carersUK

Research summary

Pressure Points:
carers and the NHS

This report examines the role of carers in reducing emergency admissions and delayed transfers of care from hospital.

We asked carers who had used 999 or Accident & Emergency services over the previous year why they turned to emergency care. Those caring for someone admitted to hospital in the previous year were asked about whether they thought the admission to hospital could have been prevented and how well they felt supported by the discharge process and the services put in place to support them at home.

Key points

- Significant numbers of carers are taking the person they care for to Accident and Emergency (A&E) because of a lack of access to other community health and social care services. Carers need support from these services to prevent unnecessary admissions to A&E.
- Carers are not being consulted about the discharge process, or only being consulted at the last minute. Whilst delays around discharge are often due to a lack of social care packages, not involving carers is resulting in the discharge process being poorly managed and timed.
- When carers are consulted about the discharge process they are more likely to say that they feel they have a choice about caring for the person they look after and that the discharge timing was just right.

Introduction

The pressure on A&E often grabs the headlines but the factors behind it are complex and symptomatic of wider pressures on the NHS, social care and a lack of support for those caring for family and friends in the community.

Demands on the NHS and care services are increasing from a population which is living longer but often with a combination of long-term health conditions. At the same time financial demands on both the NHS and social services are increasing. Acute services in the NHS are under strain in several areas and A&E attendances each year are increasing – over 500,000 more visits to A&E in the first quarter of 2016 than the same period last year[1] though in many cases A&E is not the most appropriate care setting. This is contributing to delays in treatment and transfer from acute care and along with delays in discharging patients from hospital is increasing bed occupancy rates.

The pressure on A&E often grabs the headlines but the factors behind it are complex and symptomatic of wider pressures on the NHS, social care and a lack of support for those caring for family and friends in the community.

The NHS Five Year Forward View has a strong focus on out of hospital care and avoiding unnecessary admissions. Given that the bulk of care in the community is provided by families and friends caring unpaid, a focus on how they are making decisions and using services and on supporting them, is an essential part of the future of the NHS. Without putting in place community health and care services that back up carers, our health and care system will not be able to be able to transform the way it delivers care to meet the needs of our ageing society.

A relative or friend coming out of hospital often marks the beginning or a change in a caring role. It's a crucial time for people to get the information and support they need before discharge to make a decision about whether they can take on what it often a significant caring role. Health professionals must involve carers and put the necessary steps in place to give them the short and medium term support they need and ensure they have access to the information and advice they need to provide care without putting their own health and employment in jeopardy.

Our research with carers looked at their experiences of using emergency care and their reasons for turning to hospital rather than to a community health service.

Our research with carers looked at carers' experiences of using emergency services like 999 or going to A&E and their reasons for turning to hospital rather than to a community health service, we also asked carers about what could have made a difference to preventing an emergency care admission or supporting them to care effectively at home without damaging their own health in the process.

1 https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2016/06/Monthly-AE-Report-June-16.pdf

Context

There has been a dramatic rise in the number of delayed patients...delays in discharging people from hospital are also bringing enormous costs for the health service.

At the end of the last financial year 2015/16, the proportion of patients waiting more than four hours from arrival to discharge, admission or transfer in all A&E departments in England was 12.1% - this is 5% above the target and the highest percentage since targets were introduced.[2] There has been a dramatic rise in the number of delayed patients and in June 2016 there were 35,300 patients who were delayed more than four hours from decision to admit to admission, which is 85.2% higher than 19,100 for the same month last year.[3]

Delays in discharging people from hospital are also bringing enormous costs for the health service – for older patients alone, the National Audit Office has put the cost of delayed transfer at £820m a year.[4] The latest figures released show that in June 2016 there were a total of 171,300 delayed days, of which 115,400 were in acute care – an increase of 31,800 from June 2015.[5]

The causes of delayed transfers of care from hospitals to the community are complex but the proportion of delays attributed to social care has increased over the last year. Nearly a third (32%) of delays in June 2016 were attributable to social care, with 60% attributable to the NHS and 8% to both social care and the NHS.[6]

The main reason for social care delays was patients awaiting a care package in their own home, accounting for 35% of all social care delays.[7] However, there is also a real risk of emergency readmission if a patient is discharged prematurely. The cost of this can be significant to the NHS and, more importantly, it causes enormous worry and stress for all of those involved. Carers are a vital part of the hospital discharge process, both in preventing any delay in discharge, and in preventing unnecessary readmission into hospital. They also have vital rights at this juncture to ensure that they are not left without the right support.

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How can the NHS bring change?

The NHS Five Year Forward View recognises the critical role carers play, pledging more support for carers as well as highlighting their huge contribution to the NHS, stating: "*The five and a half million carers in England make a critical and underappreciated contribution not only to loved ones, neighbours and friends, but to the very sustainability of the NHS itself*".[8] It is important that this is recognised across the NHS and truly taken into account, especially when developing services to support out of hospital care. The

2 https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2016/06/Monthly-AE-Report-June-16.pdf
3 ibid
4 https://www.nao.org.uk/wp-content/uploads/2015/12/Discharging-older-patients-from-hospital.pdf
5 https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2016/06/Monthly-AE-Report-June-16.pdf
6 ibid
7 https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2016/06/June-16-DTOC-SPN.pdf
8 NHS England, Five Year Forward View (2015)

Carer passports are one way in which the NHS can make sure that carers are identified and signposted to available support.

Government's 2016-17 Mandate to NHS England also highlights the critical role of carers, stating: "*Carers should routinely be identified and given access to information and advice about the support available*".

The NHS Commitment to Carers also recognises and highlights the importance of carers to the NHS, setting out how NHS England will take practical steps to support carers.

Carer Passports are one way in which the NHS can make sure that carers are identified and signposted to available support. Carers UK has written a research summary on Carer Passports[9], drawing on existing best practice that looks at how hospitals can introduce passports in order to identify carers as well as promote additional support in hospitals for carers, such as discounted or free parking.

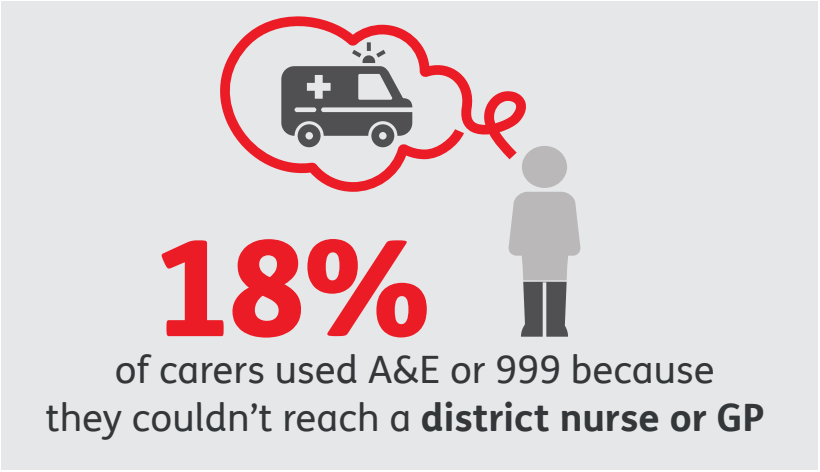
9 Carers UK (2016), Carer Passports

Research summary*

Carers use emergency services as the last resort

9% of carers in our survey used 999 or went to Accident and Emergency (A&E) because they didn't know where else to go.

- 1 in 10 of carers (9%) in our survey used 999 or went to Accident and Emergency (A&E) because they didn't know where else to go.
- Nearly a fifth of carers (18%) used 999 or A & E because it was difficult or impossible to get a district nurse or a GP out of hours.



A lack of support in the community for carers is leading to emergency admissions

61% of those caring for someone who had an emergency admission in the previous 12 months thought that it **could not** have been prevented. Of those carers who felt that the emergency admission **could** have been prevented:

22% of carers looking after someone over 65 said they were not consulted at discharge and 39% said they were consulted but only at the last minute.

- 27% of carers whose family member or friend has had an emergency admission in the previous 12 months thought this could have been prevented with more time before discharge.
- A third (32%) of carers whose family member or friend has had an emergency admission in the previous 12 months thought this could have been prevented with more support for them as a carer.
- 40% of carers who have childcare responsibilities for a non-disabled child in addition to their caring responsibilities (known as the "sandwich generation") felt that more support for them might have prevented an admission into hospital for the person they care for compared to 29% of those without childcare responsibilities.
- The older the person cared for, the more likely a carer was to say that more time was needed before discharge and more likely to say that replacement care when the carer needed medical treatment might have prevented admission into hospital.

Carers are not being consulted or involved at discharge

- Of those who were discharged in the last year, 26% of carers were not consulted about the discharge and a third (33%) were only consulted at the last minute.

* Carers UK, State of Caring surveys 2015 and 2016 – surveys of over 5,000 carers

- 6 in 10 (59%) of carers said they did not feel they had a choice about starting to care for them when the person they look after left hospital.
- Where carers said they were not consulted or only consulted at the last minute about the discharge, 73% said they did not feel they had a choice about starting to care when the person they look after left hospital.
- Where carers were consulted about the discharge, 42% said they did feel they had a choice about starting to care for them when the person they look after left hospital.
- 22% of carers looking after someone aged over 65 said they were not consulted at discharge and 39% said they were consulted but only at the last minute.
- Carers for a disabled child under 18 were more likely to say that they were consulted about the discharge (46%) but 30% still said they were not consulted.
- Where carers were consulted about the discharge process, 65% said that the timing of the discharge was just right.
- Where carers were not consulted or only consulted at the last minute, 79% said the discharge was too early.

In Carers UK's survey, carers were asked which NHS services they had used when they were acutely worried about the health of the person they care for over the previous year.

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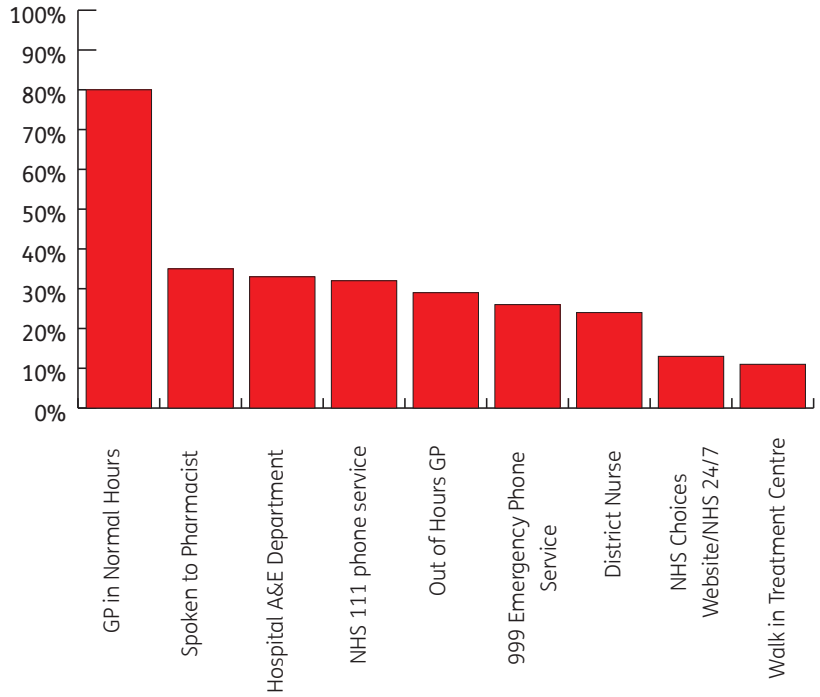
Of those who used an NHS service over the previous year, the vast majority (80%) visited a GP during normal hours. A further 29% of the carers surveyed had also accessed a GP out of hours. More carers had rung 111 than 999 (32% versus 26%) which shows how the service can reduce some calls to 999.

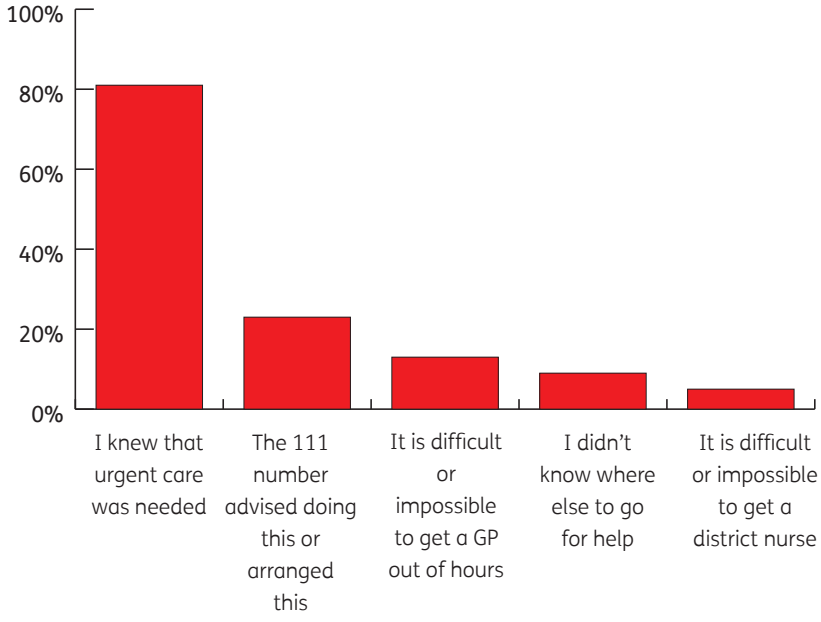
Using Emergency Services

In the last year, have you used any of the following NHS services because you became acutely worried about the health of the person you care for?



Why did carers use A & E or 999?

If you used the '999' emergency number or went to the Accident & Emergency department of your hospital, why did you do this?



"I knew mum needed care; A&E not the place for dementia-related conditions but there is nowhere else to go out of hours.

Supporting carers to choose the most appropriate NHS service

Whilst the majority of carers surveyed (83%) used A & E or 999 because they knew urgent care was needed, there was still a sufficiently large and important proportion using those services because of a lack of a more suitable option. This is a needless expense for the NHS and an unnecessary trip to A&E is also distressing for the carer and patient.

1 in 10 (9%) of carers used the emergency services because they didn't know where else to go. Whilst this is less than the general population – it is estimated that about one quarter of A&E attendances could have been treated elsewhere[10] – it still represents a high number of people who are potentially using A&E and 999 unnecessarily. It is also somewhat surprising given the high levels and often long-term contact most carers have with the NHS. Every visit to A&E costs the NHS at least £124[11], some of which could be avoided. More importantly, because these respondents tend to be caring for people with more multiple or complicated conditions, any discharge back into the community will be far more complex, taking more time. Campaigns, such as *Choose Well,* have tried to tackle this, helping patients to get the right care in shortest time possible whilst ensuring that ambulance and emergency services are able to care quickly for the most seriously ill. However, it is clear more must be done to ensure people seek out the correct medical service when they or the person they care for fall ill.

"The GP told us to use 999 service as he would not make a house call and the patient was immobile and in a great deal of pain.

"Out of hours doctors seem extremely reluctant to come out into the countryside. I have found it impossible to get one to come out.

Carers, especially those who are looking after those with complex needs and/or life-threatening conditions, are more likely to use the NHS, emergency services and social care services than most and therefore are an important group for the NHS to identify and inform about what the most appropriate services are to use. This includes providing information on other aspects of caring such as equipment – carers mentioned in the comments that when something goes wrong with the specialist equipment the person they care for uses, they didn't have any idea of who to turn to or where to go to fix it.

Access to NHS treatment in the community

"On one occasion the GP refused to come out. He called my mother and told her to give my father plenty of water and pain killers. After 24 hours my father was still ill. When my mother called another GP, he came to their home and stated my father had had a stroke. He could have died.

However, other carers have experienced real difficulties accessing the support they need from primary and community services, and have felt they had no option but to turn to emergency care because they have nowhere else to go. This could be because other services were unavailable due to night time or weekend/bank holiday closures, or that there is more generally a problem with the availability and accessibility of the service.

Our findings show 17% of respondents used the emergency services because they found it 'difficult or impossible to get a GP out of hours'. Many of the comments reflected this, with carers expressing frustration that they could not get a GP appointment within a reasonable timeframe or that their GP refused to conduct a home visit.

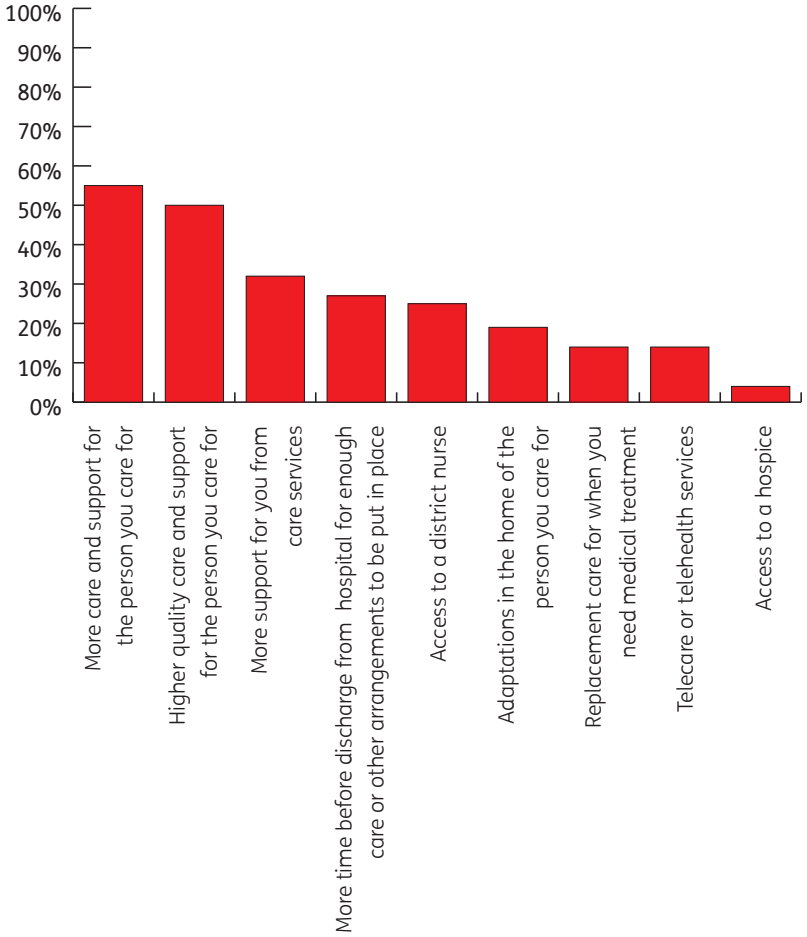
10 Cooperative Pharmacy (2011) Reducing needless A&E visits could save NHS millions; NHS Networks (2011) New Choose Well Campaign; Self Care Forum (2012) Over 2 million unnecessary A&E visits "wasted"; found at: http://www.selfcareforum.org/2012/10/30/over-2-million-unnecessary-ae-visits-wasted/

11 NHS Networks (2011) New Choose Well Campaign

Preventing emergency care admissions

Carers UK asked carers where the person they cared for had been admitted to emergency care in the previous 12 months what could have prevented this. Whilst the majority (61%) said that it was unavoidable, of those who said that it could have been prevented, there was a significant number that suggested the admission, in their opinion, could have been prevented with certain support, access to the right services or equipment.

Do you think that the emergency admission could have been prevented by any of the following?



Need for affordable care and support services for those self-funding as well as ensuring that the right level of support is identified during needs assessments and reflected in the person's care and support plan.

More support for the person cared for and higher quality of care

Over half (55%) of respondents said that more support and care for the person they care for could have prevented the admission into hospital. This indicates a need for affordable care and support services for those self-funding as well as ensuring that the right level of support is identified during needs assessments and reflected in the person's care and support plan.

Further to this, 50% said that higher quality of care and support could have prevented the admission. In *Quality of Care and Carers,* 53% of carers said that poor care services affected the amount of care they had to provide themselves. This can mean that carers end up taking on more than they can

cope with, their own health suffering as a result.[12]

Equipment, adaptations and technology in the home

> Quicker response from GP. GPs to work weekends.

Carers UK also found that a fifth (19%) of carers felt that the admission into hospital might have been prevented with better adaptations made to the home or the use of telecare and telehealth services (14%). This is a cost effective service to provide to carers and the person they care for which could reduce the number of emergency admissions yet previous research carried out by Carers UK suggests that families are not aware of the benefits of technology and where to get hold of it.[13] Many carers mentioned using the emergency services because the person they cared for had taken a fall; with better and more suitable housing and equipment, it could be that these falls would not have happened. Suitable housing is vital in providing safe and effective care yet Carers UK's research on housing, *Caring Homes*, found that 1 in 5 carers are waiting for adaptations to be made.[14] Providing swift and easy access to adaptations would help in the timely transition between the hospital and home care settings.

> Able to get a GP appointment sooner than weeks away.

GP out of hours access

Carers were not given the option to cite access to a GP out of hours as a reason but this was the most mentioned reason in the comments. It is also reflected in the reasons carers gave for using emergency services, with 19% doing so because they were unable to access a GP (by appointment or out of hours), a significant number of carers felt that if they had seen a GP within a reasonable timeframe, the admission might have been prevented.

> If the GP had made a regular home visit the emergency could have been avoided.

Ensuring carers are looked after

Carers must be supported in their caring role in order to be able to care well. Without such support – including access to care services, regular breaks from caring and access to medical treatment – carers' own health can suffer and in some cases this will lead to a breakdown of the caring role.

12 Carers UK (2014) Quality of care and carers
13 Carers UK (2013), Potential for Change
14 Carers UK (2016) Caring Homes

With more support for the carer, the admission into hospital for their loved one might be preventable, reducing the stress on the family unit as a whole.

Nearly a third (32%) of the carers surveyed cited more support for themselves in their caring role as a factor in preventing hospital admission. This indicates the importance of having a Carer's Assessment which looks at the needs of the carer and informs the support that the local authority and NHS should provide to support the carer and ensure their well-being is maintained.

Interestingly, 40% of those carers who had childcare responsibilities for a non-disabled child under 18 said that more support for themselves could have prevented the admission compared to 29% of those without childcare responsibilities. This is hardly surprising as these 'sandwich' carers are juggling caring responsibilities with childcare responsibilities. With more support for the carer, the admission into hospital for their loved one might be preventable, reducing the stress on the family unit as a whole.

Hospital discharge

> "While home for a weekend from psychiatric hospital, beds were so short that he lost his bed and was discharged.

With increasing delayed transfers of care, the NHS needs to focus on what they must do to have well-planned and well-timed discharges without compromising patient care. With the cost of readmission estimated to be £1.6bn annually, it is vital that patients are not discharged too early or without appropriate support in place.[15] Social care, including delays in putting in care packages, accounts for a third of delays and it is clear social care underfunding must be addressed. The social care crisis is impacting on the sustainability of the NHS not only through delayed transfers of care leading to longer hospital stays but also through increased A&E attendance from older people with complex needs as their carer suffers from burn out or no longer able to cope.

The most recent ADASS Budget survey outlines the unprecedented pressure on adult social care departments; with an extra £1.1 billion investment needed to simply maintain care provision at the same level as last year.[16] Without support from social care, carers' own health will deteriorate and place greater pressure on the NHS.

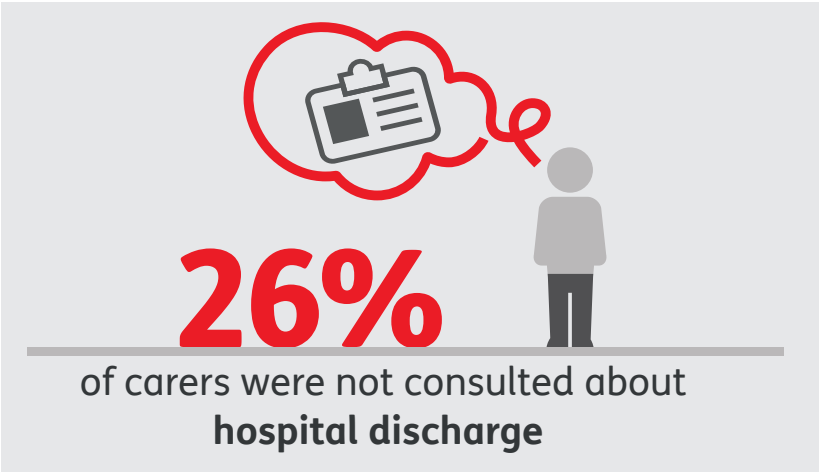
> "My husband informed me he was being discharged so I went in straight from work. The ward staff had informed "Hospital at Home" on the morning that he would need support on discharge and sent them a request to come to the ward to discuss his needs. However, by teatime, they hadn't turned up so they discharged him without the home support!

Currently 25% fewer older people are receiving social care support compared to five years ago.[17]

Coming out of hospital at the right time

In our survey we asked carers whether the person they care for had been discharged from hospital in the previous year. Nearly a thousand people cared for someone who had been discharged from hospital in the previous year.

We then asked them about the timing of the discharge and whether they were consulted. Over half (58%) of carers said the person they care for had been discharged too early. It is important that the timing of the discharge isn't too early as this can have serious consequences for the patient's health and well-being as well as the health and well-being of their carer.



15 Robinson P . Hospitals readmissions and the 30 day threshold. London: CHKS, 2010 http://www.chks.co.uk/assets/files/Hospital_readmissions_and_the_30_day_threshold_final.pdf
16 ADASS (2016) Budget Survey
17 Kings Fund and Nuffield Trust (2016), "http://www.kingsfund.org.uk/blog/2016/07/taking-control-our-socialcare-system" www.kingsfund.org.uk/blog/2016/07/taking-control-our-socialcare-system

> They were discharged 4 days after having pneumonia because the hospital was short of respiratory beds..

A quarter of carers (25%) said that discharge was too early because the person they care for wasn't ready to come home; 21% said the support was not available for them to be at home. Awaiting care and support packages is a key reason for the delay in the transfer of care but this survey shows that many patients are being discharged without the right care package in place, suggesting that some hospitals are discharging patients too early to meet a demand for beds. As well as creating stress and anxiety for carers and their families, early discharge is counterproductive as 12% of carers said that the discharge was too early and the person they care for had to be readmitted.

When the person being cared for is over 65 years old, 62% of carers said the discharge was too early – 4% more than all carers. This could be because the level of support and care needed is higher or more complex. Notably, the survey showed that the older the person who is cared for is, the more time needed before discharge to put in place support and care arrangements.

This is reflected in other research; a 2015 Healthwatch England Special Inquiry, *Safely Home*, noted that "*older people also told us that they struggle to access support after discharge. Many said that after returning home from hospital nobody had followed up with them, they did not know where to turn for support, and they had been left to arrange their own aftercare*".[18] The report found a range of physical and emotional effects stemming from this, including readmission such as from additional falls in the home. Over the last decade, emergency readmission for those aged 75 and over has increased by 88%.[19]

> Although I rushed to the hospital to bring my husband home, I wasn't told till the last minute and we had to wait around 3 hours for the medicines to arrive.

Carers of working age are more likely to cite time before discharge as a way in which the emergency admission might have been prevented. Working carers can often find the discharge process more difficult as they are unavailable during standard working hours. This can lead to difficulties in coordinating the care for the person leaving hospital.

The 2014 report by Carers UK, *Quality of Care and Carers*, found that 50% of carers have experience difficulties in the way NHS and social care services work together. This lack of cooperation can cause significant problems for the person being cared for as well as the carer.

There have been various initiatives by hospitals to better include carers as partners in discharge and the implementation of the stronger duties to assess carers under the Care Act 2014 brings new opportunities to put in place the right support for carers at discharge as well as ensure they are involved in decisions about the care of the person they support. However, it is clear that there is still much to be done to ensure carers are fully involved in the discharge process and enough time is allowed to ensure that patients are not rushed back home and the proper support is put in place. Otherwise, the patient is much more likely to be readmitted – and at a greater cost overall to the NHS than allowing the patient a slightly longer original stay in hospital in order to have a well-planned and well-timed discharge.

18 Healthwatch England Special Inquiry: Safely Home (2015)
19 Nursing Times 'Growing readmission rate sparks concern around early discharge' (2013) www.nursingtimes.net/nursing-practice/ specialisms/older-people/growing-readmission-rate-sparks-concernaround-early-discharge/5054823.article

More support for carers at the point of hospital discharge

Carers' Rights at Discharge

When the person being care for is nearing their expected date of discharge the following steps should be taken:

- An assessment should be carried out to see if they are medically fit to be discharged.
- A discharge assessment should be carried out to see if they need support once discharged
- A carer's assessment should be carried out (or at least arranged), to see whether the carer needs support once the person they care for is discharged
- A written care and support plan should be given to the person they care for (and a support plan for the carer if they have had their own carer's assessment), which outlines the support required and how this will be provided.
- The support outlined in the care and support plan (for the person being cared for) and the support plan (for the carer) should be put in place.

For more information see Carers UK's Coming out of Hospital Factsheet.

Coming out of hospital is a critical moment for many families, often the start of their caring role or a deterioration in the condition of the person they care for. The discharge process should be a key time to ensure that carers have the support they need in the short-term and that they know how to find out more about their rights to support. Without being connected early to support, carers can damage their own health in the longer term, become isolated and see their employment and finances affected. Carers UK's paper on *Carer Passports* explores best practice in identifying and supporting carers early.

Case Study

Susan, 48, looks after her father, 90, who has had a stroke and suffers from chronic kidney disease, a fractured spine and dementia. In April, Susan's father was admitted to A&E with severe pain and confusion but was discharged after one night with minimal changes to his medication. There was no care plan in place, Susan hadn't had a recent carer's assessment and she was not consulted about her father's discharge. There was no support in place, something which Susan believes she could have benefitted from as she was also working part-time and recovering from a recent serious operation at the time. When her father's pain returned, he had to be readmitted.

It is important that carers are included in the hospital discharge process and that their needs are addressed properly. Carers must be informed throughout the discharge process and especially when there are any changes in discharge planning so that they have sufficient time to prepare for the return home, for how their role might change or what support they might

> The hospital had not considered offering any support or whether I would be able or willing to cope. The lack of support caused me to feel stressed, isolated and overwhelmed; reaching crisis point after one week.

> I was completely ignored by the senior staff and most of the nurses [...] At no time during this discharge did they consult with me, even to tell me about the additional medication my wife had to take.

> On discharge, no support was put in place or discussed. I had to lift my 6 foot husband around day and night. I am 70 and 5 foot. No help was offered despite many visitors. I asked for help at the beginning of November and we got support from the beginning of January after a hospital discharge on 1st October.

have to give to the person on their return. Whether or not sufficient support is in place is likely to affect whether someone is willing or able to provide this level or type of support and care. Almost 6 in 10 (59%) carers said that they did not feel they had a choice in starting to care when the person left the hospital.

Where carers said they were not consulted or only consulted at the last minute about the discharge, 73% said they did not feel they had a choice about starting to care when the person they look after left hospital. Even where carers were consulted about the discharge, only 42% said they did feel they had a choice about starting to care for them when the person they look after left hospital This suggests that even where some level of consultation is taking place, people may feel obliged to pick up the care regardless of whether they are in a situation to do so. Over a quarter (26%) of carers said that they were not consulted about the discharge process, with a third (33%) only being consulted at the last minute. 39% of carers looking after someone over 65 were only consulted at the last minute and 22% were not consulted at all. Carers for a disabled child under 18 were more likely to say that they were consulted about the discharge (46%) but 30% still said they were not consulted at all.

Our research showed that where carers were consulted about the discharge process, almost two thirds (65%) said the timing of the discharge was just right. Where carers were not consulted about the discharge process or only consulted at the last minute, 79% said the discharge was too early (compared to 58% of carers overall), of which 15% said the person was readmitted in the following couple of months. The cost of readmitting patients within 30 days has been estimated at £1.6bn annually so it is vital that carers are included in the discharge process.[20]

The nature of care required following discharge must be clearly communicated to carers – technical, complex, medical conversations about the person they care for can be confusing and cause unnecessary agitation and stress. If there is a lack of understanding and involvement, the consequences can be serious for the carer, the person they care for and is likely to lead to a further emergency admission.

This is supported by findings from Healthwatch England – which found that 1 in 5 (22%) patients did not feel that their friend/relative was fully involved as an equal partner in decisions concerning hospital treatment and planning discharge.[21]

20 Robinson P. Hospitals readmissions and the 30 day threshold. London: CHKS, 2010 http://www.chks.co.uk/assets/files/Hospital_readmissions_and_the_30_day_threshold_final.pdf
21 Healthwatch England (2015) Special Inquiry: Safely Home

Conclusion

The approach of winter often drives activity to prevent people from spending time in hospital when they could be better cared for in the community. Yet, a shortage of funding and the progress still needed to reconfigure and coordinate health and care services to meet the needs of an older population with multiple long-term health conditions means that in reality our emergency services are under pressure all year round.

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As this research demonstrates, preparing, informing and supporting unpaid carers with access to high quality community health and social care services is essential both, to enable people to get the most appropriate care, and to facilitate a timely discharge from hospital. Without the support they need, carers will be unable to care well and safely. A resulting breakdown in the caring role in turn places further pressure on the NHS and social care.

Discharge from hospital can be a particularly critical time for families, with many people finding they become carers overnight when their family member or friend comes home. Even those who have been caring for a long time can face new and difficult challenges looking after someone as their needs for support may increase. It must be treated as a key opportunity to put in place sustainable support for the patient and carer. Carers should be involved in decisions about treatment and support, and must be consulted when it comes to planning around discharge.

This research that shows identifying and linking carers to community support early and investing in community health and care services, housing, equipment and technology that give them the support they need where they need it could reduce the use of emergency services. The multiple benefits for carers, patients and the sustainability of the system are compelling.

It is vital that carers are a clear group that are identified and supported.

As the NHS, local authorities and social care services look to reconfigure services locally through a variety of mechanisms, including Sustainability and Transformation Plans, it is vital that carers are a clear group that are identified and supported. Mainstreaming carers into the plans, ensuring that their identification, involvement and support is integral will be critical to the future of carers' ability to care.

Recommendations

Recommendation 1:

Government should introduce a new duty on the NHS to identify carers to promote the development of a Carer Friendly NHS.

Government should introduce a new duty on NHS bodies to identify carers and promote their health and well-being. This would embed the principle of supporting carers, rather than relying on champions and good practice. It would address some of the imbalances that carers face between health and social care.

The Government's publication of the new cross-Government Strategy for Carers needs a well-developed plan of activity that looks at improving carers' health and well-being.

Recommendation 2:

Government needs to improve funding for social care over the short and longer term.

Government needs to review social care funding, substantially increasing funding to ensure that disabled and older people and their families have sufficient care to live fuller lives.

Recommendation 3:

NHS England should continue to improve support to carers, to help support the development of a Carer Friendly NHS.

NHS England already has its programme of support for carers in place, the NHS Commitment to Carers. This work needs to be continued and supported throughout NHS England in order to respond to the findings set out in this report. Areas which could benefit from particular focus include:

- Evaluation of the Department of Health Mandate for the NHS – how are CCGs identifying carers.
- Data from the next wave of the GP practice patient survey – on how carers are being supported and health conditions that they have.
- Checking Sustainability and Transformation Plans (STPs) for how well they look at carers' needs, treating carers as partners in care and ensuring they are involved.
- Ensuring that the work on the digital strategy for health and care and the digital roadmaps being developed locally continue to look at integrating carers' own needs for information, advice and support and smooth the caring journey.
- Renewed awareness of online patient records encouraging carers to sign up to using records and looking at proxy use.
- A focus on apps that help and support carers in particular, for example, Jointly.
- A national review of out-of-hours services looking at carers'

experiences, and those with complex needs and how they fit with different emergency services such as 111, ambulance services, paramedics and A&E departments.

- Leadership, in partnership with local authority representatives around examples where integrated care supports carers well – putting the Memorandum of Understanding into practice. This could provide a sound basis for looking at STPs.

Recommendation 4:

Footprint areas developing Sustainability and Transformation Plans (STPs) need to "stress test" the plans from a carers' perspective and this needs to be an ongoing exercise as plans are put in place.

Recommendation 5:

Carers need to be alongside patients and service users at the heart of changing services so that they are developed on a co-produced basis, with the end goal of improving outcomes and health for everyone.

Recommendation 6:

NHS Trusts, CCGs and local authorities need to work on integrated discharge policies

Good practice

Several areas have worked and are working on integrated policies around hospital discharge to ensure that there are shared visions and goals for carers. These areas say that this makes a difference to the delivery of successful outcomes.

Some areas are developing new service models such as Portsmouth Council Adult Social Care which is developing a new Integrated Discharge Service working with local acute health trusts.

The Royal Surrey County Hospital NHS Foundation Trust

Royal Surrey County Hospital NHS Foundation Trust is developing a system of identifying unplanned admissions which are caused by carer breakdown.

Recommendation 7:

NHS Trusts, CCGs and local authorities need to know what causes re-admissions in order to build solutions

The research highlights areas where readmissions are likely due to carers feeling unprepared and unsupported. The example of Lister Hospital shows that a whole systems approach, which understands and recognises carers, may hold part of the answer. Where carers understood a condition and the situations with it, knew where to go with issues around medication, had a reliable care package, there were no readmissions and improved health and well-being of carers.

Case Study

East and North Herts NHS Trust: Lister Hospital

Hertfordshire County Council and predecessor to the CCG Herts Valley funded the original pilot in Lister Hospital which looked at creating a carer friendly hospital starting with different areas. Key elements included: a strong local partnership with Carers in Herts, the local carers organisation, the local CCG and local authority. This was underpinned by their health and well-being strategy and a strong focus on carers' health and well-being, prevention and a robust approach to gathering data and outcomes. Key elements of the work included:

- A carers lead
- Carer awareness training, led by carers and the local voluntary organisation, Carers in Herts
- Key posts: hospital liaison workers.
- When the project start this resulted in:
- 155 direct referrals to Carers in Hertfordshire (zero in previous year).
- Carers identified at Lister Hospital were identified earlier than the average carer elsewhere in the Trust hospitals, allowing carers to be supported earlier.
- The Lister Hospital Team during the pilot carried out 54% more carers' assessments than the previous year.

Before:

- There were on average 10 readmissions per month of older people due to carer breakdown.
- Less focus on preventing unnecessary first admissions

After:

- There were 0 admissions solely due to carer breakdown; all admissions were because of medical reasons
- There were no readmissions where a carer had been supported by a Carers Lead
- Investment of £50k leads to net saving about £350k of activity per year.

Key elements for success included:

- A Carers Lead within Integrated Discharge Team
- Initially focused on stroke ward, but spread to Elderly wards (highest readmission rates)
- A Trust-wide carers' policy
- Increasing carer awareness (guidance for staff, carers' notice boards and coffee mornings etc. provided through partnerships with Carers in Hertfordshire)
- 56 staff trained, 65 briefed (80% said they had an improved knowledge of carers and who to refer them to)

Having learned from this practice, West Herts Hospital Trust is now following the model with Herts Valley CCG and Hertfordshire County Council and rolling this out in Watford General Hospital.

Recommendation 8:

NHS Trusts should start identifying and supporting carers whilst in hospital – using carer passports – making care seamless

Carers UK has researched the benefits and implementation of different carers passports schemes in different NHS Trusts. The briefing can be found at: www.carersuk.org/for-professionals/policy/policy-library/carer-passport-identifying-carers-and-improving-support

Case Study

Carers' Support Centre North Bristol and University Hospitals Bristol Trusts

On admission, a patient is asked whether they have someone who supports them. If they do, staff will speak to the carer and see if a referral to the Hospital Liaison Worker is appropriate. On meeting with the carer, a conversation takes place to see if the carer would like to be involved in providing care for the patient whilst in hospital.
Carers are issued with a badge that allows open visiting. They are also provided with a swipe card that enables access to the staff canteen for low-cost meals and given significant car parking concessions. Whilst there is no physical passport for carers, a logo is in the process of being developed that will be placed on a patient's chart and for use in all communications with carers.

The Hospital Liaison Workers are employed through the local carers' support centres and are there to support carers in the hospital setting, ensuring they are involved in the patient's treatment and supported through the discharge process. The liaison workers also look more widely at the support the carer has, and can give help with benefits and carers' assessments. There are also GP Liaison Workers placed at GP Practices to identify and support carers.

The value of this has been calculated using Social Return on Investment methodology and found to save the equivalent of £3.6million a year, including £239,000 in health services costs avoided. These gains have been attributed as £1.9m for the state and £1.7m for individuals.

Recommendation 9:

Local authorities and CCGs need to look at improving training and advice and knowledge for carers so that they know how to manage conditions and increase their confidence about what to do in an emergency.

Several local authorities and CCGs have commissioned training packages for carers helping them to understand different aspects of caring and what to expect. In mental illness, for example, this has existed for many years around schizophrenia, what to expect, different aspects of the condition, medication and side-effects. Similar learning

and training opportunities for dementia and other conditions have been developed.

Some local carers organisations also offer regular first aid training courses to support carers about what to do in an emergency.

Good practice

Portsmouth City Council offers a whole range of different training opportunities for carers.

Carers learning and training

Portsmouth CITY COUNCIL

E-learning

- Autism awareness
- Caring with confidence
- Dementia awareness
- Mental capacity and decision making
- Mental health awareness
- MND
- Parkinson's
- Safeguarding
- Young carers

Health and social care

- Emergency first aid
- Moving and handling
- Mental capacity
- Safeguarding
- Lasting Power of Attorney
- Long term conditions – Parkinson's, Arthritis, Stroke
- Dementia
- Autism and Asperger's syndrome
- Challenging behaviour
- Epilepsy
- Mental health – supporting someone else's recovery, understanding depression, psychosis and schizophrenia, personality disorder, self-harm, OCD, bipolar disorder

Wellbeing

- Stress management
- Confidence building
- Assertiveness
- Mindfulness

Employment

- Skills assessment
- Employability skills
- CV and cover letter writing
- Career advice

Computing

- Computers for absolute beginners
- Learn to use a tablet
- Learn to use Facebook & Skype
- Shop, bank and use public services online
- Digital pictures, Photoshop
- MS Office

Life skills

- English, Functional English
- Maths and numeracy skills
- Money management, budgeting
- Foreign languages
- British Sign Language

www.portsmouth.gov.uk

Recommendation 10:

Local authorities and NHS Trusts should ensure that carers are better equipped to deal with emergencies – working with local carers organisations and care providers.

Many local authorities commission local organisations and have partnerships with them to deliver emergency planning, in particular, when carers are not able to care at very short notice. Since so many carers are providing complex care, not being able to care would place someone at risk, and would necessitate entry into residential care or a trip to A&E.

Many organisations have an emergency card for carers, including, North Yorkshire County Council, and emergency responses are built into care planning.

Case Study
Devon County Council, NHS Northern, Eastern and Western Devon Clinical Commissioning Group and NHS South Devon and Torbay Clinical Commissioning Group

Together, these organisations have an "alert card" in Devon which is only issued when a contingency plan is registered with the call handlers, currently Devon Doctors on Call. The "alert card" serves several purposes and is principally designed, like many other similar schemes, to provide short term help if something happens to the carer. In this situation, the standard health protocol is to look at their record and any health related information. In an emergency, this then alerts the health professional to the fact that someone else needs care at very short notice. Evidence shows that it not only increases carers' confidence, so they know what will happen if they cannot care for some reason, but the fact that Devon Doctors on Call are the response service also increases the confidence of health and social care staff.

The alert card also doubles up as a means for identifying carers in hospitals in Devon where they can access free car parking and other facilities.

Carers are encouraged to sign up to the local support services run by Devon Carers where they are issued with an alert card as part of the support package; in 2016/17 this had been given to over 3,800 carers.

Devon County Council also has a "reactive" hospital discharge service. This is used by carers where either they or in some circumstances, the cared for person has been discharged from hospital and found that they need extra help at short notice. In the first quarter of 2016/17, 45 carers were referred or referred themselves for help. One of the people part of this service found the "alert" card mentioned above and contacted Devon Carers, who then contacted urgent social care services.

Recommendation 11:

CCGs need to look at systematically developing Carer Friendly Primary Care Services with integrated support across health, social care and the voluntary sector

These have the potential to reach carers earlier in their caring journey and to link carers into important services which prevent conditions from developing or an emergency.

Where CCGs invest in local primary care services, more carers are identified.

Case Study
Hertfordshire and Surrey

Herts Valley CCGs: A system programme of support in Hertfordshire over several years has resulted in GP practices providing more referrals for Carers In Hertfordshire, the local carers organisation, than any other route. This is a system of referrals rather than signposting, which ensures a high rate contact rate, for the carers concerned.

Surrey have been looking at an integrated model of support throughout the NHS, working closely with the local authority, Surrey County Council, Trusts in the local area, Action for Carers Surrey to develop Carer Friendly Primary Care Services. The key focus here is early identification of carers and prevention.

The model focusses on key elements that support prevention: The key service offer is a Carers Prescription, which is part of the social prescription model. Around 11,000 carers prescriptions have been issued, the majority of which have come through primary care, where the majority of carers will have first contact. In the practice setting, after the GP practice identifies the carer using the carer read code, the referral is made to a local organisation which discharges the all actions requested.

128 practices and two Ministry of Defence practices that employ approximately 680 GPs are now signed up to the service and this model was rolled out across the whole healthcare system in Surrey in November 2015. Since then there has been a 25% increase in carer prescriptions on a quarterly basis from other NHS providers – i.e. acute settings, community providers and mental health trusts. The offer is the same across all health providers, using the same entry portal. The work is managed through the Surrey Carers and NHS Providers network which now has a membership of over 60 carers' health leads. This work meshes with other 'NHS Carer Friendly' initiatives such as the Carers Passports in each of the major acute trusts. The model is also moving into pharmacy with the aim of identifying new or hidden carers.

The Carers Prescription is built on a separate stand-alone IT platform provided by Formsite, which allows secure data transfer between professionals. The system was co-designed with practitioners across health, social care and the voluntary sector. Health professionals like

the Carers Prescription because it is quick and easy to use and takes around two minutes to complete. It is a practical tool which allows the health professional to do something to support the carer; they receive confirmation when the prescription has been discharged so they know that their referral has been acted upon, creating greater trust and confidence in the system. Carers like the prescription because it provides timely support, often within a day of referral.

The Carers Prescription includes several different universal offers depending on what the health professionals consider to be required. This includes a carers information pack, manual handling training, young carers services referrals, support from Crossroads Care which provides breaks, and dementia services. A digital offer for carers has now been added to the menu of 13 options of support. This includes online learning for carers to increase resilience, Jointly, an app to help manage care, and a quick tailored information prescription that a carer can complete in a matter of minutes to give them a bespoke response that they can come back to time after time. The digital offer is provided through Carers UK and adding it to the carers prescription has seen a vastly increased uptake as a result. The option of a referral for a carer's assessment was added to the menu of the carers' prescription – this resulted in 451 carers' assessments requested by health professionals – by far the highest ever referral rate from professionals.

The success of the model to date has been strong partnerships and arrangements between Surrey Independent Living Council, Action for Carers Surrey, other local carers organisation, Surrey County Council, NHS Providers in Surrey and NHS Guildford and Waverley, Surrey Downs and East Surrey CCGs – which also has a dedicated post supporting and developing partnership and integrated services across health care settings, and the local Trusts.

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