

SNAPSHOT REPORT

What support do local people want following hospital discharge after a Stroke?

Public event held 20th September 2019

Note: The purpose of engagement work by Healthwatch Wigan and Leigh to get a better understanding of how local people experience local health and social care services. Our approach is to be constructive in sharing what we find and we will always strive to identify good practice as well as areas for improvement. This report is based on observations made by our representatives at the point they visited the service.

Purpose	To hear about the changes to Community Stroke Services in the Borough and to hear of local people's experiences about support following hospital discharge after a stroke
Where	St Peters Pavilion, Hurst Street, Hindley, Wigan
When	Friday, 20 th September 2019
Who	54 people attended the event, took part in table discussions and had the opportunity to speak with 10 organisations who attended to offer information on their services
Why	Working in partnership with Wigan Borough CCG, Stroke Association and Thinkahead, we held a Stroke Information Event to engage with patients, carers and families about their experiences if they have accessed stroke care but also to ask if people knew what is available.

1. Acknowledgements

Healthwatch Wigan and Leigh would like to thank Thinkahead Community Stroke Group, the Stroke Association, Wigan Borough Clinical Commissioning Group, Wrightington, Wigan and Leigh NHS Trust and all the organisations who supported the event by bringing their information along and to everyone who took part for sharing their views and experiences

2. Disclaimer

This report relates to verbatim comments gather during table discussions and is not a portrayal of the experiences of all patients, carers and family members, only an account of what was contributed on the day.

3. Background

The NHS wants to significantly improve stroke care across the country. It is included in the NHS Long Term Plan as one of the major health conditions for which local services need to provide better care.

To provide integrated stroke care health, social care and the voluntary and community sector need to work together.

Working in partnership with Wigan Borough CCG, Stroke Association and Thinkahead we held a Stroke Information Event to engage with patients, carers and families about their experiences if they have accessed stroke care but also to ask if people know what is available within the community post hospital discharge. We also heard from Wrightington, Wigan and Leigh NHS Trust about the changes to Community Stroke Services in the Borough.

4. Project anticipated outcomes

- Better informed communities
- Feedback for services on what works well and what could be improved
- Identify gaps in communication
- Improve the quality of post-discharge stroke care for Wigan Borough

5. Methodology

Healthwatch Wigan and Leigh working in partnership with Thinkahead, the Stroke Association and Wigan Borough CCG to host an information event. Wrightington, Wigan and Leigh NHS Trust were invited to explain the changes to community Stroke Services and organisations were invited to bring along their information to share with local people.

Information was circulated across the Borough inviting stroke patients their families and carers to attend an information event and to take part in table discussions, to hear about their experiences and give their views on what support would help within the community.


54 people attended and 75 comments were gathered.

Four questions were asked during the table discussions:

1. What was important to you post-discharge?
2. What support do you want within the community?
3. What works, what could be done better in terms of community stroke services?
4. What information do you know now that you would have liked post-discharge?

6. Comments

1. What was important to you post-discharge?

-  To be independent and not reliant on family;
- As a family we wanted to be there;
- Being alive;
- It was good how quickly everyone, physio + SLT + Stroke Association came out, but the gap is too long between community stroke team and neuro and you can go backwards;
- Hard to change from between teams, community stroke team and neuro;
- Getting stronger to be more independent;
- Shock, emotional impact - reassurance. Impatient, anger felt guilty. Don't believe that you will get better - doubt it magical - not mystery tour - things ahead but don't know how to trace them. More information for family members;
- Salford Royal - no information - need information at that point - Neuro patient and users meet every 3 months - can't process it at the time of the stroke;

- Full-time employment, mortgage employer, sick pay - info aimed at older. Urgency to deal with situation - financial insurance. Invasion of privacy. Lived on own. Intrusive in to private life;
- Benefits information at point stroke;
- Condensed information;
- On the ward - volunteer to ask 'what are you worried about';
- Trying to get physio;
- Staying alive;
- Waiting time between physio etc.;
- Determined to walk - would not leave until I could walk;
- Waiting time for lift, door, adaptations done;
- The Stroke Association and Thinkahead sorting things out for me;
- Help and information (not written). Felt left alone and abandoned at 6 weeks. Needed more information to carer about what is going to happen;
- I want to get back driving but have waited 3 months to see the specialist at Boston house. I spoke to the DVLA about being re-assessed but I need advice about what to do to be able to drive again;
- Understanding that therapy works towards an achievable goal;
- Needing ongoing active programme not dictated by staffing but by need;



2. What support do you want within the community?



- More emotional support for carers;
- Practical help for carers e.g. respite, befriending etc.;
- Face to face support to tackle loneliness;
- More access to drivers and transport
- More physiotherapy;
- Less documentation, more appropriate information;
- Can't complain about community input. Therapies were brilliant;
- Transport;
- I had to rely on people to take me to places;
- Support in work place, home etc.;
- Need training courses for family carers on how to deal with stroke - experience of stroke difficulties yourself to understand;
- Make it a routine part of service offering (not have to seek it out);
- Need it all to be linked up as time goes on - eg develop new issues (dementia etc.) so don't fall between services;
- Follow-up clinics - consultants to know specifics of their condition not to generalise but read notes before appointment - not just look at physical but emotion aspect;
- Somebody coming to us as we didn't know what to do. Stroke Association was fantastic. They gave us 2 hours and answered loads of questions. They explained medications, helped to understand symptoms and frustrations;
- You need to be honest with the professionals or they can't help;
- I was discharged but didn't feel ready and I'm still getting headaches. My GP changed my medication and I'm going back to the consultant, but I would have like more support so I'm not doing all the running around myself;

- My biggest problem has been getting continued physio. I was discharged even though I didn't want to be, and I've been trying for 12 months to be rereferred as I need continued support;



3. What works, what could be done better in terms of community stroke services?

- Quick access works;
- Everybody is kind and supportive;
- More information on the stroke pathway. At the moment information is patchy and disjointed;
- Therapy works but more would be better. Quicker access to social services for help with direct funds for carers;
- Therapies - don't think anything could be better - physio, OT, SLT, reablement;
- Community in Wigan is better;
- Pavements are bad in some areas;
- People with electric scooters need more teaching and instruction;
- Lots of things available - need help to understand how to do things/look after - how to get them to engage with them;
- When a person is discharged, contact them within 48 hours, support when it is needed. Close support after 6 weeks is needed;
- Be clear who everyone is;
- GPs to be more aware and central to referrals;
- Central IT - shared data;
- One to one support is great in the early days, but more group work would help later;
- I feel like I'm constantly on people's cases to fight for my wife for physio and speech and language. The care she has received has been amazing but the wait in between therapies is far too long. She is only 36 and we feel that she has been left high and dry;
- Move from 6 weeks to 6 months therapy. If it wasn't for me and our parents I don't know where we would be. We have 2 small children, I work full-time, and I don't have time to be chasing people for help and support. She needs more therapy and it's been 12 months since she had any and we feel adrift;



4. What information do you know now that you would have liked post-discharge?

- More information of what to expect - stroke happens in 30 seconds, the recovery lasts years
- Trafford leaflet called 'A Hero's journey' was useful
- More help with benefits and form filling
- It would be good to meet an inspiring stroke survivor in the early days to give us hope
- A lot more money needs allocating to all stroke services - on the ground work not management



- Addressing other health issues in a timely manner! - knowing who to speak to
- Would like to know who people are: therapies eg information about who does what, maybe colour code of uniform
- Therapists good at explaining and adjusting their terminology to suit the stroke survivor and family
- Need a basic information pack to explain what happens next
- Empathy North West, 55A Wallgate, Wigan offer counselling for a small fee if you can afford it
- On ward camaraderie
- If in just one night its very isolating as can't discuss with other stroke survivors
- Everything learned from Thinkahead and the Stroke Association
- Reactive solutions eg, rails, rather than preventative
- Benefits advice - not loads of leaflets - all in one place and person to advise
- Training for professionals/community in psychological impact of disability
- More information on post-stroke seizures. We weren't told anything - people need to be made aware of the possibility of these
- Information about driving and how to get your licence back. I was told by Salford to hand my licence in to the DVLA and I've had some very helpful information today about who I need to speak to
- More information from Salford about the Stroke Association if you are discharged home and not to the stroke team. I have missed reviews etc. because I was missed from the system between Salford and Wigan



6. CONCLUSION

Following the assessment of responses we have identified a number of recommendations that we urge the Healthwatch Board of Directors to consider sharing at the appropriate forums:

- The most important things to a stroke patient post-discharge is the need for clear information both for themselves and for their family members and for that to be delivered in a way that is based on each person's need and not what is dictated or set down as general information
- Patients and family members said that they want more emotional and practical support to carers and family members with less documentation and more appropriate information
- The need for face to face support was highlighted, eg the way the Stroke Association and Thinkahead give their time to answer questions, explain medications, help people to understand their symptoms and frustrations
- We were told that what could be done better in terms of community stroke services is quicker access to therapies, quicker access to social services for help with direct funds for carers and for GPs to be more central to referrals
- Patients explained that post-discharged they would have liked more information about what to expect such as post-stroke seizures. A basic information pack to explain what happens next, with benefits advice, contacts of where to find help with form filling, etc.

- The need for better communication for those patients who are discharged from Salford directly home as they often slip through the net and do not get referred to the Stroke team or the stroke Association or Thinkahead

“a stroke can happen in 30 seconds - the recovery can last for years”

We request that the Healthwatch Board of Directors use this report to discuss and debate the points raised by the findings and suggestions from both Healthwatch and the public.

7. NEXT STEPS

- 7.1 Feedback to Providers - November 2019
- 7.2 Draft report submitted to Advisory Committee for logging and action - November 2019
- 7.3 Full report submitted to Healthwatch Wigan and Leigh Board of Directors for noting and action - November 2019
- 7.4 Confirm appropriate forums to share this to discuss recommendations set out below and arrange for report to be added to agenda - November/December 2019
- 7.5 Develop action plan that will be used to monitor impact - November 2019. This should ascertain what the intelligence tells us about access to Primary Care, communications, discharge from hospital and overall patient journey within health and social care.
- 7.6 Identify how Healthwatch Wigan and Leigh can help promote services, good stories from visit we want to capture and share as good practice -November 2019.

Date approved by Healthwatch Wigan and Leigh Board of Directors:

Date shared with provider for comment:

Date for review of progress against recommendations: