NHS and local authorities about where the responsibility for funding should lie can see older people kept in an institution for longer than necessary or discharged back to the community without the right support.

Health and social care staff often face difficulties in negotiating the procedures and assessments that are required. The lack of integration and co-ordination between the various organisations involved in assessing, funding and providing care adds to this complexity.

Communication failures and a lack of collaboration between primary and secondary care providers are often also to blame. We heard hundreds of stories illustrating how hospitals and primary care are failing to work together to ensure older people have a safe discharge.

We also heard about a lack of awareness, compassion and training amongst health and care staff about entitlements to aftercare and how to address the needs of older people with specific conditions, such as Parkinson’s, Dementia and those who are deaf-blind.

A shortage of care homes and other residential care was also common, alongside reductions in community care and social care funding for those leaving hospital.

**What needs to change?**

We heard about many examples of good practice, some of which we have highlighted in this report. However, services are inconsistent and good practice is not being replicated across the country.

Both health and care workers need to be better trained in how to help care for those with specific conditions. Patient-centred care should be made a reality, with people’s individual needs addressed and the patient, family members and carers involved and informed at every stage.

The Government must ensure there is a mechanism to learn from people’s experiences, particularly when things go wrong. Linking to a recent report published by Healthwatch England on the state of the complaints system\(^3\), particular assistance should be given to those older people without someone to advocate on their behalf, to enable them to raise concerns or a complaint and to demonstrate lessons are being learned when things go wrong in the discharge of older people.

Older people and their families want more clarity about the discharge process and more information about their conditions and medication post-discharge. A lack of information leaves people feeling unsupported as they do not know that they are

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\(^3\) Healthwatch England report ‘Suffering in Silence’

[http://www.healthwatch.co.uk/complaints/report](http://www.healthwatch.co.uk/complaints/report)
entitled to services available in the community. People feel that they are discharged too soon, before time has been given to ensuring that they have everything that they will need.

In order to ensure that older people are treated with compassion and dignity at the end of their lives, there must be better efforts to discharge people from hospital as soon as possible after health workers have identified that they can no longer be treated. With care homes being used more and more to care for people at the end of life, it’s vital that care workers are adequately trained in palliative care. Care homes also need to have more access to pain relief and equipment to ensure people have the most comfortable and peaceful death possible.

It is inevitable that reduced spending on social care is having an impact on older peoples’ care post-discharge, but poor links between health and social care data at a national level, means it is difficult to quantify that impact. Data must be made available to increase understanding in this area.

As the population continues to get older both the NHS and social care services will face new challenges in caring for older people and will need an innovative, concerted and dynamic approach to fulfilling that challenge. Listening to older people, involving individuals, families and carers is a vital part of this journey.

This report focusses on thousands of experiences of older people we have heard from. We recognise there is a huge amount of work being done to make improvements in this area and that the incoming Care Act may address some concerns. However we would welcome further insight on the potential impact of these efforts on older people and on how we can turn people’s powerful expectations into reality.

Older people in the UK

There are more than 10.3 million older people over the age of 65 in the UK. This represents an 80% increase since the 1950s. When the NHS was created, almost half the population died before the age of 65. Now life expectancy is 79 years for men and 83 years for women, with those over 85 years of age being the fastest growing demographic in the country. The population will continue to grow older, with the 65+ population expected to reach 16.9 million by 2035

Almost half of the 15 million people admitted to hospital last year were over the age of 65 and many had existing and complex medical conditions that require particular consideration and care in planning discharge and aftercare at home or in the community.

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7 Hospital Episode Statistics, Admitted Patient Care, England (2012-13), Nov 2013
Today, family members provide the majority of informal care to older people at home or in the community. As yet the proportion of older people who are divorced is small, but is rapidly increasing. People born since the mid-1950s, however, have shown different patterns of family formation and dissolution, and the longer-term prospects for the familial support of older people are therefore likely to be less favourable\(^8\).

\(^8\) Rutherford (2012)
People are being discharged without the right support in place

“I was told I could go home without the assessment, but I couldn’t get up the stairs. I had to sleep downstairs for nearly six weeks.”

During our inquiry we heard from hundreds of older people like Elsie who had left hospital without adequate assessments and care plans in place - sent home without the emotional and physical support they need.

In 2013 Age UK reported\(^9\) an estimated 830,000 older people in need of care, were not receiving any formal support, while local authorities cut back on the support provided to older people with ‘moderate’ needs. Through our inquiry focus groups and interviews, we were told that many older people struggle to cope with everyday activities post-discharge, like washing and cooking and are unable to leave the house to get to the shops. After they had returned home, nobody had followed up with them to check they were OK and many we spoke to did not know where to turn for support and had been left to arrange their own aftercare.

These people felt abandoned by the system and had been left isolated and alone back in their homes or communities. Being discharged without the right support in place can have a significant impact on individual’s wellbeing. Evelyn shared the experience below with her local Healthwatch;

_Evelyn’s\(^{11}\) story_

“I had an operation for my left hip replacement in June 2011. I had a care package when I returned home and within six weeks I was able to manage all my personal and domestic responsibilities without help. My right hip replacement was later planned for February 2013.

As I am the carer for my 85 year old husband [who has dementia] I had to make plans for his care while I was in hospital. I arranged a care plan for [my husband] for which I paid. I made these plans confident that a few days after my operation I would return home with a care plan in place as last time to help me get back ‘on my feet’ as soon as possible. As my husband’s carer it was in the best interest of the ‘state’ for me to be able to take over my caring role within a few weeks.

[A few days after my operation] a student social worker came to see me.”

After a number of exchanges and while being wheeled out to the ambulance to go home, Evelyn was told “You can’t have a care plan. There aren’t any

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9 Elsie, local Healthwatch focus group, Midlands
11 Throughout this briefing we have anonymised or pseudonymised people’s experience to protect their identity.
carers. I haven’t been able to fix anything, not even for you to pay for. I’ll keep trying.”

“I was shocked. I knew I needed help. I had had a care plan [last time]. I had understood the ‘up to six weeks care on discharge’ was part of the system. I was very upset. I didn’t know how I would cope, with myself and with my husband. He, in addition to everything else, has Reynard’s disease which affects his hands which are swollen – he cannot grip and would be quite unable to help me with my personal care, nor with the domestic needs such as meals. How could it possibly be that I was about to be sent home without any help! To organise friends would not be easy. Sadly when you reach 80 most of your friends are either dead or not as fit and agile as you are.

[The ambulance drivers] left me standing in my kitchen supported by two crutches. I am no wimp but on that afternoon I was devastated. I had not felt so abandoned since my mother died when I was 25. Bossy, organising me didn’t know how I was going to cope. Even now, several weeks on, I find it difficult to talk about, or even as I write, without crying.”

It took from Wednesday to Monday following many phone calls, to get the care plan working. During this time Evelyn says she was vulnerable and in serious danger of needing to be re-admitted to hospital.

Evelyn’s story is a powerful illustration of how even the most empowered older people can feel particularly vulnerable when they return from hospital. A lack of care and attention led to Evelyn feeling ‘abandoned’ by the system that she thought would always be there for her in a time of need.

Reablement is a short term intensive period of support (normally a maximum of six weeks) for those who need support to regain skills and confidence to care for themselves and live independent lives again after a period of hospitalisation. The promotion of reablement services within the 2012 Care and Support White Paper firmly establishes it as a priority for local authorities and data suggests that the number of people offered reablement / rehabilitation is increasing in line with the rise in those accessing services12. However as we have heard from Evelyn’s experience and that of others, many are still missing out.

And when the care plan and support is in place we also heard from a small number of people that the process can be chaotic with dozens of carers going in and out of older people’s homes.

“A patient can be confused [when discharged from hospital] and needs to be confident in the people around him/her13”

A number of people told us that their visiting carers were kind, but that they were overworked, forced to fit too many visits in to a short space of time and were rushing from one house to the next. Older people are forced to explain everything

12 QualityWatch ‘Supporting older people’s recovery after illness’ (2014) http://goo.gl/k3AYc7
13 Jean, individual written submission, local Healthwatch, North of England
to the carer each time a new face arrived at the door. People told us they found this distressing and that they would have liked to see more continuity in their care post-discharge.

People also stressed the need for follow up post-discharge and after a care package has finished.

We heard the story of Usman from a local Healthwatch.

Usman was a widower living on his own and was given a six week care package following his hospital discharge - to help with every-day care like cooking and cleaning. After the six weeks ended he soon became unwell again, he was unable to cope on his own and to take care of himself. A local community group tried to help Usman as they were concerned his living conditions had become unsanitary so reported this to the local authority, who later assessed his flat to be of an ‘acceptable standard’. A few months later the community group requested a reassessment through Usman’s GP. Unfortunately before the assessment could take place Usman was hospitalised with a respiratory infection and compromised immunity and died soon after on his 88th birthday. The local authority was later found guilty of neglect.

Dying older people discharged without adequate end of life care

We also heard about the discharge experiences of older people at the end of their lives. Of the 569,024 people who died in the UK in 2012, 91% were aged over 65 and three quarters over 75. Data suggests that older people have the least choice over where they die and have the least access to specialist palliative care. For example only 8.5% of those over the age of 85 dying of cancer, die in a hospice, compared to 20% of all cancer deaths and only 15% of over 85 year olds have access to palliative care when dying.

The UK has some of the best end of life care in the world, but many people are not accessing this level of specialist palliative care. Currently an estimated 92,000 people die every year without the support they need. Something has to be done to ensure people die without unnecessary pain, with their dignity and in surroundings in which they feel comfortable.

We heard from a number of family members and voluntary sector organisations that some older people are being discharged from hospital to care homes that are ill-equipped to deal with their palliative care needs, or are dying at home without adequate support, causing added stress and concern for them and their families.

14 Submission from local Healthwatch, South East
Some people are dying in pain and discomfort, leaving families distraught that they were unable to do more for their loved one at the end of their life.

“The home didn’t know my mother was in need of palliative care (I didn’t know either), they didn’t have the equipment she needed (the hospital hadn’t sent a nebuliser over), the discharge plan was carried out over the phone to a nursing care member of staff who didn’t record anything. It was appalling. My mother could’ve had a much more peaceful and dignified death.”

One voluntary sector organisation told us that people are spending the last few weeks and days of their lives trying to get equipment like hoists, hospital beds, commodes and shower stools. We heard that family members are often performing too much of a coordinating role, trying to get the right services and medication, or chasing people, services or equipment that has not arrived. This is all happening when they should be able to spend time with their loved one as they approach the end of their life.

**Older people, their families and carers are not meaningfully involved in the discharge planning**

Throughout the inquiry we heard from older people and their families across the country that the discharge process can be chaotic and assessments inadequate, and that assumptions are made about family support and home settings.

“I rang shortly after lunch to be told [Mum] had been discharged. I was shocked. She lived alone and was still delusional. A neighbour rang to say mum had been brought home by ambulance in her nightgown and left at the cold house after the driver got a key from another neighbour. The elderly neighbour stayed with her all night. She was readmitted the next morning.”

We heard from many others like Julie, who felt that as family members or carers they were neither sufficiently involved in discharge planning nor adequately informed about what was going on. Family members are often not asked about the level of support they can provide and we were told about a number of examples of incorrect information being recorded about an older person’s ‘home’ situation, which was never checked with family members.

Bob was being discharged back home where he lives alone. His daughter Pauline lives in a different part of the country but told us she had been reassured by the hospital that Bob would be looked after by visiting nurses for the next two weeks as he was frail and confused after his hospital stay. This did not happen - carers called Pauline’s sister in law, Margaret, to express their concern for Bob’s situation and that he was very frail and vulnerable - Margaret is the closest relative living 50 miles away but also had a broken leg at the time so was restricted in how she could intervene. Occupation Health visited Bob and advised family on changes made at Bob’s home, but Pauline, Margaret and the rest of the family soon

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18 Marion, online written submission, local Healthwatch, South of England
19 Julie, family member, online written submission to Healthwatch England
realised they needed to arrange carers to help with the routine every-day tasks. “There was a presumption that we were available to care for Dad and that we knew the system and what to do. None of this was true”

We heard from a number of family members like Pauline, living far away from their parent or elderly relative, feeling uninformed and helpless about how to help. If they had been informed of Bob’s condition and the support he really needed post-discharge then they could have been involved in the planning of adequate support for their father before he was discharged back to his home alone.

The story we shared earlier from Evelyn also highlights the additional complications for those older people admitted to hospital who are also carers for family members at home. We heard a number of examples suggesting health and care workers are not considering this adequately during the assessment process and that there is a need for an assessment process that starts early, is flexible and tailored to each individual’s needs, and we explore this further on in the briefing.

**Older people are discharged without the information they need**

All older people and their families/carers should have sufficient information about their own condition or illness, to know what to look out for, the danger signs or complications. Missing vital information and not planning adequate support for people post discharge can have a big impact on older people’s mental and physical wellbeing.

We heard the shocking example of Jack, who had to read about his mother’s cancer diagnosis for the first time in a discharge letter once she had returned home. None of the family had been told about the diagnosis or the prognosis and Jack was left with many questions and wondering how to tell the rest of the family.

Older people and their families also told us they don’t know what they are entitled to. The assessment process is too complex and there is a lack of understanding by both patients and health care staff. We have been told that people often emerge from assessments ‘bewildered and disappointed’.

Hundreds of older people, their families and front-line workers told us how important it is to be involved in planning for discharge and informed about the ongoing treatment and care they are entitled to and to know what will happen during and after discharge.

“My father [was] discharged from hospital late 2013. At no time has he been assessed as to whether he can climb stairs, get into a shower or bath. My mother is of poor health herself and is struggling to cope. My mother has not

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20 Pauline, written submission, local healthwatch, North of England
been told of any services she may be eligible for, to help my father. She is relying on word of mouth from other people.”

The government is committed to bringing shared decision-making into everyday practice in the NHS, but from what we have heard this is not happening consistently. This is corroborated by a recent national study of 62,400 patients in England, which found that 46% of people did not think they were fully involved in decisions about their discharge from hospital.

Alfred shared his experience of the assessment process with us;

“I was deeply concerned whether I would be able to cope on my own in a first floor flat with no lift. When I challenged [the assessment that I did not need support] on the basis that they hadn’t even seen where I lived, I was told that they couldn’t spare the staff for a home visit.”

A lack of information and involvement in discharge planning can lead to uncertainty and to added stress and worry for the older person being discharged from hospital.

**People are being discharged with the wrong medication or prescribed dose**

This lack of information and involvement can directly impact medication reconciliation at the point of discharge and adherence post-discharge. More than 90% of older people are discharged with different medications to those they were admitted with, with 60% having three or more medicines changed during their hospital stay and adverse drug events occur in up to 20% of patients post-discharge.

These changes in medication understandably cause a lot of confusion for people and we heard many older people either continue to take their old and new medication post-discharge or are confused what and when to take it.

Ivy told her local Healthwatch that a hospital pharmacist had tried to change her medication to a drug she had experienced bad side effects with in the past and which was recorded in her notes. Ivy queried the change but her query was dismissed. “When a patient says they can’t have a specific drug, the pharmacist should listen and not dismiss their knowledge.”

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21 James, written submission, local Healthwatch, South of England
23 Alfred, online submission, local Healthwatch, North of England
24 Royal Pharmaceutical Society, ‘Keeping patients safe when they transfer between care providers – getting the medicines right’ (3: 2012)
25 Ivy, focus group, local Healthwatch, Southwest of England
A Healthwatch England survey completed by over 100 pharmacists from around the country found that a breakdown in communication and confusion can lead to older people taking multiple drugs simultaneously post-discharge, which can result in adverse drug reactions, medication errors and re-admission.

Too many older people end up being readmitted within 30 days

If older people are discharged too soon or without the right support, whether that is due to a lack of involvement, inadequate assessment or poor communication, one of the outcomes is that they can often end up back in hospital, within just 30 days of leaving.

Like Bill, discharged from A&E following a fall - readmitted nine days later for surgery following correct diagnosis by a fracture clinic.

We also heard about 82 year old Iris, who had fallen and injured her right knee. After a visit to A&E and an x-ray, Iris was told to go home and rest. No follow up was arranged. On arrival home, she was carried from the car to her bedroom by her friend’s husband. That night, despite borrowing a walking-aid, she fell twice while going to the toilet.

After two weeks Iris had a visit from her GP, who immediately made a correct diagnosis and referred Iris to an orthopaedic surgeon where she had surgery. Iris was in plaster for nine weeks and now walks with crutches and feels very angry about the delay in her treatment due the initial missed diagnosis.

In 2010-11 201,000 older people over the age of 75 experienced an emergency readmission.

Healthwatch England has estimated the cost of a potential ‘unsafe discharge’, highlighted in appendix A, on page 32. The graphic highlights the shocking story of Judith, who had been admitted for a broken wrist following a fall at home. The month that followed highlights a catalogue of errors in communication and understanding Judith’s condition and her needs as an elderly frail lady also suffering from dementia. She was discharged and readmitted no less than four times during that month, each time heightening Judith’s confusion and suffering. Judith’s family expressed frustration at how little they were informed in what was happening and that they were not involved in any of the decision-making.

We also heard from voluntary sector organisations about older people reaching the end of their lives, discharged to care homes, who were then subsequently re-admitted as care home staff were unable to provide adequate pain management, symptom control and support.

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26 Focus group, voluntary sector organisation, South of England
27 Nursing Times ‘Growing readmission rate sparks concern around early discharge’ (2013)
http://www.nursingtimes.net/nursing-practice/specialisms/older-people/growing-readmission-rate-sparks-concern-around-early-discharge/5054823.article
As the graphic in appendix A of Judith’s experience shows, Healthwatch England analysis suggests those emergency readmissions, additional treatment and a short stay in a nursing home had cost the system an estimated £18,258. So a significant human cost to the individual and their family, and a significant financial cost to the health and social care services.

Readmission rates are getting worse and are increasing more rapidly for older people. In the last decade, emergency readmission for those aged 75 and over, has increased by 88%28 and as we revealed earlier in the briefing, emergency readmissions are thought to cost the NHS more than £2 billion every year29 and so there is a clear cost as well as human justification to invest more in reducing readmission rates for older people.

Why is this happening?
A lack of integrated care and poor communication was behind many of the experiences we heard, both within hospital teams, between hospitals and primary care and between NHS and social care. We have heard examples of GPs not being ‘kept in the loop’, of a breakdown in communication between ward staff and hospital pharmacists and of elderly people left to organise their own aftercare.

When a person is discharged, a summary of their care and treatment should be sent to their GP so that prescriptions for new medication can be generated. In a 2009 report the CQC found that ‘Information shared between GPs and hospitals when a patient moves between services is often patchy, incomplete and not shared quickly enough’30. Since April 2010 there has been a national standard to address this. Hospitals must send a discharge summary to the patient’s GP within 24 hours however as we have heard this does not always happen31 and we also could not find evidence showing compliance against this standard. We also received anecdotal evidence to show that when summaries are received by the GP, the details within the summary are not always acted upon.

The lack of available data makes it difficult to attribute older people’s poor experiences of the discharge process and their wellbeing and recovery post-discharge directly to any cuts being made to spending on social care. However, the stories we have shared do illustrate a lack of support, continuity, communication and collaboration between both NHS and social care, and between primary and secondary care, as well as increasing readmission rates. Many older people we spoke to around the country shared their frustration at what they saw as reduced entitlements and access to care and services post-discharge over the years.

Patient and public involvement and shared decision-making are now buzzwords in the health and care sector and widely acknowledged as important by all

29 NAO report (2013)
31 British Medical Association (2014) ‘Hospital discharge; the patient, carer, doctor perspective’
stakeholders. However, efforts by providers and policy-makers can sometimes be
tokenistic, with patients and family members being asked to engage in order to
‘tick the box’, rather than to gain valuable insights into their situation and
condition to reach a shared and agreed decision.

“...The government wants shared decision-making to become the norm in the
NHS, but there is confusion about why it is important, what it involves and
what the implications might be for patients, clinicians and the wider health
service...”

What needs to change?

The need for dynamic assessments and a process understood by all

Similar to the experience of Evelyn, we heard from other older people who are
also full time carers for their partners with disabilities, degenerative diseases and
/or chronic conditions. They all spoke of similar concerns about the need to
return home with adequate support so that they can recover as quickly as possible
and return to their caring responsibilities. However people told us their assessment
process did not take into account their partners condition and needs and was
therefore inadequate. Dennis shared the distress he felt when being discharged
from hospital.

“Will someone please accept that a permanent carer and cared-for relationship
is a combined unit where this individualising policy causes more problems than
it cures. I understand this is a difficult process, but like many others this is
when you just give up, because you simply can’t get past the wall! The anxiety
with the overall situation has intensified, am I going to be OK, how do I re-plan
our increasing care needs, is it decision-time for the dreaded care-home and its
financial implications?”

Every effort should be made to support older people to stay in their homes for as
long as possible if that is their wish. The point at which an older person is
discharged from hospital is a crucial time for a thorough assessment to be made as
to their current and anticipated ongoing care needs.

Assessments must be dynamic. We heard about a number of people who had not
been eligible for certain forms of support at the point of discharge, but who had
become eligible just a few weeks later, however there was no-reassessment or
anticipation that their situation could deteriorate, and as such they had missed out
on the support - a rigid assessment process is leaving people without the help they
are entitled to and need. Assessments should factor in and plan for anticipated and
changing needs and follow up arrangements should be put in place, particularly for
vulnerable older people living alone.

32 The Kings Fund, Coulter (2011), ‘Making shared decision-making a reality, no decision about me
without me’  http://www.kingsfund.org.uk/sites/files/kf/Making-shared-decision-making-a-reality-
paper-Angela-Coulter-Alf-Collins-July-2011_0.pdf
33 Anonymous online submission to Healthwatch England, North of England
Follow up and support older people post-discharge to ensure they have appropriate arrangements in place

The voluntary and community sector can provide a lifeline to older people being discharged. We heard about Sheila through an outreach worker working for a voluntary sector organisation, supporting deaf blind people.

“[Sheila], in her late 70s, was taken into hospital with a severe bronchial infection. She was discharged after about two weeks. She lived on her own. She was dual sensory impaired and also had trigeminal neuralgia, which gave her a lot of pain down one side of her face. She was very weak and thin when she came out of hospital. Her only family member left was her sister but they had no regular contact with each other. She could no longer manage to get up and down stairs safely so she slept on the couch in the living room. She had no way of getting into town so she just went out once a week to the post office and small shop just around the corner, where she got her pension and just a few items of food. The money was kept in the house as she couldn’t get to the bank and the food she bought were things like bread and cheese as she could no longer see to cook. She kept the front door unlocked and slightly open because she was afraid that someone might call and she wouldn’t hear them knocking so that made her quite vulnerable. She had hearing aids at home but they hadn’t worked for a long time (the hospital hadn’t checked to see if she had any).

I was contacted by her neighbour as she was worried about her situation. I contacted social services and they set up meals to be delivered, the local Deaf services put in a flashing doorbell and I introduced a communicator guide who made a huge difference to her quality of life. Goodness knows how she was discharged without making sure the right support was in place. Thank god for a good neighbour.”

It is through this type of support provided by organisations like Sense and through services like the Hospital to Home initiative run by Royal Voluntary Services and others, that many older people do get the support they need when leaving a health or care setting and returning home. The voluntary sector is clearly providing a vital role in delivering services to support older people post-discharge and new funding has recently been announced by the government to expand such services.

However, services are patchy and, even where they do exist, are not necessarily available to all who need support. A number of older people also told us they would like to know more about the services available in the community. There is a need for improved signposting at the point of discharge, at least to those services that do exist.

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34 Case study, voluntary / community organisation submission, August 2014
Improving communication flows between hospital and community care - the example of Pharmacists

During the inquiry we heard from individual pharmacists, the Royal Pharmaceutical Society and Pharmacy Voice about the potential for pharmacists to become more involved in support for older people in their discharge and in improving the discharge process. Recognising that improving the transfer of information about medication across all care settings can help to reduce incidents of avoidable harm to patients and hospital readmissions.35

We were told about a recent project in the Isle of Wight highlighting the potential impact of hospital and community pharmacy teams focusing on effective reablement. Hospital pharmacists helped patients to understand their medicines while they were in hospital, addressing concerns and providing them with support for taking their medicines both in the hospital and when they left. Following patients’ discharge, community pharmacists were given the results of the patients’ hospital assessments then visited their homes to offer them further support with their use of medication, assessing how they were doing in their own homes and reinforcing the previous advice and help given.

Older people also told us they would like more information about the medicines and to have some kind of 'medical booklet' when they are being discharged, "something that tells you what, where and how". During the inquiry we came across My Medication Passport36. Designed by patients for patients, the passport enables the user to record medications and other key medical information in a pocket size booklet easy to carry across care settings to ensure accurate transfer of information. More efforts like this should be made to inform older people and their families with the information they need about their medication.

Improving communication with the individual and their family members

“When you are being discharged you should be given all the information you need about your condition and clarity about any preventative measures you need to take to ensure your health doesn’t worsen or deteriorate.”37

If people have more information about their condition, what is happening to them and what to expect, then they can become more involved in the decisions that affect their lives. If for example Evelyn had been informed during her pre-op assessment that entitlements had changed around reablement and other support post-discharge, then she, together with health and social care staff may have been able to plan for this ahead of her admission, however, Evelyn and others in her situation were not informed or involved in the process until after things had gone wrong.

35 Royal Pharmaceutical Society report (2014)
37 Local Healthwatch focus group, South of England
We call on the government to ensure that patients and their families are at the heart of decision-making in their own care and also around changes to services.

**Training for care homes and hospital staff on end of life care**

Through the inquiry we came across a number of good practice examples where hospice staff and other experts in palliative care are training key staff at local care homes and hospital trusts on end of life care so that they can improve the support for older people at the end of their lives. We would like to see this more widespread across the country. Rapid efforts must be made to give people more choice at the end of their lives and ensure people do not die in unnecessary pain and without their dignity.
Others are kept in hospital too long, waiting for assessments and for social care while physical and mental wellbeing deteriorates

In contrast to those discharged without the right support are those older people clinically ready for discharge, kept in hospital waiting for intermediate care, assessments and after-care packages to be put in place.

Age UK recently reported that since June 2010 the NHS has lost almost 2 million bed days owing to patients waiting for social care assessments, a care home place, a care package or adaptations to be made to their own homes.38 The cost to the system is an estimated £526 million. 80% of all delayed discharges or transfers of care are experienced by people over the age of 7039 so this issue is affecting older people more than any other group and below we explore the experiences we collected through the inquiry.

Older people waiting for assessments, adaptations and intermediate care

Last year, on average older people were having to wait almost a month before they could be transferred to a residential home, for grab rails or ramps to be fitted at home, or for social care packages to be put in place40. And it’s getting worse, with waiting times increasing steadily since 2010.

Jackie told us about the experience of her father:

“Staff on the ward are really supportive but the process of discharge is confusing at best and damaging to wellbeing at worst. It’s the communication and expectations that is very hard to keep track of: decisions reversed with no notice, no clear guidance to the family of who makes the decision.

They had suggested that they wanted to get my father into a community hospital. Staff talked to him about going, his expectations were raised and he wanted to go. The message comes back that the community hospital wouldn’t take him and he needed to stay at hospital to finish his IV antibiotics.

My stepmother [is] distraught at another two weeks of driving in to see him; he’s disheartened and I’m trying to manage the process from the family’s point of view. As we thought he was going into a community hospital we were advised not to go looking at nursing homes again. Getting into the right one is really critical to his wellbeing from here and so now we are ringing around

38 Age UK (2014) ‘Nearly 2 million NHS days lost to delayed discharge’
40 Age UK (2014)
(with the help of the onward care manager) trying to sort something out that might be suitable.

We questioned whether he would get any rehab support and this has led the team to re-considering what [Dad] might be able to achieve. We are now back into the possibility of him being sent to a community hospital but we don’t know until they’ve done more base line assessments and in order to know what’s happening I need to give up work a couple of afternoons a week to go in and talk to staff.

I’m self-employed so I’m fortunate in having the ability to control my time however I would have really valued having access to a member of the medical team to be able to talk to / email with so not to be losing work as well.”

We also heard about Albert, a Parkinson’s patient, who didn’t get the right support in hospital while waiting for assessment and for intermediate care - his medication was not given on time and the limited physiotherapy he received while in hospital was inadequate. Health staff did not seem to realise the importance of administering Parkinson’s medication at specified times and the direct impact this can have on mobility if medication times are not adhered to.

Albert’s daughter described a shocking lack of awareness by healthcare staff of the specialist care a Parkinson’s patient needs. He was kept in hospital waiting for assessment and then for a place in a rehabilitation unit. By the time the rehabilitation place became available his mobility had deteriorated so badly that they could no longer do anything for him. During the hospital stay his physical health had deteriorated to a point beyond repair. Albert has now been moved into a care home, where his health has continued to go down-hill, to the extent he cannot walk at all now. Albert did not qualify for NHS continuing care and all of his savings have now been spent on care home costs.

“He was left confused, neglected, a lost cause. It has affected everyone’s lives.”

**Continuing Care vs Social Care**

NHS continuing care is arranged and funded solely by the NHS for adults with ongoing primary health care needs outside of hospital. Individuals can receive NHS continuing healthcare in any setting, including their own homes or in a care home. NHS continuing healthcare is free, unlike support provided by local authorities - Community Care, where a financial charge may be made depending on income and savings.

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41 Jackie, online submission, local Healthwatch, South West of England
42 Parkinson’s ‘Get it on time’ campaign’ For more information; [http://www.parkinsons.org.uk/content/get-it-time-campaign](http://www.parkinsons.org.uk/content/get-it-time-campaign)
43 Lisa, online submission, local Healthwatch, North of England
44 Department of Health ‘NHS Continuing Healthcare and NHS Funded Nursing Care’ Public Information Leaflet (2013)
Department of Health and NHS guidance recognises that assessments for NHS Continuing Care and Community Care need to take place as soon as possible and well before a person is discharged but people have told us that often this is not happening.\(^{45}\) We also heard that there is huge variation in the way assessments are undertaken and decisions on eligibility for NHS Continuing Care are made, both in terms of process and criteria used, in different parts of the country. A national framework was introduced in 2007 to avoid this, so why is this still happening?

For thousands of people NHS continuing care can be a lifeline, but people feel the system isn’t working and is shrouded in mystery and disarray, leaving thousands of ill people with no choice but to pay for care.\(^{46}\) All of this can leave people vulnerable, placing them in precarious and difficult situations with their basic needs remaining unmet. More must be done to create a fair and simple system that is applied equally and is understood by all.

**John shares his wife’s experience of delayed discharge from a care home and of applying for NHS continuing care**

“The [care] home manager claimed she did not know an assessment was required. After six weeks we were informed of the continuing healthcare outcome, given the poor standard of the assessment, unsurprisingly we failed to qualify.

At this point the care home attempted to discharge Jane home, however the local authority took the decision to stop the two overnight ‘sits’ they had provided for several years as they reassessed this to be a primary health need and not personal care.

It took another four weeks before I could negotiate a safe level of care so discharge could take place. My wife had to endure an unnecessarily prolonged stay in the care home because of the administrative failure of all concerned.

I as the main carer could not manage [all] the ‘night sits’, having severe sleep apnoea I was already paying for a one night sit each week to cope. The guidance states when such an impasse occurs a mechanism to resolve the issue should take place - this never happened. I had to involve my MP and negotiated evening sits to be [exchanged] for night sits.

I am glad to say we were eventually awarded full Continuing Healthcare via the local Independent Review Panel taking 18 months and after much determination and effort.”\(^ {47}\)

The experience of John and his wife Jane highlights the frustration and stress that some older people are having to go through in order to get the care and

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\(^{45}\) Department of Health (2010), ‘Ready to Go? Planning the discharge and the transfer of patients from hospital and intermediate care.’

\(^{46}\) Voluntary / community sector organisational submission

\(^{47}\) John, online submission, local Healthwatch, Midlands
support they need so that they can stay living in their homes for as long as possible. The initial decision not to award continuing care was presumably because Jane was assessed as not having a primary health need and the subsequent decision by the local authority to withdraw care because they assessed it as a primary health need, shows the ‘horse trading’ between NHS and local authorities in disagreement over who should fund the care or equipment.

We heard many other anecdotal examples about the delays caused by the assessment process. Hollie, a nurse, reported to her local Healthwatch that she had been trying to arrange intermediate nursing care for an elderly patient, Rita. On admission Rita had been given a likely discharge timeframe of six weeks, however four months later Rita was still stuck in hospital. The continuing care team had taken two weeks just to ‘type up the report’ and the nurse had been unable to reach the team to chase the case. The nursing home would not allow the individual to be moved until the documentation was ready.

**Older people are waiting hours for medication and transport**

In addition to those waiting for continuing care assessments, we also heard from hundreds of others who had experienced delays on the day of discharge, sometimes waiting all day in the discharge lounge for medication or transport.

“The doctor came at 9.30 a.m. and said that I could go home but needed medication and would have to wait for that. At 12.45 I was still there waiting and apparently all I needed was some paracetamol.”

For particularly elderly and frail people and for those with conditions such as dementia or hearing and sight loss, having to wait for hours on end in a discharge lounge, can be very distressing and disorientating.

Bernie told his local Healthwatch that he had gone into hospital for observation and some tests. “Discharge depends on medication being sent to the ward from [the] dispensary and [a] nurse writing the discharge letter, this can take hours” Bernie felt that no extra thought or care was given to older people in hospital, even he reflected there seemed to be ‘plenty of staff’.

We heard numerous examples of older people waiting in hospital all day for medication and other arrangements like transport to be organised so they could go home, either to be told they would need to wait until the next day or to be discharged late at night. We heard a number of examples of older people being discharged past midnight in their nightwear, with just a blanket in the middle of winter. There were also many examples of older people arriving at their care homes unexpectedly, or arriving home with no food, heating or support because they live alone and family members had not been informed.

This lack of consideration of how and when older people are discharged from hospital is highlighted in Doris’ story:

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48 Jim, local Healthwatch submission, East of England
“When discharged, [Doris] was sent home with just an incontinence pad between her legs with no knickers or net to hold in place. [Family] had taken in Doris’s medication, but the hospital could not use it, but [also] did not return it. The hospital discharged Doris with new medication but no explanation of how to proceed, or how much was given that day.”

Many of the stories in this briefing point towards a lack of compassion for older people and a lack of due consideration to their particular needs. Many older people and their families directly expressed that they felt compassion was missing from their care. This is corroborated by a recent study which found that 64% of older people think health and care staff don’t always treat older people with respect for their dignity. Each service area must collaborate and co-ordinate their activities to work together to improve the discharge process for older people so that this improves.

**Delays leave too many older people dying in hospital before they can be discharged**

Two thirds of the UK’s population want to die at home, while a further 28% would prefer to die in a hospice, just 9% want to die in a hospital or care home. The sad reality is that only 20.8% die at home and just 4.5% in a hospice. While the majority die in hospital and care homes (54.8% and 17.8% respectively) Findings by the National Audit Office suggest that 40% of end of life care patients have no medical need to be in hospital.

Current support for individuals at the end of their life includes hospice care, nursing and care homes. For those who choose to die at home, support systems include GP’s, district nurses, Marie Curie and Macmillan Nurses, other hospital or community palliative care teams, physiotherapists, support and spiritual groups. However during the inquiry we heard that thousands of terminally ill older people are struggling to access these services and are dying in hospital due to delays in discharge planning, insufficient hospice places, poor communication and a lack of support for those who wish to die at home.

“The treatment [during his hospital stay] has restored my father to a state of relative comfort. He is now anxious to come home, where he wishes to die. The hospital is just as keen to discharge him, in order to free up the bed. However, the discharge process has been a fiasco.”

At least a fifth of NHS costs are thought to be spent on end of life care, highlighting that there is also a financial importance of properly assessing potential

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49 Case study, voluntary / community sector organisation submission, August 2014
50 Age UK Factsheet (2015)
53 Case study, voluntary sector organisation submission, July 2014
54 Demos ’Dying for Change’ report (2010)
savings arising from earlier hospital discharge of terminally-ill patients. The estimated cost of a day of community care at the end of life is £145 compared to the cost of £425 for a specialist palliative care bed day in hospital. This indicates that changing the setting of care of a patient at the end of life has the potential to reduce the daily cost by £280.55

Older people with terminal illnesses should not have to die in hospital if they do not wish to do so. Family members have complained that health staff frequently focus on continued treatment of the condition rather than controlling symptoms or providing pain management. When people are at the end of their life they should have the opportunity to be in a peaceful environment with loved ones around them and the Government must respond to address this most fundamental of issues.

A voluntary sector organisation supporting people at the end of their lives, told us that almost all discharges require specialised equipment such as a hospital bed, air mattress, bed rails, safety bumpers and moving and handling equipment. These orders have to be authorised by an external source and then a same day or next day delivery is arranged. If the authorisation is queried by the Clinical Commissioning Group (CCG), then this causes delays in discharge. Access to medication in a rapid discharge situation is challenging and leads to delays as many hospices do not have in-house pharmacists and delays can occur when local pharmacists are unable to dispense medications fast enough.

Many people with terminal illnesses access hospices for short periods of time for particular procedures or for specialised symptom management, before returning back home. However a voluntary sector provider reported to us that they are increasingly finding that people lose their social care support package as soon as they are admitted to the hospice, even if it’s only for a day or two. They are then informed they have to be reassessed, which can cause delays in discharge from the hospice and preventing others from being admitted. It is reported that even if they are granted a new care package this can cause difficulties with continuity of care as people have to then get used to new professionals or care providers that may not be familiar with their needs and routines. All of this is avoidable and causes undue stress and delays to the individual.

**Why is this happening?**

Older people know there is a lack of co-ordination between the services involved in their discharge. The report has highlighted experiences which show a failure to work together at three levels, internally between hospital teams, externally between primary and secondary care and between different agencies such as local authorities and the NHS and this has a significant impact on how quickly people can be safely discharged from a health or care setting.

The challenges people face in being assessed for NHS Continuing Care and Community Care provides the strongest example of this disconnect between the NHS and local authorities. A voluntary sector organisation reported to us that

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55 Nuffield Trust ‘Exploring the cost of care at the end of life’ (2014)
problems arise with these assessments, particularly for people with degenerative and progressive long-term conditions;

The assessment process usually starts when the individual is in hospital. In these circumstances most local authorities will not be prepared to assess someone with a progressive or non-improving long-term condition until they have been ‘ruled out’ of NHS Continuing Care eligibility. However CCGs are reluctant to assess the individual until they have completed their rehabilitation so that they can have a clear picture of probable future care needs. This means that the assessment process doesn’t even begin until they are ready, or almost ready, for discharge. If they are then found ineligible for NHS Continuing Healthcare, then the ‘social care’ assessment process begins\(^{56}\). This highlights how the lengthy delays can occur.

Another problem is the lack of clear definition of what a primary health need is, and a clear definition (particularly in law) that defines what constitutes a ‘health’ care need as opposed to a ‘social’ one. At this stage the priority for the individual (and the hospital) is to get out of hospital and multiple assessments and the delays in discharge brought about by them are bewildering and frustrating.

A pharmacist told the inquiry about a time she paid for an older person’s Haleraid (a device that helps frail older person who haven’t got the strength to compress an inhaler to get the drug out) as it is not available to prescribe on the NHS. It costs just £1.50 and can save lives\(^{57}\).

Many family members told us that health and care staff lacked awareness and training on specific needs of those with conditions such as Parkinson’s, Dementia, dual sensory and sight loss and those at the end of their lives with palliative care needs.

We heard again about variations of spending across the country in the care of those at the end of life, which could partly explain why some go without specialist support at the end of their lives. A National Audit Office report found spending by Palliative Care Trusts varied from £154 to over £1,600 per person\(^{58}\). While we understand there is some need for local variation depending on costs and needs in particular parts of the country, there should however be a basic minimum standard that all those should be entitled to at the end of their lives and from the experiences we have heard through this inquiry many older people are not getting the support they should, to have a peaceful and dignified death.

People reaching the end of their lives also find it difficult to get a social care package put in place quickly enough to enable their discharge from hospital before dying, despite the ‘fast track’ system designed to escalate assessments for those nearing the end of life. A lack of availability of palliative care services in the community 24 hours a day, seven days a week could also be a factor which means

\(^{56}\) Voluntary/community sector organisation submission, August 2014
\(^{57}\) Pharmacist, focus group discussion, September 2014
\(^{58}\) National Audit Office (2008)
it is not safe for the hospital to discharge the patient. A lack of communication between hospital and primary care was said to also be an important factor.

**What needs to change?**

There needs to be a clear strategy in place to avoid older people receiving such markedly different care and support post-discharge, just because of where they happen to live. Despite frameworks and guidance being in place, local authorities, CCGs and NHS trusts are still free to make their own decisions on what to spend money on. The Government should ensure decisions and funding of services and support should be transparent to all, for example publishing more data on Continuing Care assessments.

Urgent efforts must be made to join up care with better sharing of information across teams and between the NHS and local authorities. There should be an assessment process that is simple and understood by all and efforts must be made to ensure staff can support older people and their families through the process.

There should be more multidisciplinary teams involved in the assessment of older people as soon as possible after admission to hospital so ensure their specific needs are planned for at the earliest possible point, and so their discharge is not delayed.

For those at the end of their lives there should be rapid assessment processes, suspension of normal rules to enable rapid access to 24/7 palliative care and discharge of the individual to home or to a hospice before they become too unwell to be moved.

**My Discharge Project - Royal Free**

During the inquiry we came across the ‘My Discharge Project’ at the Royal Free Hospital in London which aims to support the discharge of people with dementia. Patients are assessed for discharge within 24 hours of referral to build understanding of their needs in order to be discharged home safely and to remain there. Patients are also provided with intense therapy and a named individual acts as a single point of contact for patients and carers. They can also help family members prepare for how to cope with a dementia patient once they return home.

When patients are discharged, they leave with a discharge letter and emergency phone numbers and are accompanied home with food and clothes if needed. The team will also liaise with social care colleagues and voluntary sector organisations to get care visits set up and equipment in place.

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This service helps people with dementia to stay in their homes after discharge, reduces readmission and discharge to nursing homes and supports family members to care for their partners in their own home.

**Palliative care - good practice examples**

A number of good practice examples were shared with us during the inquiry, which highlights efforts being made to support care homes in palliative care training and to ensure effective discharge from hospital.

Enabling people to be discharged from hospital/ hospice as quickly as possible, St Christopher’s Hospice\(^{60}\) in South London has set up a service to enable local residents thought to be in their last six months of life to receive personal care in their own homes following discharge from hospital or hospice.

Another service in St Catherine’s Hospice\(^{61}\) in Scarborough is piloting four nurse-led end of life care beds to help facilitate rapid discharge from Scarborough hospital for patients in their last days of life. This has helped increase patient choice, enabling patients to receive high quality end of life care in a hospice setting and has helped reduce unnecessary deaths in hospital.

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\(^{60}\) St Christophers Hospice, for more information: [http://www.stchristophers.org.uk/](http://www.stchristophers.org.uk/)

\(^{61}\) St Catherines Hospice, for more information: [http://www.stcatherineshospice-nyorks.org/](http://www.stcatherineshospice-nyorks.org/)
Emerging recommendations

Throughout the inquiry we asked people what would have made a difference, what would have made their experience better. We list below what we heard and the emerging recommendations so far. We will use these as a basis for discussion with stakeholders, and hope that this will help to generate our final conclusions and recommendations that will set an ambitious direction for the future.

A simplified and comprehensive discharge and assessment process, involving older people and their families at the heart of planning and decision-making

Older people and their families want to know as early as possible what to expect from the discharge process and what they will be entitled to. They also want to be involved at every stage so they can feed into the process, providing accurate information and actively participating in assessments. Finally people should have all the information they need about their condition.

- A clear definition of NHS Continuing Care and Local authority funded Community Care - clearly setting out what constitutes a health care need as opposed to a social care need, so that subjective decisions by assessors can be avoided

- An assessment of older people’s needs in their discharge and continued support in the community, should take place at an early stage including decision-makers from all agencies

- Increase awareness about the needs of older people to demystify assumptions and improve awareness and sensitivities to individual people’s needs, including those with specific conditions such as dementia, Parkinson’s, sensory and sight loss and for those needing palliative care

“Better understanding by hospital staff of Parkinson's and a proper meeting with all healthcare professionals involved in my dad’s care may have given us a better outcome than him having to go into a care home”  

- Hospitals should ensure that people are informed of exactly what to expect as soon as they enter hospital or a care home. This includes being fully involved in the discharge process and knowing what they are entitled to and what support they can purchase beyond this. This level of information must be maintained throughout a person’s stay, especially when they are being discharged.

- Hospitals should use discharge checklists for patients which embed patient consent

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62 Lisa, online written submission to local Healthwatch, North of England
• When admitted to a hospital setting all providers issue older people with a ‘passport’ which includes the details and milestones of their treatment and care that will aid planning for their discharge

• Health and care settings should provide signposting to relevant community services for people who are being discharged and should ensure people have all the information they need about their condition.

“There seems to be little ‘in-between’ care. I did discover, as a result of my contact with the multiple sclerosis nurse department, the existence of [a] neuro rehab unit where I live. It turned out that I didn’t need it but why are these places so little known-of? Perhaps there aren’t that many.”63

**Coordinated support post-discharge**

After being discharged people wanted regular support and especially close support when they are first discharged, ‘someone to check if I was doing ok’. Older people suggested that ‘GP’s should do more’ and take on more of a coordinating role and responsibility for older people post-discharge.

“I did not see anyone until 11 days later when I had rung the district nurse to see if she was coming to take out my stitches. She had no knowledge of me so would not have come if I had not rung. When she came she had to send for the doctor because my wound had become infected. I was then put on a course of antibiotics64.”

• be given a discharge package that ensures older people have everything they need in the first week after discharge, this might include; food, electricity, medication and follow up visits from professionals

• receive a commitment from Government and all discharging agencies to follow up with older people within 7 days of discharge and 28 days after to identify and address additional or change assessments or on-going needs

• Advocacy in hospitals so people are told about their rights at point of discharge and are able to access support for someone to speak on their behalf - someone who can stand up for the patient/carer to tell them what they should expect

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63 Joe, online submission to local Healthwatch, North of England
64 Vera, Online written submission to Healthwatch England
Questions for you

In response to this briefing we are asking you to consider:

a. Are there any key issues we did not capture that must be reflected in our final report?

b. Do you have further insight into the cause and why some of these issues might be occurring?

c. Are there other strong examples of best practice we should highlight in the final report?

d. Do you have ideas for how the emerging recommendations could be strengthened? Or are there any recommendations missing? Please indicate where any recommendations might fall short of our aspiration of guaranteeing the continuity of people’s support and eradicating poor discharge.

e. What role(s) you or your organisation can play in implementing these recommendations (or the ones you have suggested)?

f. What challenges do you think we might face in getting these recommendations implemented a. locally, b. nationally?

g. We particularly welcome further insight on;

   o understanding the impact that the current policy work and improvements (including the Care Act) will have on improving discharge for older people

   o why there are such disparities in the way NHS Continuing Care criteria is being applied in different parts of the country despite having a national framework to avoid this, and how the Continuing Care assessment process could be simplified and better integrated with Community Care assessments

   o In 2014 the Secretary of State announced a commitment to a named clinician for all older vulnerable people post discharge. We call for further insight into how this is being implemented and how GP’s are taking a bigger role in the discharge of older people from hospital.

Please provide your feedback on any of the issues raised in this briefing to specialinquiry@healthwatch.co.uk by 10 February 2014
Appendix A: The costs to the system of not supporting Judith during discharge

The additional cost of unsafe discharge to the health and social care system: An older person

Judith* and her family told us about her experience of being admitted to hospital after having a fall at her home, and injuring her arm and her leg. In 26 days, she was discharged and readmitted from hospital 4 times, due to a lack of involvement of herself and her family in planning her aftercare.

*Pseudonym used to protect the identity of the individual.

The estimated additional costs of her unsafe discharge was £18,258

<table>
<thead>
<tr>
<th>Event</th>
<th>Cost</th>
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<tbody>
<tr>
<td>Prior discharge</td>
<td>£273</td>
</tr>
<tr>
<td>Total cost of hospital stay and treatments</td>
<td>£1,935</td>
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<tr>
<td>£349</td>
<td>Transport + Readmission back to ward</td>
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<tr>
<td>£2,168</td>
<td>Treated for a previously unrecognised fracture to the arm and social care assessment</td>
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<tr>
<td>£235</td>
<td>Stay in care home against family’s wishes</td>
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<tr>
<td>£1,496</td>
<td>Readmitted and another procedure undertaken on her arm</td>
</tr>
<tr>
<td>£8,958</td>
<td>Additional stay in hospital for 13 days and reablement package</td>
</tr>
<tr>
<td>£1,000</td>
<td>Additional stay in hospital</td>
</tr>
<tr>
<td>£3,779</td>
<td>Cost of stay in hospital and time from social worker</td>
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</tbody>
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Day 1: Judith due to be discharged
Day 2: Judith is discharged home with appointment to return for X-ray
Day 3: Ambulance called as Judith is unable to move her legs. Readmitted to ward
Day 4: Assessment by social worker to determine if patient should be discharged to care home (against family’s wishes)
Day 7: After a stay in a care home, patient is readmitted to hospital again
Day 21: After a major procedure on her arm, Judith is discharged with a reablement package
Day 23: Patient is readmitted to hospital
Day 26: Patient is discharged for the final time and complaint made to social worker