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healthwatch Lincolnshire

Stroke Report

Insight into stroke services in Lincolnshire
A patient and carer perspective

April 2020

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Executive Summary

Stroke can affect anyone at any time, so it is no surprise to see that stroke is a priority for the NHS Long Term Plan, and why in Lincolnshire specifically, we are seeing targeted work being undertaken (the 100 day challenge) to look at the prevalence of stroke, our stroke services and how to improve prevention, early detection, treatment and survivorship.

The National Institute for Health and Care Excellence (NICE) Quality Standard for Stroke requires a shift in commissioning to provide a coordinated, multi-agency approach across the whole stroke care pathway.

Understanding stroke survivor experiences

It was these NICE requirements and the movement across the Lincolnshire health and care system, to challenge or test existing behaviours that led us to explore and share the public voice of patients, family and carers impacted by stroke. The Lincolnshire public were also telling us that stoke services were a priority for them.

Summary of experiences table

Good experiences of stroke services	Where stroke services could be improved
Care received in hospital	Improved personal care in hospital
Ambulance – Emergency services	More after care support (Social care, financial, return to work etc.)
Assisted Discharge Stroke Services team (ADSS)	More therapies available
Wellbeing Services (including Allied and Libertas)	Improved discharge
	More carer involvement throughout
	Improved communication
	Improved diagnosis / Early diagnosis

- In our findings it was clear that some of the real issues lay with early detection by medical professionals to identify the early warning signs of a stroke.
- Whilst we appreciate that the majority of patients receive prompt assessment and diagnosis on admission to hospital, we still heard cases where delays in tests meant delays in ongoing treatment and care.

- All along the pathway we heard that communicating effectively with patients, loved ones and carers is vital in alleviating unnecessary worry and anxiety. Making sure everyone is informed and involved in decision making can make a world of difference to the experience and potentially, the outcome for a patient and their family.
- We saw that initial intensive 5 day rehabilitation therapies were inconsistent in terms of how they were communicated to patients, family and carers, and certainly in terms of how and when they were delivered across different hospital sites. However, it was also noted that where the Assisted Discharge Stroke Service was involved in patient care, their interventions were valued.
- We heard that, despite good medical care, some of the basic care was not being delivered. Things like support with toilet needs and being washed and clean mean a lot, and impact on our general wellbeing.
- As with many life changing conditions we see the specialised psychological support not being carried out in conjunction with the medical care. Patients told us that they received no support for their mental wellbeing following a stroke.

Our overarching suggestions and recommendations (page 5-6) encompass all the above with a need for improved communication and pathways looking at the patient and their support network holistically, ensuring they receive what the NICE guidelines say should be in place as a minimum.

We have been in a privileged position along this journey, with personal insight from patients and their loved ones, along with access to some of the exciting developments that are emerging around stroke services delivery. We wish our patients, families and those who are working so hard to get things right first time all the best. We will also retain a watchful eye to ensure changes have a tangible impact for people experiencing and living with the effects of a stroke.

Suggestions and Recommendations

Whilst there were a lot of positive comments on all parts of the stroke pathway we did identify some inconsistencies and gaps in the care and services that Lincolnshire patients are receiving.

Healthwatch was invited to be part of the local NHS 100 day challenge and the stroke rehabilitation project group and as a result we recognised that the service providers and commissioners were already aware of some of the comments below. However, we feel that as part of our project reporting it is important to raise these issues in this report. The points listed below are considered most important for us to highlight as we consider they do or will affect most or all stroke patients. For a full list of our suggestions and recommendations see p25 & p26.

- Increase clinical psychologist provision for all stroke patients (NICE Guidelines - Adults who have had a stroke have access to a clinical psychologist, with expertise in stroke rehabilitation who is part of the core multidisciplinary stroke rehabilitation team [new 2016])
- A 'go to' person is made available for all stroke patients irrespective of which pathway they are on (this does not need to be at clinician level and could be provided by one of the many voluntary and community services (eg Stroke Association, Social Prescribing, HWLincs) as a commissioned service
- Timely and ongoing access, as appropriate, to therapies once transferred from stroke acute care
- Improved communication, carer and family involvement along the whole pathway but especially in relation to therapies and discharge
- 6 month, 12 month and ongoing annual health and care reviews are carried out for all stroke patients (NICE Guidelines - Adults who have had a stroke have a structured health and social care review at 6 months after the stroke, 1 year after the stroke and then annually *[new 2016])*
    - Opportunity for patients to re-contact stroke team within 6-12 months of discharge in the event of anything untoward happening eg increase in falls, continence issues, generally not making the progress expected

Introduction

What is a stroke?

There are over 1.2 million stroke survivors living in the UK. A stroke strikes a person every five minutes in the UK. Stroke can strike anyone - young, old and everyone in between.[1]

A stroke happens in the brain, the control centre for who we are and what we can do. When a stroke happens, part of the brain loses its blood supply. This may be caused by a clot or a bleed and it damages the brain. The impact of a stroke varies depending on which part of the brain is affected and how much the brain was damaged.[1]

As part of the NHS Long Term Plan, stroke has been identified as a key clinical priority and is part of the ongoing Lincolnshire Acute Services Review.

What is the picture in Lincolnshire?

The prevalence of stroke has been increasing steadily year on year and is expected to rise to 3.1% of the population of Lincolnshire by 2020.[2] This increase will have a considerable impact on health service provision and require more and more support from family members and carers.

Geographically, the highest prevalence of the disease, within Lincolnshire, is seen in East Lindsey (2.9%) with the lowest seen in the district of Lincoln (1.8%). The Lincoln figure is likely to be a reflection of the younger population living in Lincoln. United Lincolnshire Hospital Trust received 1,109 emergency admissions with a primary diagnosis of stroke in 2017/2018.[2]

100 day challenge

In Lincolnshire, NHS service providers, charities and social care services have come together to start to work collaboratively to improve care for stroke patients (100 day challenge).

100 Day Challenges are intensive periods of action and collaboration that involve representatives from health, social care and voluntary organisations. Frontline practitioners and stakeholders set ambitious goals, and develop and test creative solutions in real conditions.

The Lincolnshire 100 day stroke challenge took place from 31st July 2019 – 6th January 2020 and has worked collaboratively with Lincolnshire Community Health Services NHS Trust (LCHS), United Lincolnshire Hospitals NHS Trust (ULHT), Lincolnshire County Council (LCC), Neighbourhood Teams, The Stroke Association, other partners including Healthwatch Lincolnshire and patients.

[1] Stroke Association, State of the Nation: Stroke statistics, 2018, https://www.stroke.org.uk/system/files/sotn_2018.pdf

[2] http://www.research-lincs.org.uk/UI/Documents/JSNA_Topic_Stroke_v3.1_210316.pdf

NICE Guidelines

The 2010 NICE Quality Standards for Stroke gave clinicians and therapists the standard to work towards the delivery of stroke rehabilitation. It covers the care provided to adult stroke patients by healthcare staff during diagnosis and initial management, acute-phase care, rehabilitation and long-term management.

We have used the NICE Quality Standards in our project work as a bench mark of what patients should receive as part of their stroke treatment in Lincolnshire. These have formed the basis of our work and the questions asked to patients and their carers.

NICE Quality Statements 2016

The NICE quality standards are expected to contribute to improvements in the following outcomes:

- mortality rates of adults who have a stroke
- long-term disability of adults who have a stroke
- patient experience of stroke services
- experience of carers looking after people who have had a stroke.

NICE Quality statements 2016

- **Statement 1** Adults presenting at an accident and emergency (A&E) department with suspected stroke are admitted to a specialist acute stroke unit within 4 hours of arrival. **[2010, updated 2016]**
- **Statement 2** Adults having stroke rehabilitation in hospital or in the community are offered at least 45 minutes of each relevant therapy for a minimum of 5 days a week. **[2010, updated 2016]**
- **Statement 3** Adults who have had a stroke have access to a clinical psychologist with expertise in stroke rehabilitation who is part of the core multidisciplinary stroke rehabilitation team. **[New 2016]**
- **Statement 4** Adults who have had a stroke are offered early supported discharge if the core multidisciplinary stroke team assess that it is suitable for them. **[New 2016]**
- **Statement 5** Adults who have had a stroke are offered active management to return to work if they wish to do so. **[New 2016]**
- **Statement 6** Adults who have had a stroke have their rehabilitation goals reviewed at regular intervals. **[2010, updated 2016]**
- **Statement 7** Adults who have had a stroke have a structured health and social care review at 6 months and 1 year after the stroke, and then annually. **[New 2016]**

The Purpose of the Activity

Understanding Stroke Survivor Experiences

Healthwatch Lincolnshire stroke project work was carried out for two key reasons:

1. Firstly, Stroke came out as a key priority area for Lincolnshire people when we asked them to help shape our priorities back in 2018.

2. Secondly, we had the knowledge that the Lincolnshire health system had begun some activity around stroke services (Acute services review) and as a result there was potential for Healthwatch to support this work to ensure the patient voice was heard.

As part of our evidence gathering we included not only the patient voice but also those closest to them including family and carers. This enabled us to gather robust and wide ranging information.

Collecting Information

A mixed method approach was used to obtain a range of stroke survivor perspectives on their diagnosis treatment and rehabilitation, including:

Exploratory Survey

Between February and September 2019, we conducted an exploratory piece of work with a short survey directed at those who had experienced a stroke and where possible carers and family members. These were identified through ward visits, existing support groups and carers receiving services from Carers First.

From this survey, we received 100 responses, 55 of those were male and 42 female (3 unidentified).

61 of the respondents had experienced a stroke in the last year.

Summary of Results - Key findings from the survey:

- 80% (57 people), said the initial contact with the emergency care services and transfer to hospital was good.
- 88% (66 people) said their treatment whilst in hospital, including therapies, was good
- 74% (23 people) said the support services in place immediately leaving hospital e.g. home care services/aids and adaptations were good
- 55% (16 people) said access to services and therapies needed after leaving hospital was good
- 67% (39 people) said the regular reviews of health and care needs was good
- 55% (6 people) said the support for returning to work was poor
- 62% (40 people) said the information & advice received throughout was good

We asked the following two questions as part of the exploratory survey and below are responses:

'Was there anything particularly good about your stroke care that you would like to highlight?'

The vast majority of comments related to the fantastic care received by staff across the full stroke pathway but in particular the care received in hospital, from nurses, doctors, consultants and those providing treatment, therapies and home care.

"Initial care in the hospital was good. The home care was excellent and everyone who visited me at home were excellent."

"Nurses were excellent they came for 8 weeks and were rather good they came to my mum and dads house and gave me exercises to do."

"The amazing doctors on the stroke unit answering questions we had, showing us the scans, helping Mick with reading and writing and doing tests with him."

"Ashby Ward Lincoln County were very good teaching her how to walk and talk again."

'Was there anything about your stroke care that could be improved?'

The top area highlighted where their stroke care could have been improved, was more therapies available and for longer time periods especially more physiotherapy.

"More therapies after coming home from hospital"

"Not enough physio need to spend more time with patients."

"Had to pay for own Physio. More Physio. No home assessment by O/T (Occupational Therapy)"

"When the nurses stopped coming everything stopped. I tried to find a speech therapist but couldn't find one in Lincoln, we had to drive to Leicester and after this we did the sessions on skype. Work Paid. The NHS speech therapist didn't know what to do with me because I speak. Work paid for a psychiatrist which I saw once a week at Birchwood this wasn't offered at all. Everything within the NHS was a long time afterwards, it needed to be straight away."

"Physiotherapy after 6 weeks post discharge is non-existent. Leaving patient to regress if they can't afford private treatment (which we can't)"

"Stroke patients could be given more continuing help with therapies, speech, etc. I was given 5 or 6 weeks then advised by Pilgrim that's all they could do. Physio at Johnson Hospital allowed only limited access. Long term care could be improved."

"Getting regular reviews but services required are not available eg neurology. Little support to get back to work ie need neurology which is not available."

Another big concern was for patients to have better communication throughout all stages of the care and support they receive.

“As an outpatient I have found it very frustrating knowing what is happening. Improvements: Better communication between departments in the hospital, to me as an outpatient, such as, How long to my next appointment, has the appointment been made, Expected times to appointments etc. Consistency through the staff there in what will happen next to be told one thing and then get told something different next time. Although I have not been massively affected and realise I am low priority compared to others having more feedback, information on waiting times would really help.”

“Explaining slowly and quietly what was happening and who people were. Whole process was confusing and I didn't know who people were.”

“Cross county boundaries, communication and access to services.”

“More communication to keep patient informed.”

“It would be helpful if Drs spoke slower so I could understand what they are saying and listen when I try to give or ask a question it's so frustrating.”

Additionally, our survey highlighted the need for earlier and better diagnosis of stroke.

“Some issues around diagnosis stroke v Neurology v brain, so no stroke treatment whatsoever. Met with the Stroke Association who are putting him for assessment.”

“The 111 service didn't realise it was a stroke until part way through the phone conversation”

“Initially came in for a couple of days after a fall with face drop and garbled speech. Symptoms disappeared so went home. A day and half later my leg felt funny- called ambulance and brought me in. Been to various different wards before stroke ward.”

What we did

Interviews

Following our preliminary survey, we conducted 10 semi structured qualitative interviews. This allowed us to gather more in-depth experiences of stroke patients and in some cases their carers, face to face. These interviews were primarily conducted in the patient's homes, this being the easiest place for in-depth conversations to take place with minimal disruption and additionally where the stroke patient felt most comfortable.

Participant's details

ID	Gender	Age	District	Marital Status	Employment status (at time of stroke)	Returned to work	Other long term condition	Stroke Condition
P01	M	65-74	East Lindsey	Married	Retired	n/a	Y	1st Stroke
P02	M	75-84	East Lindsey	Married	Retired	n/a	N	1st Stroke
P03	F	75-84	West Lindsey	Married	Retired	n/a	Y	1st Stroke
P04	M	75-84	Lincoln	Married	Retired	n/a	N	1st Stroke
P05	M	25-34	Lincoln	Divorced	Employed	Y	N	1st Stroke
P06	M	55-64	South Holland	Single	Employed	N	N	1st Stroke
P07	F	55-64	South Holland	Married	Employed	Not fully	Y	1st Stroke
P08	M	75-84	South Kesteven	Widow	Retired	n/a	Y	1st Stroke
P09	M	55-64	North Kesteven	Married	Employed	N	N	1st Stroke
P10	F	75-84	North Kesteven	Married	Retired	n/a	Y	not first stroke

The following information has been split against the NICE Quality Standards and is based on information gathered from one to one interviews. People talked to us about a range of good experiences and several areas where their experiences could be improved.

Signs of a stroke

The signs and symptoms of a stroke vary from person to person, but usually begin suddenly. We spoke to several patients who had experiences of presenting to health professionals with a suspected stroke, told they had not had a stroke, only to have a stroke in the next few hours, days or weeks.

Patients felt more could have been done to pre-empt their stroke. Some patients already had existing complex multiple conditions.

"For 9 days neurology and stroke between them were looking at the same scans, neurology were saying "A stroke" the stroke team "No stroke" so I was still stuck on A3 waiting."

P07 Stroke Patient

A transient ischaemic attack (TIA) or mini-stroke is the same as a stroke, except the symptoms resolve themselves quickly. They may only last for a few minutes or hours, and are completely gone within 24 hours. Ominously, TIAs are also known as warning strokes, because they often come in the days before a full stroke occurs. The Stroke Association states that one in 12 people have a stroke within a week of having a TIA. After three months, 17 percent of people who had a TIA have also experienced a full stroke.

A report in America[3] showed that in 13 per cent of stroke cases, the patient had reported to an emergency room in the prior 30 days without having their stroke diagnosed. Of those, one in 10 were discharged with headache or dizziness.

Patient went to hospital (Kings Lynn) feeling unwell, complaining of headache, trouble with getting their words out. They were given blood tests along with other tests, asked to walk in a straight line for example.

Speech was getting worse but told to go home and ask doctor to give them aspirin.

"I said well there must be something wrong because by this time his speech was getting worse and I wasn't terribly impressed with the doctor and he said well there's no sign of a stroke he just said go home and ask your doctor to give you some aspirin so we came home"

Patient visited Kings Lynn hospital less than 24 hours prior to having an identified stroke.

P06 Stroke Patient

Family were told in the ambulance that the patient had a bad stroke. Went to Pilgrim went straight into a CT scan.

At which point was told by the consultant patient hadn't had a stroke but instead had a minor bleed to the head. Then told *'gonna send patient to Nottingham cos that was best place for him'*

Queens's hospital Nottingham had patient for 4 days, no deterioration so sent them back to Boston Pilgrim was back at Pilgrim for a day and a half and then had a major stroke. Blue lighted back to Nottingham.

P01 Stroke patient

[3] Newman-Toker, D. E., Moy, E., Valente, E., Coffey, R., & Hines, A. L. (2014). Missed diagnosis of stroke in the emergency department: a cross-sectional analysis of a large population-based sample, *Diagnosis*, *1*(2), 155-166. doi: https://doi.org/10.1515/dx-2013-0038

Emergency Services

The ambulance service and 111 play an important role in identifying a suspected stroke and getting patients to the right hospital as quickly as possible. Many people we spoke to highlighted the excellent support they received from ambulance staff and how quickly they responded to the 999 call.

All patients we spoke to were transported to hospital by ambulance, except one who was driven to A&E. Patients reported that ambulances generally arrived quickly.

However, in one incident the ambulance crew informed husband they were taking his wife directly to Queens Hospital, Nottingham because she had a serious bleed on the brain but for some reason it was diverted to Lincoln Hospital.

There is a necessity for clear information to alleviate worry and anxiety for the patient or in this case the carer.

"Ambulance was good it was very good, I thought quick"

"The ambulance arrived "Very quickly"

Paramedic car – *"Yeah it was very quick. He come in with all the gear."*

80%* of respondents said the Initial contact with the emergency care services and transfer to hospital was

GOOD

*** Good 80% (57 people), Poor 13% (9 people), neither good or poor 7% (5 people)**

A small number of comments received through the survey referred to long waiting times for the ambulance with some waiting over 2 hours.

"Initial wait of 2 hours for ambulance"

"Had to wait 2 hours for an ambulance then via A&E onto ward prior to stroke unit"

Prompt admission to specialist stroke unit

NICE Statement 1 - Adults presenting at an Accident and Emergency (A&E) department with suspected stroke are admitted to a specialist acute stroke unit within 4 hours of arrival. [2010, updated 2016]

Admission should be within 4 hours of arrival at the A&E department for adults with suspected stroke, following an initial assessment (unless their care needs should be provided elsewhere, such as an intensive care unit).

- Patient experience overall was positive and described the access to acute stroke units as *'very quick'* and often received scans on arrival at hospital before being moved to stroke ward.

One patient with more complex health needs and where a stroke was not identified told us they waited a long time for CT scan results:

"Yes I had the CT scan, we waited, we waited, we waited, it was a very very long time no doctors came to see us"

P07 Stroke patient

On both occasions the suspected stroke and the major stroke at Pilgrim the patient had a prompt admission to appropriate services and a CT scan

P01 Stroke patient

(Patient) was taken straight to stroke ward after CT scan showed he had a stroke. *'Very very very quick'*

P05 Stroke patient

Patient went straight to the stroke ward at Pilgrim hospital within an hour of having stroke.

P06 Stroke Patient

Case Study – Patient P01 and carer

Hospital arrival

Whilst in hospital at Boston Pilgrim P01 had a major stroke and was left unconscious. P01 was immediately sent to Queens Hospital in Nottingham. The quotes below are directly taken from a family member of P01

"They kept them at Pilgrim for me to go and see them where they had them all wired up and they said right, without breaking any speeding limits get yourselves over to Nottingham straightaway, so we went"

Along with the patient's family they travelled to Queens Hospital, Nottingham.

"We went to A&E and said can you tell me if P01 has arrived yet and a staff member looked at me and says 'no I'm sorry we're not expecting P01'"

The family were then sent to an office room to wait. They were then told by a member of the hospital staff:

"I suggest you go up to theatres and check theatres, so we went up and we could see the theatre lights going on so my daughter knocked on the door 'excuse me are you expecting P01?' 'No, we're getting theatre ready but it's not for P01.'"

They looked in on another theatre room and found they were setting it up for P01. Overall, it took about 3½ hours to locate the patient. Afterwards the surgeon spoke to P01's carer.

"He said, I'm sorry, I've done all I can … done the best I can but I'm not expecting them to last the night."

"And I said oh I'm telling you now … I said I'm telling you now, they are a fighter."

"We got home back here at quarter to six in morning, phoned at eleven o'clock expecting bad news and a staff member says "you're not going to believe this but patient actually sat up and spoke, I said I told you they were a fighter."

Better communication is required with carers and families. For instance is it appropriate for anyone to be knocking on theatre doors looking for patients?

In this case the family did not know who was treating P01, they didn't receive clear explanations and were not involved in decisions about their care which goes against the recognised quality standards for patient care. [4]

Family support is seen as important by patients when asked what was particularly good about their stroke journey.

[4] National Institute for Health and Care Excellence. Patient experience in adult NHS services. 2012. https://www.nice.org.uk/guidance/qs15

"Giving important information to patient who may not remember - should be involving carer and family"

'The wife' – The patient could not have managed without her and shows the importance of the unpaid carer.

Intensity of stroke rehabilitation

NICE Statement 2 - Adults having stroke rehabilitation in hospital or in the community are offered at least 45 minutes of each relevant therapy for a minimum of 5 days a week. [2010, updated 2016]

Adults having rehabilitation therapy after a stroke are offered at least 45 minutes of each type of rehabilitation therapy required on at least 5 days a week. Rehabilitation therapy is long-term support to help patients regain their independence and cope with any remaining disabilities after a stroke.

It may involve many different specialists, such as physiotherapists, speech therapists and occupational therapists.

They can help people who have problems with their memory and concentration; speaking, reading and writing; emotions and feelings; sight; swallowing and eating; strength, balance and movement. They also include help to encourage physical activity and independent living.

- Patient experience showed us that the intensity of stroke rehabilitation was extremely mixed and also varied across the different hospital sites.
- Patients are not aware of what stroke rehabilitation they should be receiving and more could be done to communicate this to the patients and carers.
- However, almost without exception the ADSS team was praised and seen as a positive intervention.

Patient was in Queens Hospital Nottingham for 8 weeks was monitored but given no therapies. Patient was then sent to Pilgrim and received 3 physio sessions, they got speech therapy but not regularly. One speech therapy session at Pilgrim.

Was then transferred to Lincoln Ashby ward and received physio, speech therapy.

Home support – when in Ashby ward – P01 was told first 6 weeks they were home they would get physio 5 days a week. But only going to receive one per week after 3 weeks

P01 Stroke patient

Patient received physiotherapy, occupational and speech therapy 6 days a week for at least 45 mins at Pilgrim Hospital while patient was there for 3 months, was then moved to Johnson Hospital Spalding where they received little support, minimal gym time.

P06 Stroke Patient

"Oh crikey! It wasn't for as long as I thought it was going to be, I think it was ten minutes the first time it was very very tiring and I think half an hour the second time."

P07 Stroke patient

Findings

Inpatient care

Our survey results indicated overall people had a positive experience whilst in hospital and this included the quality of the therapies that they did receive while admitted.

*Many comments we received highlighted the excellent inpatient care patients received (see comments below).

Some of the patients interviewed did not always receive the help and care they needed with general activities such as toilet needs, medication and washing.

"..he phoned me and he said I've pushed for a bed pan and he says we'll see how long it takes them cause he kept saying how its taking them hours to come each time.." **P01 - Boston Pilgrim**

"…40-50 minutes now that my wife's got a real terrible headache and no-one's come to her and he [nurse] says 'I am doing the drugs on this side I don't do that side'…" **P10- Lincoln Hospital**

"…doctors had put on the board that she must be lifted with hoist into an armchair…she hasn't been moved for four days"

Dignity and respect, Carer of P10 overheard the nurse saying to P10:

"this is disgusting, this is filthy fancy mucking and lying in it." (Boston Pilgrim)

Carers felt they needed to compensate for perceived shortfalls in the care of their relatives by washing and showering them but were often prevented from doing so.

*"…my granddaughter went to the sister on the ward and said 'please can I have a shower tray', she says 'what you want a shower tray for' she says 'I want to shower my grandad because he stinks'" (*First shower in 8 weeks in hospital) (P08- Boston Pilgrim)

'Care on the wards superb' - **Pilgrim Hospital**

'The amazing doctors on the stroke unit answered questions we had, showing us the scans helping P10 with reading and writing and doing tests with him' - **Lincoln County Hospital**

'Brilliant service on the ward - **Lincoln County Hospital**

'Ashby ward very good' - **Lincoln County Hospital**

'Dedicated and caring staff' - ***Pilgrim Hospital***

88%* **of respondents** said their treatment whilst in hospital – including therapies was **GOOD**

**** Good 88% (66 people), Poor 5% (4 people) , neither good or poor 7% (5 people)**

Access to a clinical psychologist

NICE Statement 3 - Adults who have had a stroke have access to a clinical psychologist with expertise in stroke rehabilitation who is part of the core multidisciplinary stroke rehabilitation team. [New guidelines 2016]

Many adults who have had a stroke experience psychological difficulties, including low mood and anxiety, as well as difficulties with cognition such as problems with memory and information processing.

Psychological therapies may help people and their families or carers with these difficulties. Having a clinical psychologist as part of the core multidisciplinary stroke rehabilitation team can help to ensure that people have access to psychological therapy tailored to their needs.

- When considering the support offered for people's recovery, most people discussed receiving some level of support for their physical recovery such as their speech and physiotherapy however no support was offered for their mental wellbeing following a stroke.

P05 Stroke Patient
"I think my biggest fear when I first got out was am I going to have another one, am I going to be able to call for help?"

Early discharge

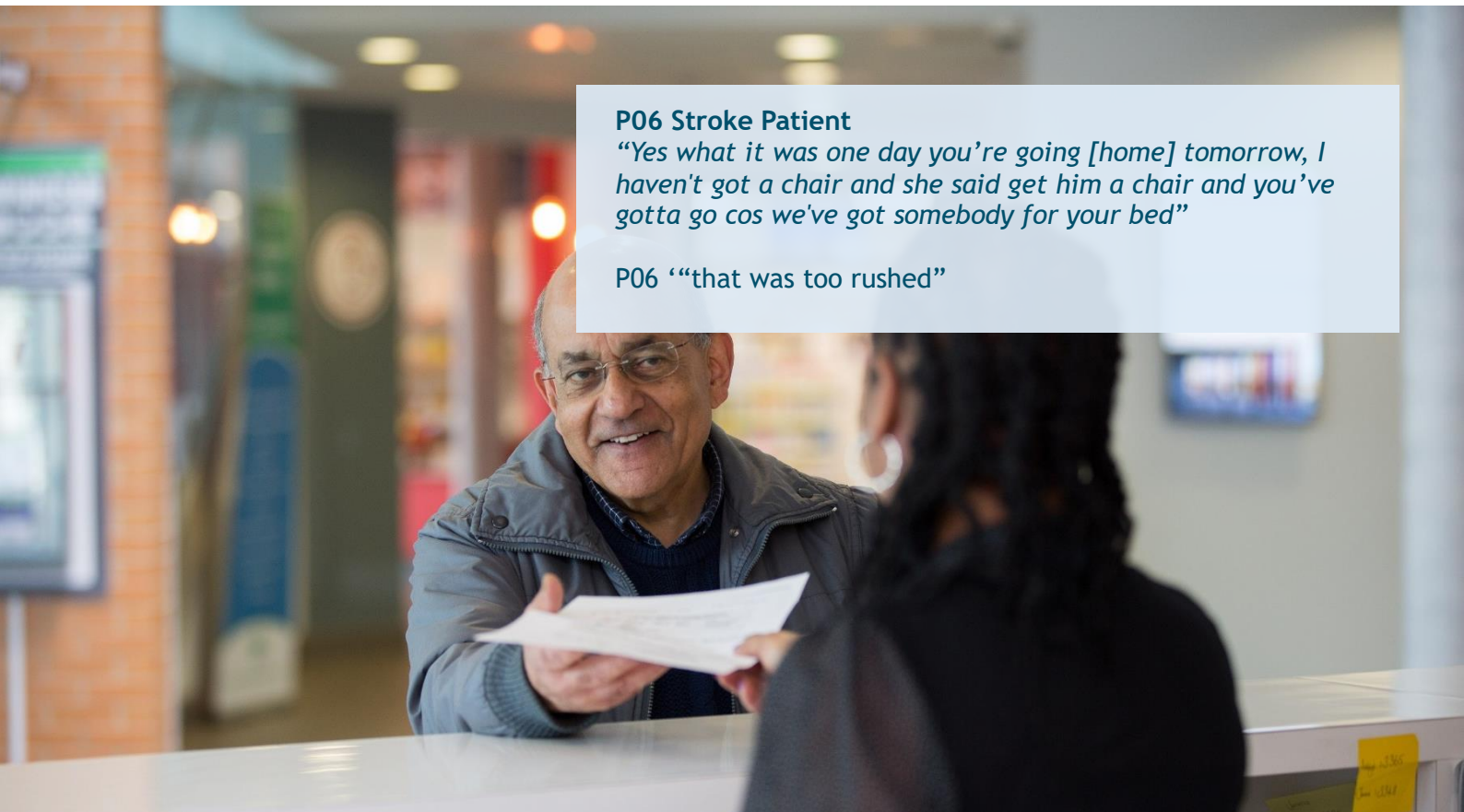
NICE Statement 4 - Adults who have had a stroke are offered early supported discharge if the core multidisciplinary stroke team assess that it is suitable for them. [New guidelines 2016]

Early supported discharge is an intervention for people who have had a stroke that allows care to be transferred from an inpatient environment to a community setting to continue rehabilitation. The intensity of care and the expertise of those providing it is maintained.

- The core multidisciplinary stroke team will assess whether early supported discharge is suitable for adults who have had a stroke. The assessment takes into account the person's functional, cognitive and social circumstances. This may include, for example, the person's ability to transfer from bed to chair independently or with assistance, and whether a safe and secure environment can be provided at home.

"I woke up on the Monday morning the ward clerk, she said "you've got a lady coming from Lincolnshire County Council" I said "What do you mean?" she said "She's called an enablement officer" so I said "what's that for?" she said "she's looking at ways to get you home and get you sorted". OK fine. 20 minutes later this lovely lady came through to me an enablement officer and she said to me "how would you like to go home today?" I went "WHAT?" I'm not being treated, well I was being treated they had started me on stroke medication by then. So she said "Yes we have carers out there that can ……" I said "well I can't obviously without carers, my husband's at home and can be at home for one more week then he has to go back to work so I need carers". "Not a problem! I can have carers to you on Wednesday, I can get you discharged today"

P07 Stroke Patient



P06 Stroke Patient
"Yes what it was one day you're going [home] tomorrow, I haven't got a chair and she said get him a chair and you've gotta go cos we've got somebody for your bed"

P06 '"that was too rushed"

Return to work

NICE Statement 5 - Adults who have had a stroke are offered active management to return to work if they wish to do so. [New guidelines 2016]

Adults who have had a stroke and wish to return to work are offered help and support to do this. This should include help to identify and manage any problems that might make it difficult to return to work.

- Many of those we spoke to were not in work before their stroke so were not looking to return to work.

One individual P06 found their employer did not visit or contact them to find out about how they were getting on. They were also unaware of the options open to them when and if they returned.

"He'd worked there for 21 years and they couldn't even send him a get well card nobody has rung only his friends"

P06 stroke patient

In contrast we spoke to P07 where their employer was much more helpful and making many reasonable adjustment and proceeding with a phased return to work.

"She's referred me to occupational health for us to start putting things in place for us, the main things are going to be some form of speech thing [device] because obviously I can't type properly well at the moment I can't write."

P07 stroke patient

P05 works for the RAF they were also actively managing the back to work process. They had 2 months off work and had a phased return and as a consequence of the stroke a change of job role from aircrew to ground crew.

"I never had an issue cos my boss at work at the time was really good"

PO5 stroke patient

Suggestion

The NHS should review back to work options at the earliest possibility in partnership with the employer (where relevant) but importantly provide lifestyle change opportunities and support where patient is unable to return to work. More support to help patient meet ongoing lifestyle when they can no longer work.

Rehabilitation Goals

NICE Statement 6 - Adults who have had a stroke have their rehabilitation goals reviewed at regular intervals. [2010, updated 2016]

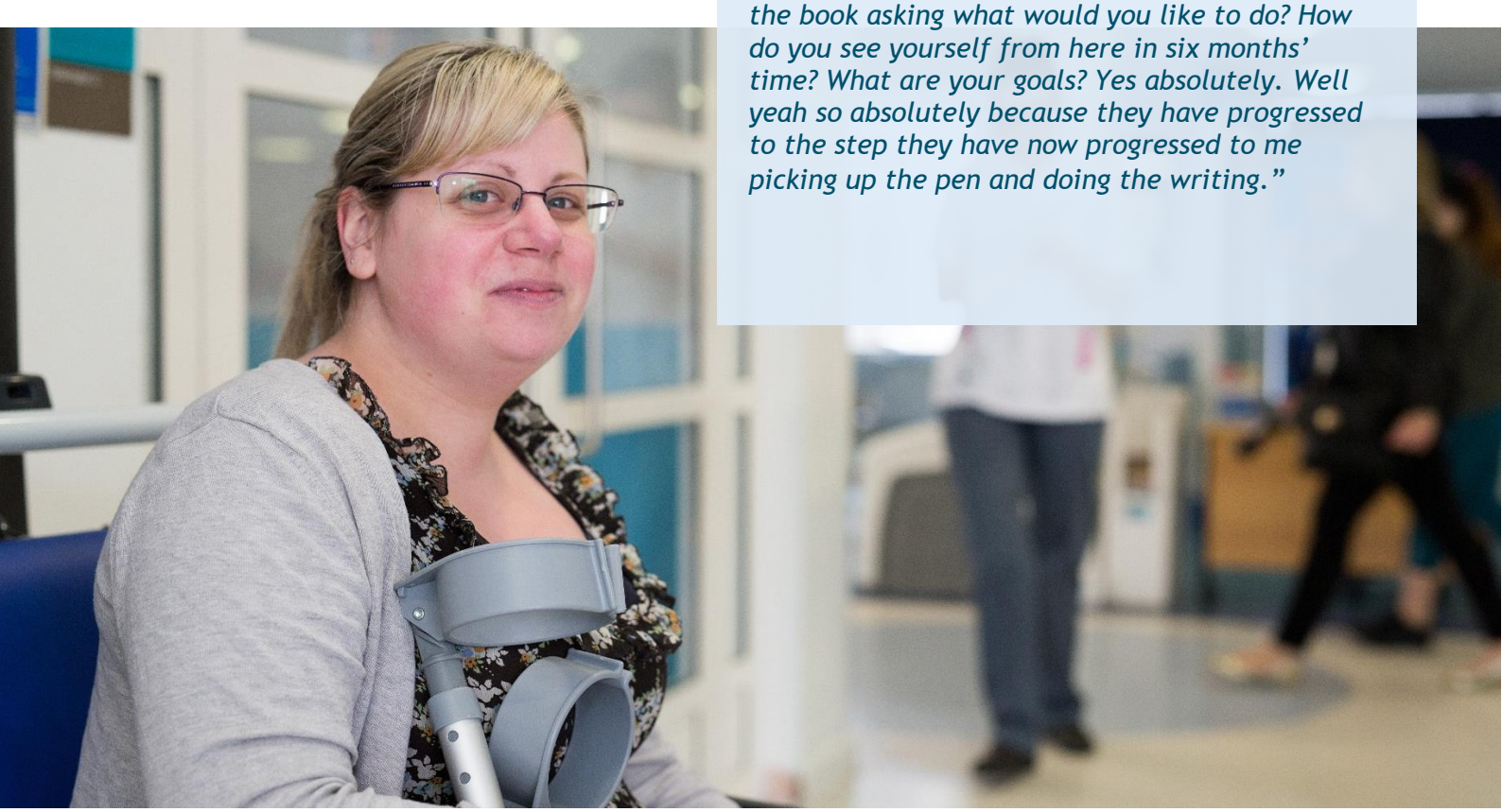
Adults who have had a stroke have the opportunity to discuss and agree goals (things they would like to achieve) for their recovery and have them reviewed regularly to ensure they are still relevant.

- In most cases patients' goals were reviewed with the patient on a regular basis. However, it was not clear to the patient that a review had actually taken place, or due to their condition had forgotten. This was evident due the progress made by some patients over the period of time Healthwatch Lincolnshire was involved with the patients and as the quotes below clarify.

P06 - Not clear whether patient was involved in setting goals or if they were received regularly.

P01 - First goal was to get off the hoist when needed the toilet and then to walk again. ADSS – not pushing the patient to meet the goal of walking again. *'Ashby Ward were pushing him, (ADSS) they are not pushing him they are holding him back'*

P07 Stroke Patient
"*Yes I was* [involved in setting rehabilitation goals] *both with Libertas funnily enough and the stream team yes. There's a thing at the front of the book asking what would you like to do? How do you see yourself from here in six months' time? What are your goals? Yes absolutely. Well yeah so absolutely because they have progressed to the step they have now progressed to me picking up the pen and doing the writing.*"



Stroke review

NICE Statement 7 - Adults who have had a stroke have a structured health and social care review at 6 months and 1 year after the stroke, and then annually. [New 2016]

Adults who have had a stroke have a check at 6 months and 1 year after their stroke, and then once every year to make sure they are getting the care and support that they need.

- From the conversations it soon became clear that 6 and 12 months reviews were not being carried out which was clarified through the 100 day challenge. We understand that Lincolnshire Community Health Service is currently looking into a commissioned service for this purpose.

Carers Involvement

A carer is someone who provides unpaid support to family or friends who could not manage without this support. Many stroke survivors are left with some kind of disability and rely on informal carers and spouses to help them remain independent.

After a stroke, survivors may not be able to fully communicate, so their friends and family play an important role in expressing their wishes and needs.

The carers of stroke survivors express a need to be recognised by hospital teams as partners in care. The workload of hospital staff mean that carers often feel they had to chase up information or services.

Patients and their family or carers particularly valued being involved in setting rehabilitation goals together.

NICE guidelines emphasise that hospital-based stroke rehabilitation services should consist of a multidisciplinary team actively working in partnership and close communication with stroke survivors and their families and carers.

NICE recommend appropriate planning and training for carers to facilitate a return home. A social care assessment should identify any practical requirements for the stroke survivor or their family/carer.

Under the Care Act 2014, carers have a legal right to a "carer's assessment" to identify what support they need and assess their eligibility for financial support from local authorities. Support ranges from direct help with their caring responsibilities, to helping carers to stay connected with friends and family or providing temporary replacement care to give the carer respite.

Carer of P01
As a carer they were not kept up to date in regards to progress while spouse was in hospital.
*"I didn't get much information at all I had to ask 'please tell me what's happening'" (*PO1)
Nurse made P01 aware that Carers First were visiting while they were in Ashby Ward Lincoln. They *"got me my blue badge"* but they were unsure whether a carer's assessment had been conducted and had no 'In Case of an Emergency (ICE) Card'. This said, they felt very involved in setting rehabilitation goals.

Carer of P07
"The hospital didn't [involve me as carer], nobody has really, I think they were disgusting, Peterborough Hospital, to be fair from my perspective… I didn't get told anything as her husband I was sat in on it but I wasn't necessarily involved."

Home Care Feedback

Whilst home care services at times are ‘hit and miss’, even where a service is provided it can on occasions involve an enormous number of carers.

At least 2 patients and carers were concerned about the size of the care team looking after them and therefore the numbers of people with access to the key safe; one said *“I am concerned about the size of the carer team with access to key safe”* and another, P06 mentioned “*they had over 30 carers see them since their stroke*”.

More timely provision of equipment (especially through Disabled Facilities Grant (DFG))

For instance patient P06 had a stroke in May 2018. They were initially spoken to by Healthwatch in Feb 2019 and said ‘they were waiting for the outcome of a DFG application for a new wet room provision’. When they were contacted again in September 2019, they were still waiting 10 months after discharge.

Carer of P07 said *“we are still waiting on a decision on French doors from bedroom 12 months on from stroke”*.

More information and training for carer and patient about self-care issues such as peg feeds and hoists was required.

Carer of P07 also only received what they described as *“nominal training on using peg feeding but felt I didn’t have a choice”* and that a hoist was provided but “*I had about 15 mins training on it*”.

Suggestions and Recommendations

Whilst there were a lot of positive comments on all parts of the stroke pathway there are inconsistencies and gaps in the care and services that Lincolnshire patients are receiving.

Healthwatch was invited to be part of the local NHS 100 day challenge and the stroke rehabilitation project group and as a result we recognised that the service providers and commissioners were already aware of some of the comments below. However, we feel that as part of our project reporting it is important to raise these issues at this stage.

- Increase clinical psychologist provision for all stroke patients (NICE Guidelines - Adults who have had a stroke have access to a clinical psychologist with expertise in stroke rehabilitation who is part of the core multidisciplinary stroke rehabilitation team. [new 2016])
- A 'go to' person is made available for all stroke patients irrespective of which pathway they are on (this does not need to be a clinician post and could be provided by one of the many voluntary and community services (eg Stroke Association, Social Prescribing, HWLincs) as a commissioned service
- Timely and ongoing access, as appropriate, to therapies once transferred from stroke acute care
- Improved communication and more carer and family involvement along the whole pathway but especially in relation to therapies and discharge.
- In broader terms, we feel more provision of support regarding return to work would be welcomed eg tailoring an intervention (for example, teaching strategies to support multi-tasking or memory difficulties, teaching the use of voice-activated software for people with difficulty typing, and delivery of work simulations). (Nice Quality Statement - Adults who have had a stroke are offered active management to return to work if they wish to do so. [New guidelines 2016]).
- Improved and consistent financial support especially around benefits (PIP, AA, Carers Allowance) but also support and information for aids and equipment and personal budget/personal health budgets (again this could be done by a voluntary and community sector organisation as above)
- Continue with an enhanced integrated approach. (The Quality Standard for Stroke requires that an integrated approach to provision of services is central to the delivery of high quality care to people with stroke).
- Review availability and options for patient not able to return to work or maintain previous activities eg encourage people to focus on life after stroke and help them to achieve their goals. This may include:

- facilitating their participation in community activities, such as shopping, sports and leisure pursuits, visiting their place of worship and stroke or carer support groups

- supporting their social roles, for example: work, education, volunteering, leisure, family and sexual relationships

- providing information about transport and driving (including DVLA requirements). Nice Guidelines - Assess people after stroke for their equipment needs and whether their family or carers need training to use the equipment eg PEG feeds, use of hoist

- 6 month, 12 month and ongoing annual health and care reviews are carried out for all stroke patients. *NICE Guidelines - Adults who have had a stroke have a structured health and social care review at 6 months and 1 year after the stroke, and then annually. [New guidelines 2016]*

    - Opportunity for patients to re-contact stroke team within 6-12 months of discharge in the event of anything untoward happening eg increase in falls, continence issues, generally not making progress expected

Acknowledgements

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- The 100 patients who spoke to us initially
- The 12 patients who gave their time for one to one conversations
- The acute hospitals serving our Lincolnshire patients, including Lincoln, Pilgrim, Kings Lynn and Peterborough Hospitals
- The ADSS (Assisted Discharge Stroke Service) team in particular Michelle
- The Seamless team
- The Stroke Association
- Carers First

We look forward to the continued review and development of the Lincolnshire Stroke Service in the hope that the efforts will make it one of the best, if not the best in the country offering patients and their families' unparalleled services when they need it most.

To access Advice, Support and Clinical Information regarding Stroke's please visit:

Stroke Association - www.stroke.org.uk

NHS - https://www.nhs.uk/conditions/stroke/

You can reduce your risk of stroke by changing your lifestyle, also learning how to recognise if you or someone else is having a stroke is very important, more information can be found using the links below:

http://www.research-lincs.org.uk/UI/Documents/JSNA_Topic_Stroke_v3.1_210316.pdf

https://www.lincolnshirecommunityhealthservices.nhs.uk/application/files/9415/4013/5087/Health_promotion_presentation.pdf

https://lincolnshireccg.nhs.uk/act-fast-during-stroke-awareness-month/