Behind the headlines: are older people and families really to blame when their hospital discharges are delayed?

We are regularly reading articles in the media about 'bed blocking' and hearing talk of older people staying in hospital when they no longer need hospital care. Sometimes there seems to be a tendency to blame the patients, it being implied that some older people and their families are 'choosing' to remain in hospital, thereby denying hospital care to others who are in greater need.

However, at Age UK we simply do not believe that the problem of older people and families staying in hospital longer than is clinically necessary is anything like as simple as it is sometimes painted, or that older people and families are usually at fault when their discharges are delayed.

This short report explains why we take that view.

There is no doubt however that delayed transfers of care are a real and growing problem for the NHS. A mammoth 1.75 million bed-days were lost from January to December in 2015, an increase of 28.4 per cent compared to 2014.

13 per cent of these lost days were attributed to so-called 'patient choice'. But calls to Age UKs information and advice line[1] shed important light on the experiences of some older people and reveal the complicated and often tragic situations behind the headlines and the reality of 'patient choice'. They demonstrate just how hard it can be to organise a safe and appropriate place for older patients to go to after they have been in hospital, where families can be sure that their loved one's health and care needs will be properly met, giving them the best chance of a full recovery.

The main problems seem to be:

- A lack of information and general confusion about what's available and who is responsible for paying for it;
- A marked shortage of good health and care services to help older people recover after they have had a spell in hospital;
- Poor co-ordination and sometimes downright buck-passing between different parts of the NHS and between health and social services, and
- Overstretched professionals and administrators, struggling with clunky systems and insufficient resources

[1] Our free and confidential national telephone service - Age UK Advice - has been running for over 15 years, speaking to over 20,000 people a month. We provide information and advice for older people, their friends, relatives, carers and organisations working for and on behalf of older people. The most common subjects that people contact us about are social care, welfare benefits and health and disability. Hospital discharge is a common reason for people needing advice. Our records from these calls showed a number of recurring issues. The case studies below reflect issues raised over the past six months. We have changed names, gender and certain details and characteristics to preserve our callers' confidentiality.

The fact is that many older people who go into hospital are already less than entirely well and not terribly resilient. As a result, a health issue that might be minor for someone who is basically fit and well can be much more serious for them. Then, once an older person has been successfully treated and no longer needs the specialist and intensive medical support that only hospitals can provide, they may be weak and have less able that they were on admission so they need to be looked after for a while in order to recover further and to regain their strength and confidence.

If you are an older person who already has some problems moving around, the last thing you need is to be lying in a hospital bed for longer than is strictly necessary. Similarly, someone suffering from cognitive impairment or dementia can find the hustle and bustle and unfamiliarity of a hospital ward confusing and disturbing.

In our experience at Age UK, while older people are usually profoundly grateful for the medical care they receive in hospital, most are only too keen to leave, for lots of understandable reasons. For example, it is hard to sleep well in hospital, the food may not be to your taste and you probably only have a few of your own things with you. And you may have important things to go home to, like caring for a partner who is themselves not very well, or looking after your pet.

After a spell in hospital different older people need different levels and combinations of support to make the fullest possible recovery. Some older people may be able to go straight back home and pick up the reins as though nothing has happened, but many will need some kind of rehabilitative help to get fully better. In particular, older people may leave hospital less physically strong and less mobile, especially if they were already quite frail. Then the priority is to act fast and buoy them back up again.

For some, the right answer could be to go home but with the help of reablement services provided by social care staff trained to encourage and support people to regain their independence. It might be time to install some hand rails and other aids at home too. For others who are less well and less robust, intermediate, short term care at home, in a community hospital, a nursing or residential care home, involving nursing support, specialist support from an occupational therapist or physiotherapist and/or practical or personal care support, may be more what is required.

Deciding what is best on the basis of a full and rounded assessment and then ensuring the arrangements are in place before an older person is discharged is incredibly important: ultimately it can make the difference between fully recovering and continuing to live independently, or having to accept that you can no longer cope at home and need some kind of residential care instead. And there really isn’t much point if whatever is agreed as right in the circumstances doesn’t start straight away. For example, delays in physiotherapy for an older person recovering from a fracture is likely to compromise recovery,More immediately, there may be no one at home to

help an older person who lives alone to get into bed, if they cannot manage it on their own on their return.

However, unfortunately, we are hearing that older people are sometimes being told they have to leave regardless, because the hospital needs their bed, without them or their families being offered help to organise support at home and without the right arrangements being put in place. For example:

> Paul's wife Mary, 85 years old, is in hospital. She has lost her mobility during her hospital stay. Yesterday the hospital told him Mary was ready for discharge today and she can't occupy a hospital bed anymore. Nobody has assessed what she will need to help her recover at home, whether she can regain her mobility, or what adaptations are available to help them manage. Paul was able to delay the discharge for a day by getting the Patient Advice and Liaison Service involved but he still wasn't given any information about her rights, or about how they are going to manage at home.
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> Guy's 97 year old father, Eric, is in hospital after a fall. He's deaf and has poor mobility. Rehabilitation has been mentioned, but nothing has been agreed. Guy's mother, Sheila, was looking after Eric before, but she was already struggling because he had become incontinent at night and Guy feels she can no longer cope with Eric's care needs. Sheila has received a call from social services saying that Eric is being discharged. The person she spoke to refused to give her a number to call so she could speak to someone about her concerns. Guy has not been told about any care that Eric will receive, or whether his medication is changing, or why he collapsed in the first place. To make things worse Eric's mental capacity is questionable and there are no legal powers in place to safeguard his health and personal welfare.
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> Liz's father John has dementia. He has been living at home with his wife Jane, who is his main carer. He has a package of support in place, but his needs have increased recently and Jane feels increasingly unable to manage his behaviour. He was recently hospitalised because of a problem with constipation, but Jane has now been told he will be sent home in the next few days. The hospital social work team does not appear to be involved and there doesn't seem to have been a review of his care needs. The Community Social Work team have said that if John returns home they will not be able to reassess him for a number of weeks.

Some older people are lucky and have friends or neighbours who step in to offer help when there is pressure on an older person to leave hospital, to free up a bed. This is especially valuable in situations where the older person has no immediate family. However, we have heard of cases where they have, in effect, been taken advantage of, ultimately leaving everyone in a very difficult position. For example:

> Brenda's friend Lesley was recently in hospital for an operation. In discussions about discharge the social worker enquired about reablement, but the reablement team said this would take two weeks to arrange. Rather than leaving Lesley stuck in hospital, Brenda invited Lesley to stay with her on the understanding that in two weeks' time she would return to her own home with a reablement package. There were immediate problems in that Lesley needed to take showers morning and evening to prevent her wound from becoming infected but she couldn't manage this on her own, and no help was offered. And then, to their horror, Brenda and Lesley were informed that reablement services would not be available when the two weeks was up as they didn't have enough carers.
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> Jackie, who is 80 years old, went into hospital following a fall, had a hip replacement and then went onto an NHS rehabilitation unit. Social Services promised further reablement in a care home, but the one they found was inappropriate because of Jackie's lack of mobility. Her friend, Ruth, found an alternative care home and both social services and the hospital promised that physiotherapy would be provided, but after a week none has been forthcoming and they're both worried that she won't be able to get back home. Jackie's GP has said he knows nothing about physiotherapy, and Ruth has not been able to get through to social services to find out what, if anything, is going on.

Older people who are sent home without the right support in place are at risk of ending up back in hospital again:

> Janet's mother Rachel is in hospital for the second time in 10 days. Rachel lives in her own home. Janet feels she shouldn't have been discharged home on the first occasion and intends to complain. Before her readmission the Intermediate Care Team agreed that she wasn't safe at home. Now that Rachel is back in hospital Janet fears the same thing will happen again. She's trying to find someone who can help them find out what the options are and wonders what the responsibilities of the hospital social worker are and who, if anyone, joins everything up.

What's actually available to older people who are about to be discharged is often very unclear to them and their families. In any case it seems to vary from place to place and from time to time and sometimes there is no one obvious to ask about it, or any comprehensive written information to read either. The circumstances under which people are eligible for public funding or are required to fund their care from their own resources can seem especially impenetrable and the decisions that are taken sometimes highly arbitrary.

Intermediate care and reablement care are publicly funded by health and/or social services for up to six weeks as an intensive input to help people recover their

strength and independence. But there is not enough available for people who would benefit from it. The NHS's own annual benchmarking survey finds consistently that there is only about half the capacity required to meet patients' needs effectively and that waiting times are increasing[2]. The result is that following an assessment, some patients are being told they need it but, when there isn't any, they are told they should find and pay for it themselves. In addition, they are not always getting guidance on where they could go to find care that would support their recovery.

> Terry's father Richard, 85, is in hospital following a stroke. He is ready for discharge and has been assessed as needing rehabilitative care through two home visits a day. However he was then told that there are no reablement services available in his area. Terry has been told to 'get his father out of hospital' and to look for and fund the care himself.
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> Anne's husband Nicholas has cancer that is now affecting his mobility. He has had several admissions to hospital following falls. They have been told that intermediate care could make him less likely to fall in the future, and this would be paid for from public funding for six weeks, but there isn't any available at the moment. Anne and Nicholas have been told the council could contact a care agency for them but they would have to pay for the care themselves without the benefit of the six weeks funding. Nicholas refuses to do this, so Anne feels stuck. Social services then tell Anne they can provide carers to get him up in the morning, but no more. Anne fears her husband will fall again and be back in hospital, possibly with a broken hip next time.

Patients and their families need to know how much care will cost, who will be responsible for funding it, and what their rights are. Unfortunately, sometimes the advice that is available seems to be inadequate or incorrect:

> Annette received care at home following a stay in hospital because of a fractured hip and is still unable to leave the house. Social services have not been clear about the cost of this care or who is responsible. Annette asked them if she was eligible for six weeks free intermediate care and they have said, quite incorrectly that 'it has been abolished'. She has still not been invoiced and is really concerned that she is getting into debt.

The lack of transparency and solid information about the provision and funding of follow up care like this is worrying as well as confusing for older people and their families. We also know of older people receiving large bills from their council for reablement care, out of the blue, and family members needing to intervene to ascertain that in fact the bill was automatically generated and they didn't have to pay.

[2] NHS Benchmarking Network 'National Audit of Intermediate Care Summary Report 2015' November 2015 http://www.nhsbenchmarking.nhs.uk/CubeCore/.uploads/NAIC/Reports/NAICReport2015FINALA4printableversion.pdf page 6

Major problems sometimes occur when older people's needs are assessed as having fundamentally changed, so that what might have been appropriate before they became ill and entered hospital aren't suitable anymore. This means there is then a need to source and secure an alternative package of support, possibly including accommodation too, and inevitably this can take time. In such circumstances older people and families sometimes find themselves under pressure to accept something they do not believe to be in their best interests. For example:

> Phil is in hospital and nearing the end of his life. The hospital says they can't do any more for him and want to discharge him. Phil lived in a care home with nursing prior to going into hospital, but this home is now unsuitable. Social services have identified a couple of alternative care homes, but his daughter Susan and her family have refused them because they are too far away for the family to visit him regularly. The family have found what they consider to be a suitable home nearer to them but there aren't any vacancies. They've asked the GP to refer Phil to a hospice, but the GP has refused because Phil's diagnosis doesn't say he has a specified time to live.
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> Hannah's father Bob has a range of health problems, including dementia. At a discharge planning meeting two weeks ago the consensus was that Bob should return to his sheltered accommodation unit with a care package in place. However, the housing association that manages the sheltered accommodation says they do not want him to return because he is no longer well enough to manage, while Social Services are saying that sheltered housing is his best option at the moment as he does not yet meet the criteria for specialist residential dementia care. Hannah feels that they are now at an impasse and that she is going to be forced to agree to something she doesn't believe to be the best option for Bob.

When an older person lacks the capacity to make their own decisions the situation can become all the more complicated and difficult for everyone:

> Alfred is in hospital following a series of strokes and is due to be discharged in the next two weeks. It is being recommended that Alfred now goes to a care home. Alfred lacks mental capacity to make decisions about his care arrangements but his son has a registered Enduring Power of Attorney for Alfred's property and financial affairs. The hospital social worker is advising the family that social services will choose the care home and that it will need to be some way away to meet local authority cost limits. The family is unhappy about this because they think he needs to be closer to them so they can visit regularly.

Unfortunately, we also know of some instances in which the rights of older people and families appear to be being bypassed.

Elsie was living in her own home with two care visits a day until three weeks ago when her carers reported some confusion. She's been in hospital since then. She has a diagnosis of Alzheimer's and vascular dementia but is able to live independently and is very clear that this is what she wants to do. However her daughter Elizabeth was called to a meeting at short notice yesterday where it appeared that the decision had already been made that Elsie must go into residential care. No other options were explored and no evidence was given that her mother had been either assessed or consulted. The social worker said Elsie's mental capacity could be assessed later. Elsie's son, Duncan, also wanted to attend the meeting but it was too short notice.

Conclusion

It is important to recognise that many transfers of older people out of hospital are well organised and successful. However, the real-life situations described here (appropriately anonymised) hopefully help to explain how difficult it can sometimes be for older people and their families to make a smooth transition out of hospital, towards what everyone hopes is a full recovery from whatever caused them to be admitted in the first place. Part of the problem is that many older people in this position are already coping with long term health conditions and are short on resilience. But the case studies sketched in here also demonstrate just how pressurised many hospitals and councils now are.

Age UK's contention is that rather than being responsible for delayed discharges, older people and families are invariably the victims. NHS and council staff are often caught in impossible situations too; trying to ration too little reablement and intermediate care support among growing numbers of older people who demonstrably require it. And all the time conscious that there are people needing to come into hospital for good reasons for whom there may currently be no bed.

In such situations older people, families and professionals are all under a lot of stress. Among other things, older people and their families may be trying to come to terms with the realisation that they will never be able to live as independently as they did before, or in some cases be able to return to their own homes at all.

Such situations are hard enough to cope with at the best of times, but made all the worse when processes and systems are under relentless pressure. Older people, families and friends, and all those whose job it is to help them make a safe transfer out of hospital and a good recovery, deserve our sympathy and active support.

At Age UK we accept that there will always be occasions when some people will behave less responsibly and reasonably than we might all like. Going forward though, it would be good to hear less about older people and their families being responsible for delayed discharges. This is not only unfair, it is also a distraction from

what we should really be focusing our attention on: strengthening the system for helping older people to get better after being in hospital, and investing sufficient resources in it to meet the needs of our growing older population.

Useful Age UK information guides and factsheets about being discharged from hospital and what happens next

Age UK Guides

Age UK produces guides that aim to inform older people of their rights and help them make choices. Relevant guides include:

Going into hospital (your rights when going into hospital and when you are discharged) http://www.ageuk.org.uk/Documents/EN-GB/Information-guides/AGEUKIG07_going_into_hospital_inf.pdf?dtrk=true

Care homes (finding the right home) http://www.ageuk.org.uk/Documents/EN-GB/Information-guides/AgeUKIG06_Care_homes_inf.pdf?dtrk=true

Care home checklist (helping you choose the right home) http://www.ageuk.org.uk/Documents/EN-GB/Information-guides/AgeUKIL5_care_home_checklist_inf.pdf?dtrk=true

Housing options(different types of housing to suit your needs) http://www.ageuk.org.uk/Documents/EN-GB/Information-guides/AGEUKIG08_housing_options_inf.pdf?dtrk=true

Adapting your home(services and equipment to help you stay living at home) http://www.ageuk.org.uk/Documents/EN-GB/Information-guides/AgeUKIG17_Adapting_your_home_inf.pdf?dtrk=true

Getting help at home (what to do if you need a bit more care at home) http://www.ageuk.org.uk/Documents/EN-GB/Information-guides/AgeUKIG23_Getting_help_at_home_inf.pdf?dtrk=true

Age UK Factsheets

Our fact sheets are more detailed and technical to support Age UK advisors in our Information and Advice Services. We are in the process of revising our Hospital Discharge Guide (FS37) and expect the new version to be available in May 2016.

The full list of Guides and Factsheets is available at

http://www.ageuk.org.uk/Documents/EN-GB/Information-guides/AgeUKIL5_care_home_checklist_inf.pdf?dtrk=true