

IS STROKE AFTERCARE AND REHABILITATION DIFFERENT FOR PATIENTS IF IT OCCURS BEFORE 65 OR AFTER?

IF SO, SHOULD THIS BE THE CASE?

SUMMARY REPORT

A REPORT WRITTEN BY
GENEVIEVE PASCAL, UNIVERSITY OF PORTSMOUTH,
SUPPORTED BY HEALTHWATCH PORTSMOUTH.

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CONTENTS PAGE:

- Introduction / Rationale 3
- Methodology 3
- Findings & Recommendations 4
- Summary & Conclusion 6
- References 6
- Appendix A - Questions for Different Strokes 7
- Appendix B - Questions for the QA Hospital 9
- Appendix C - Questions for the Stroke Café, Portsmouth 11
- Contact Us - Healthwatch Portsmouth contact details 13

INTRODUCTION/RATIONALE

Healthwatch Portsmouth is an independent statutory body that gathers the views and experiences of local people, enabling them to have a chance to speak up about health and social care services in their area. Healthwatch Portsmouth collect local evidence-based information through community engagement to ensure that the people who plan, commission and check services listen to the people who use those services.

Age is one of the biggest risk factors of strokes. As of January 2017, according to the Stroke Association; the average age for stroke in England, Wales and Northern Ireland was 74 for men and 80 for women but over the last few years this has decreased. Ageing is an unavoidable part of life making it important that we know how best to care for people in the right way.

The aim of this report is to begin to find if the age of a stroke sufferer affects the aftercare and rehabilitation they receive. It asks the question, are the needs of younger stroke survivors different from those over 65 and if the needs of younger stroke sufferers are different and the average age of stroke is decreasing should we be changing the approach to aftercare?

There are various challenges facing stroke survivors. According to the Stroke Associations Statistics for 2017 around 2/3 of stroke survivor's leave hospital with a disability but; what is the impact of this on younger people compared to older. This is looked at in regards to family life and returning to work.

Healthwatch Portsmouth and I would like to take this opportunity to thank all patients and staff who gave up their time to plan and participate in the visits and research.

METHODOLOGY

To begin answering this question, informal interviews were arranged with stroke sufferers and professional staff who work in aftercare. The interview questions were developed based on four themes; disability, emotion, social and economic. Questions were designed to be open ended, using information from the Stroke Associations Statistics 2017. Before beginning the themed questions, there were some to establish who the interviewee worked with and an overview of what they do. There were questions to end which asked interviewees what they would change and keep the same about stroke aftercare as well as whether they thought it needed to be different depending on age. Interviews were conducted in an informal setting and notes were taken on interviewees answers.

Details of questions asked can be found in the appendices to this report.

FINDINGS & RECOMMENDATIONS

The first theme was identified from looking at the Stoke Associations Statistics 2017. Around 2/3 of stroke survivors leave hospital with a disability however a survey they carried out of 1000 patients only 4 in 10 said they found the physical aspect the hardest to deal with. So this identified a question as to **whether the mental impact carried a greater weight for patients compared to the physical impact?** From the interviews, conducted as part of this study, the mental aspect of stroke seemed to be at the fore front of the recovery process. It was pointed out that there are pieces of equipment to help with the physical disabilities. The difference between the age groups came from the idea of expectation. Stroke survivors often ask why. Why has this happened to me? But it seemed that because illness and disease are linked with ageing; society is more readily accepting of strokes in older people. Some suggested the mental impact is greater on younger survivors because of society's expectation that they should be fit and well. Thinking about the future and all the things they still want to do also weighs on the mind, perhaps more so for younger survivors.

However, it was also stated that whilst in hospital the physical aspect of stroke is more concerning to patients. From speaking to a senior nurse, a patient's physical ability is a large part of determining whether they can go home or not. Yet once home, they agree that the mental side becomes much more difficult to deal with. It starts to dawn on the patient what has happened and they start to question how they are going to cope and where they go from here? Often once at home people realise they are not the same person they were when they left. Patients must come to terms with what has happened to them and how it will change their lives; but perhaps society's expectations make it more difficult for younger survivors to do so.

The second theme was **emotion**; which became more important after the influence of patient mentality had been established. Some of the most common emotions that stroke survivors seem to experience regardless of age are; anxiety, depression, denial, confusion and frustration. One of the more unexpected emotions that was reported, more in younger survivors, was embarrassment stemming from having to be helped to go to the toilet and to wash. For older survivors this was less so because those things are more generally associated with the ageing process.

Where patients felt frustrated and alone in hospital, support groups were a big aid in helping survivors to come to terms with their condition. Although many find it difficult to first come to a group, once there they have the empathy of people who understand them and are a part of something bigger than themselves. It allows them to hear other people's stories and in some instances, realise that they could be in a worse position. An important note that support groups raised is support for carers and family members; being able to meet with others in the same position and not feeling alone.

The social implications were fundamentally the same for both. For example, being able to share experiences and talk to others in the same position is important. Worrying about the effects their condition will have on their families is also common. Many survivors, particularly younger survivors, don't want their partners becoming their carer and therefore rely heavily on the community support team.

Both age groups have concerns about everyday things like picking the children up from school, cooking dinner and not being able to do their normal routine. However, from speaking to clinicians and patients there are benefits of putting younger patients together whilst in hospital. One stated that not only do the patients form friendships but their families as well. This is important as some expressed the view that as a young person there are fewer support avenues.

The final theme of work and money highlighted the strongest difference between the two age groups. It was a major concern for younger survivors and is the biggest issue they face. However, for older survivors it was simply not a topic that came up. Young survivors and those that work with them expressed views that there is a **lack of understanding from employers when returning to work**. Some go back to work too quickly because they have bills to pay or a family to support but this does more harm than good.

Recommendations

Having considered the finding's above, the following are recommendations for improving stroke aftercare.

1. As work and money worries make up the biggest issue facing young stroke survivors more support and focus needs to be provided on these issues. By providing survivors with groups and support networks specifically aimed at targeting this area; this will hopefully help to ensure young stroke survivors return to work at the right time.
2. Educating employers is also just as important. If employers are educated on the needs of their employees, survivors will be under less pressure to return to work before they are ready.
3. Thirdly as pressure not only comes from employers but the whole of society, specifically for younger survivors, educating the public is also something that needs to be addressed. There has been much effort into getting the public to recognise strokes and the actions needed with the F.A.S.T. campaign but care does not end with doctors and hospitals. For survivors to return to everyday life they need the support and understanding of the people around them.
4. Lastly it is important to note that for some people their personality completely changes after having a stroke and for the family this is like having to get to know a whole new person. This is difficult on families who need support just as much as the survivor. How else can they support their loved one?

In regards to following on this research, areas which could be considered further are as follows;

1. Perhaps looking at this from the point of view of employers. Asking their opinions and finding out what they think may enable us to provide better support and advice, for them to then play their role in helping stroke survivors to return to work.
2. Gather more information from stroke survivors themselves. Many of the interviews conducted for this report were with clinicians working with survivors. To gain further knowledge and to validate what has been found in

this report; it would be beneficial to talk to more survivors regarding this topic.

SUMMARY & CONCLUSION:

To conclude, the aftercare for stroke survivors is perhaps not different but inappropriate for their age. The main issue highlighted from interviews was that care needs to be tailored to age because there are different needs. The biggest challenge of returning to work needs far more support which includes educating employers and society. To better care for the ever-younger survivors of stroke their role in society needs to be acknowledged as well as the limitations of the condition to enable them to live their lives to the fullest.

REFERENCES:

Stroke Association. (2017). State of the nation, Stroke Statistics. Retrieved from https://www.stroke.org.uk/sites/default/files/state_of_the_nation_2017_final_1.pdf

APPENDICES:

A. Questions for Different Strokes Southampton

What are the ages of people who come to the group?

As an overview, what are the most common topics/ challenges that people are concerned with when they come to the group?

How do you normally begin a meeting and how does it normally run?

What do you think is the main thing that people get out of coming to a meeting?

1. Disability/ Physical

- *'In a survey of over 1000 stroke survivors last year, 4 in 10 told us the physical impact of stroke was the hardest to deal with.'* (Stroke Stats 2017) Is this something that you find within the group, that the physical side of having a stroke is the hardest to deal with for people? Is it one of the most common topics that is talked about?
- Do you feel that there is a stigma surrounding disability in young people or is that something that the people who come to you think? Do they feel that people will judge them or look at them differently?
- *According to stroke stats 2017, 1/3 stroke survivors have aphasia*, do you get a lot of people come to the group who have suffered with speech problems? Does that make their rehabilitation and recovery harder because they aren't able to communicate as well?

2. Emotional

- What are the main emotions you see people experiencing when they first come to the group?
- Do you get a lot of people who are reluctant to come or who are being forced to come by a relative or friend? What are the main reasons why they don't want to come?
- Do you think that someone's emotional state can impact their ability to overcome the physical implications of their condition?

3. Social

- Do many people come to the group with relatives or friends? Do you think they benefit more or no more than someone who comes on their own?
- What are the main concerns people have with their condition affecting their family? Does it differ depending on the type of stroke or do most people have the same concerns?
- Do you find people tend to feel more isolated the younger they are? Less people in the same position.
- How long on average is it between someone first coming to the group and then them deciding they don't need the support anymore? / What influences someone to decide they don't need that support anymore?

- 'A quarter of people said their stroke had a negative impact on their family' (Stroke stats 2017). Is that something you find? Do peoples relationships with their friend's/ partner/ family change after having a stroke?

4. Economic

- 'People of working age who have had a stroke are two to three times more likely to be unemployed 8 years after their stroke.' (Stroke stats 2017). Do you find a lot of people find it difficult to return to work? If so, what support is available for them?
- 'Around 1 in 6 stroke survivors experience a loss of income after stroke.' (stroke stats 2017) Is money and returning to work a major concern for people?
- What are the main challenges people face when returning to work?
- What are people's concerns/ feelings about returning to work?

Other questions: -

- If you could change something about the way your aftercare was handled by the NHS what would it be and why?
- If there were to be a complete revision about the way stroke patients are cared for and their aftercare, what would be one thing you would say needs to be kept the same?
- Do you feel like younger stroke sufferers are treated differently to those who are over 65 and if so in what ways and why do you think this is? Are they less or more of a priority or no different?
- Do you think that the aftercare and rehabilitation process should be different for young people? / Do you think there are different needs?

B. Questions for QA Hospital

1. What is the average age of people you work with?
2. What is the average/ common length of stay for people?
3. Do you get younger people come onto the ward? Is there a way that patients are organised on wards? Do you try to put younger patients together or is it more dependent on where a bed is available?
4. How do you determine when someone is ready to go home?
5. What's the routine for discharging a patient? Support and advice, they are given?

1. Disability/ physical

- *'In a survey of over 1000 stroke survivors last year, 4 in 10 told us the physical impact of stroke was the hardest to deal with.'* (Stroke Stats 2017)
Speaking to stroke survivors - mental side is harder to deal with particularly for younger stroke survivors. Is it the same for older people? Which do you think is harder for people to overcome?
- Do you think there's a stigma surrounding disability in older people or is that something that patients think? Do they feel that people will judge them or look at them differently?

2. Emotional

- What are the main emotions you see people experiencing when they realise what has happened to them?
- Do you ever get people who are reluctant to accept what has happened and thus reluctant to accept help?
- Do you think that someone's emotional state can impact their ability to overcome the physical implications of their condition?

3. Social

- What are the main concerns people have with their condition affecting their family?
- Does it differ depending on the type of stroke or do most people have the same concerns?
- Do you think that being on a ward with other people in the same situation is helpful for patients? Having people to talk to who understand from their point of view.
- What kind of social support is available for patients? Do you suggest the same advice for all patients or is it different?

4. Economic

- Is money a concern for people?
- Do people get concerned about returning to work?

Other Questions: -

- If you could change something about the way your aftercare was handled by the NHS what would it be and why?

- If there were to be a complete revision about the way stroke patients are cared for and their aftercare, what would be one thing you would say needs to be kept the same?

- Do you feel like younger stroke sufferers are treated differently to those who are over 65 and if so in what ways and why do you think this is? Are they less or more of a priority or no different?

- Do you think that the aftercare and rehabilitation process should be different for young people? / Do you think there are different needs?

C. Questions for Stroke Café Portsmouth

What are the ages of people who come to the group?

As an overview, what are the most common topics/ challenges that people are concerned with when they come to the group?

How do you normally begin a meeting and how does it normally run?

What do you think is the main thing that people get out of coming to a meeting?

1. Disability/ Physical

- *'In a survey of over 1000 stroke survivors last year, 4 in 10 told us the physical impact of stroke was the hardest to deal with.'* (Stroke Stats 2017) Is this something that you find within the group, that the physical side of having a stroke is the hardest to deal with for people? Is it one of the most common topics that is talked about?
- Do you feel that there is a stigma surrounding disability in older people or is that something that the people who come to you think? Do they feel that people will judge them or look at them differently?
- According to stroke stats 2017, 1/3 stroke survivors have aphasia, do you get a lot of people come to the group who have suffered with speech problems? Does that make their rehabilitation and recovery harder because they aren't able to communicate as well?

2. Emotional

- What are the main emotions you see people experiencing when they first come to the group?
- Do you get a lot of people who are reluctant to come or who are being forced to come by a relative or friend? What are the main reasons why they don't want to come?
- Do you think that someone's emotional state can impact their ability to overcome the physical implications of their condition?

3. Social

- Do many people come to the group with relatives or friends? Do you think they benefit more or no more than someone who comes on their own?
- What are the main concerns people have with their condition affecting their family? Does it differ depending on the type of stroke or do most people have the same concerns?
- How long on average is it between someone first coming to the group and then them deciding they don't need the support anymore? / What influences someone to decide they don't need that support anymore?
- 'A quarter of people said their stroke had a negative impact on their family' (Stroke stats 2017). Is that something you find? Do people's relationships with their friend's/ partner/ family change after having a stroke?

4. Economic

- 'People of working age who have had a stroke are two to three times more likely to be unemployed 8 years after their stroke.' (Stroke stats 2017). Do you find a lot of people find it difficult to return to work? If so, what support is available for them?
- 'Around 1 in 6 stroke survivors experience a loss of income after stroke.' (stroke stats 2017) Is money and returning to work a major concern for people?
- What are the main challenges people face when returning to work?
- What are people's concerns/ feelings about returning to work?

Other questions: -

- If you could change something about the way your aftercare was handled by the NHS what would it be and why?
- If there were to be a complete revision about the way stroke patients are cared for and their aftercare, what would be one thing you would say needs to be kept the same?
- Do you feel like over 65 stroke sufferers are treated differently to those who are younger and if so in what ways and why do you think this is? Are they less or more of a priority or no different?
- Do you think that the aftercare and rehabilitation process should be different for young people? / Do you think there are different needs?

CONTACT US:

For more information about Healthwatch Portsmouth, please contact the team at:

- Email - info@healthwatchportsmouth.co.uk
- Tel - 02393 977097
- Web - www.healthwatchportsmouth.co.uk
- Post - c/o Learning Links, Unit 3, St Georges' Business Centre, St Georges' Square, Portsmouth PO1 3EY.