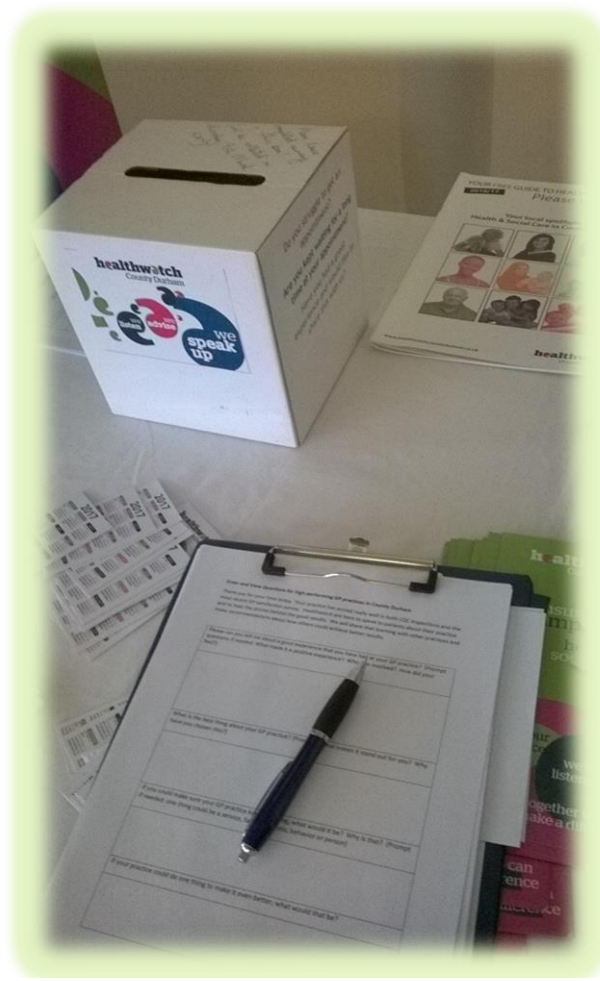


Stroke Support Services in County Durham

Research into patient access to stroke support services in
County Durham



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Healthwatch County Durham (HWCD)

On the 1st April 2013 under the provisions of the Health and Social Care Act 2012 152 local Healthwatch organisations established throughout England.

These local Healthwatch have been set up across England to create a strong, independent consumer champion whose aim is to:

- Strengthen the collective voice of citizens and communities in influencing local health and social care services to better meet their needs
- Support people to find the right health and social care services for them by providing appropriate information, advice and signposting
- To encourage and support people and groups to share their views about services; listen to people's needs and experiences of services

We achieve this by:

- Listening to people, especially the most vulnerable, to understand their experiences and what matters most to them
- Influencing those who have the power to change services so that they better meet people's needs now and into the future
- Empowering and informing people to get the most from their health and social care services and encouraging other organisations to do the same



We advise



We listen



We speak up

Executive Summary

In March 2017 stroke patients were advised by the Stroke Association that they would no longer receive support services from them as the service was being de-commissioned by North Durham and Durham, Dales, Easington and Sedgefield Clinical Commissioning Groups (CCGs). 46 service users contacted Healthwatch County Durham (HWCD) to raise concerns about lack of engagement or information about alternative provision.

HWCD contacted the CCGs to raise concerns about the change to services, the way in which this had been communicated and the impact this was having on service users and carers. The CCGs responded to the concerns raised and also advised that the current contract with the Stroke Association had been extended to the end of July 2017 and that following our involvement they would be undertaking engagement with stroke patients to help shape the new clinical services. The CCG engagement team submitted a work plan request to the HWCD Board for the support of HWCD, as an independent body, who can speak to patients and gather rich feedback to help identify the best clinical services and pathways for stroke patients. This was agreed in principle by the Board on 1 June 2017 but outstanding concerns about timescales and gaps in service provision were raised with the CCGs and Adult Health Overview and Scrutiny Committee (Appendix 1). These were addressed as the existing service was extended till March 2018 and the period of engagement agreed till December 2017. The CCG engagement team produced a questionnaire with input from Healthwatch County Durham and other Voluntary Organisations and commissioned HWCD to deliver independent engagement activities to complement their own, and to collate all completed questionnaires. This engagement took place from the beginning of September to mid October 2017.

The CCG engagement team arranged for a letter (Appendix 2) from both CCGs and HWCD to be sent to all stroke patients who had a stroke within the last 12 months. An online survey was created and the link was included in the letter, in our e-bulletin and in social media posts. The survey was also widely promoted by partners. HWCD carried out engagement over a 10-12 week period with identified patients and using a range of consultation method including phone calls, drops ins at community venues and home visits. Additional engagement activities were carried out by the Engagement Leads at both CCGs (Appendix 4) but this report details the findings and recommendations of the work done by HWCD.

HWCD consulted with 155 stroke patients over the consultation period using a mixture of on line surveys, postal questionnaires and face to face engagement.

The responses showed a wide variance of experience for patients recovering from a stroke. Some of the key things they told us were:

- Most patients told us they were given clear information about their medication when leaving hospital
- Patients who had a TIA (minor stroke) seemed to indicate they had not received the same information/support as a patient being admitted to hospital

- There is an element of fear and anxiety for many patients, not being clear about what they can do to prevent future strokes
- Care planning seems to be an area where there is some confusion and disparity. A high percentage of patients told us they do not have a care plan, however the small number that indicated they do have one, are not aware of what is included in the plan
- Patients are not clear about the range of support which might be available, this includes physical, emotional and financial support. Approximately 46% of patients told us they were not given clear written information on discharge
- Having timely appointments for therapeutic support and care was identified as problematic for 25% of the patients (29 individuals) who responded to the question
- The majority of patients told us they felt that health professionals had listened to them when they discussed their care
- Most patients said they felt confident managing their health at home, although some had struggled to get aids and adaptations sorted out
- Many carers felt they were not given information and advice

Recommendations

Some of our key recommendations, based on what patients and carers told us, for commissioners to consider as part of their development of new services are:

- There needs to be a clear pathway of support for patients who have strokes. This should include support for those who suffer from TIA
- All patients should be given a care plan, either on discharge or shortly after they return home. Care plans should be discussed with patient and carers to help them understand what support can be provided. These plans should be person-centred and appropriate for the needs of the individual, we recognise that some will be very simple, but being personalised is so much more useful than just being given a leaflet
- There should be clear and simple literature giving patients, families and carers information about the support available in their locality. This should include emotional/mental wellbeing support as many patients told us they had struggled emotionally to come to terms with the effects the stroke had on their lives
- Patients should be given advice from appropriately trained practitioners about healthy lifestyles and what preventative measures they can introduce into their daily living

Background to the work

In March 2017 North Durham and Durham, Dales, Easington and Sedgefield CCG's advised the Stroke Association they were no longer going to commission support services from them, giving them an opportunity to re-focus stroke services for patients in County Durham. This proposal advised that the core provision from Durham County Council and NHS Foundation Trust would be strengthened by:

- Reinvestment of funding into clinical stroke support services based around GP practices. This is to provide support for local patients of stroke based on their on-going rehabilitation needs.
- The service will undertake recommended needs based reviews in partnership with Primary Care, community services and charities, to support and signpost patients and carers to the most appropriate services.
- Making effective use of the existing services provided via Durham County Council including
 - Hospital from home
 - Care Connect
 - Social Care Direct
 - Health Trainers
 - Intermediate Care Services

HWCD was contacted by both the Stroke Association and 46 service users who were concerned about the de-commissioning of the service, the short transition time and the lack of detailed information on what any new service would look like.

HWCD contacted the CCGs to raise the concerns about the change to services, the way in which this had been communicated and the impact this was having on service users and carers. Marianne Patterson the Project Manager of Healthwatch County Durham also spoke at the North Durham CCG Patient Public and Carer Engagement Committee about the need to escalate the concerns identified and then met with Sarah Burns, Director of Commissioning for DDES CCG and Brian Jackson, Chair of HWCD.

The CCGs responded to the concerns raised and also advised that the current contract with the Stroke Association had been extended to the end of July 2017 and that following our involvement they would be undertaking engagement with stroke patients to help shape the new clinical services. The CCG engagement team submitted a work plan request to the HWCD Board for the support of HWCD, as an independent body, who can speak to patients and gather rich feedback to help identify the best clinical services and pathways for stroke patients. This was agreed in principle by the Board on 1 June 2017 but outstanding concerns about timescales and gaps in service provision were raised with the CCGs and Adult Health Overview and Scrutiny Committee (Appendix 1). These were addressed and due to the timescale for meaningful engagement and analysis of the data the existing contract was extended for a further eight months to the end of March 2018.

What we did

The work was part of a process to identify and improve clinical outcomes for stroke patients.

A letter from both CCG's and HWCD (Appendix 2) was sent out to all stroke patients who had a stroke within the last 12 months. An on-line survey was created (See Appendix 3) and the link was included in the letter, in our e-bulletin and in social media posts. The survey was also widely promoted by partners. Telephone details were included in the letter to offer patients an opportunity to call us. A total of 22 patients called to advise us of their stroke experiences and to go through the survey. A home visit was undertaken at the request of one stroke patient. Healthwatch carried out engagement over a 10-12 week period with identified patients and using a range of consultation methods. Six drop-in appointments were arranged in community buildings across County Durham and four stroke patients were interviewed on a one-to-one basis. These venues included Stanhope, Stanley, Tudhoe, Barnard Castle, Chester-le-Street and Peterlee.

What we heard

In total HWCD engaged with 155 stroke patients over the engagement period, which was a mixture of on line surveys, postal questionnaires and face to face engagement and

- 73% who completed the survey were stroke patients
- 13% had a caring responsibility
- 14% were a family member or relative of someone who has had a stroke
- 44% experienced their stroke in the last 6-12 months
- 88% of those responding were aged 60 -80yrs +

As part of the equality data collected we asked for the town or area stroke where patients lived. Although a high number responded stating they lived in County Durham, there was still a good geographic area covered in the other responses provided across County Durham.

Some of the key messages from the questionnaires are outline below and a full summary of all responses can be seen in (Appendix 5)

Support

We asked patients what support was provided to them when they left hospital to help them settle in at home. From the 146 that replied,

- 56 (38%) received information leaflets
- 28 (19%) advised us they received no support.

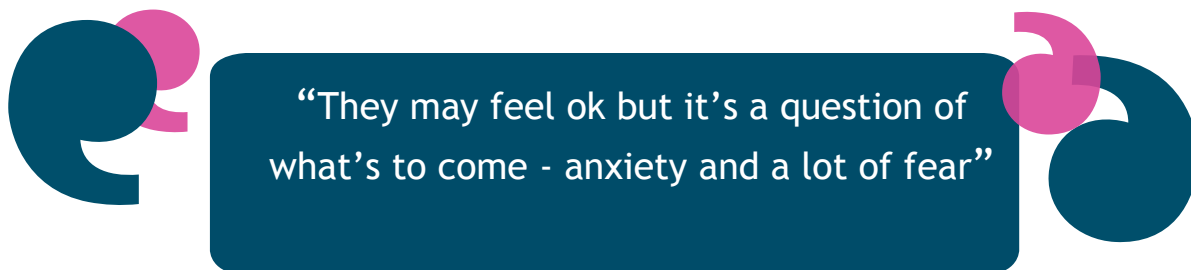
Common themes for the types of support provided were from stroke nurses and other therapists.

54% of patients advised us that they did know where to go for support however 37% did not know.

When asked if patients were confident accessing other support groups or activities, 39% told us they were not.

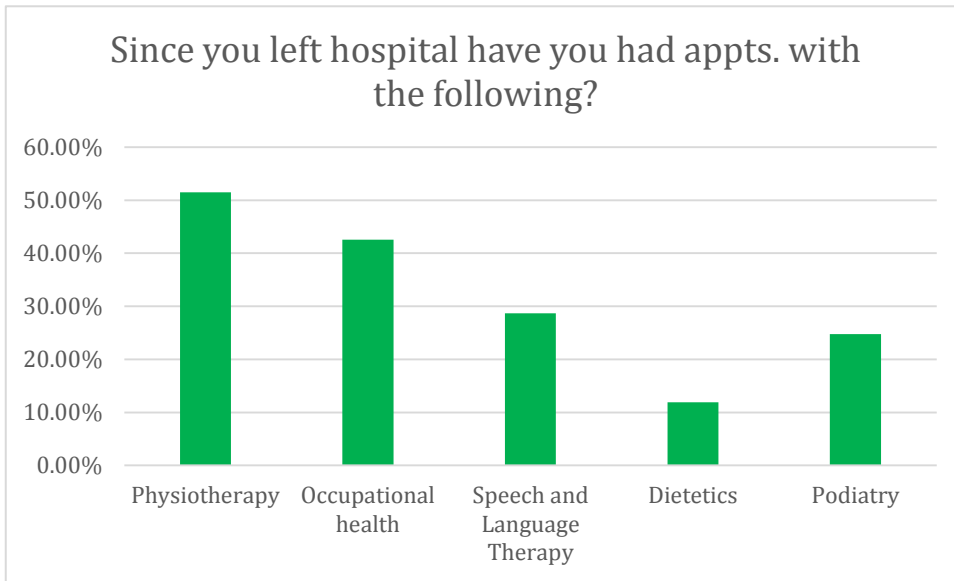


Patients commented that the most important information for them when leaving hospital and returning home are details of stroke groups and what help is available if required.

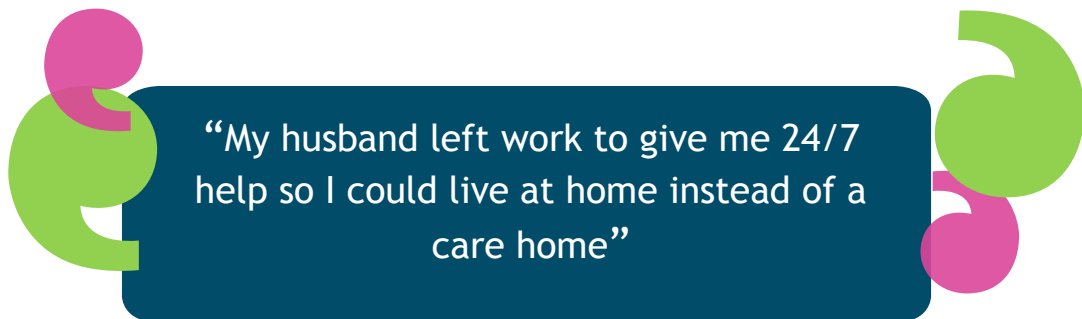


We asked patients about the types of support they received after discharge from hospital. As well as the appointments identified below, 36% of the respondents told us about appointments they had attended for other therapies/assistance these included physical support and follow-up

GP appointments. A small percentage mentioned that they had received no support.

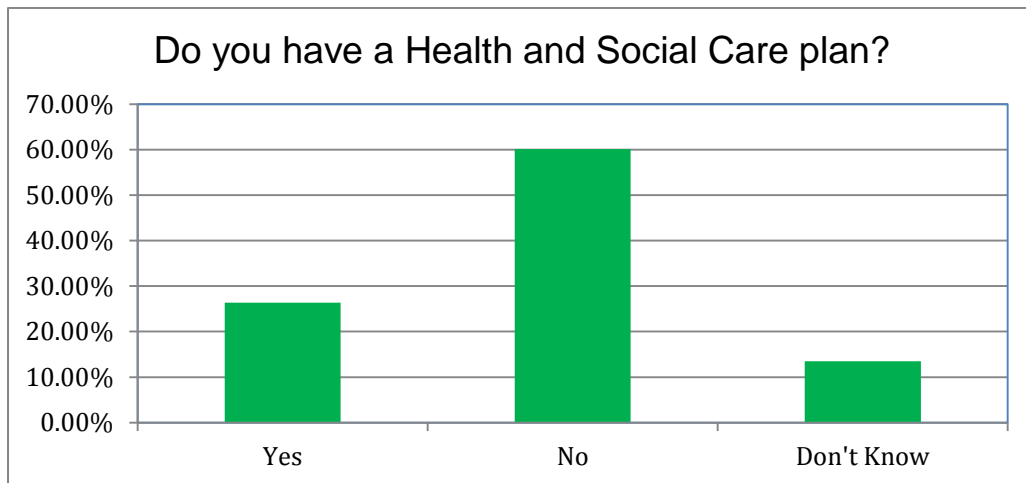


We asked stroke patients what could make them more confident to manage their own health, 61 (39%) patients responded and mentioned that they rely on family members and carers for support, others told us they have had to have mobility aids in their homes such as stair lifts, toilet risers and personal aids such as walking sticks.



Care Plans

60% of stroke patients stated that they did not have a health and social care plan. However a higher percentage did respond to some of the further questions we asked in relation to care planning, which leads us to believe it is an area of confusion for many stroke patients.



A large proportion of patients did not know what was in their plan and also many patients stated they did not have care plans explained to them. Almost 40% of the respondents told us they had been unable to ask questions about their care plan.

Analysis of data

We have analysed the responses on the questionnaire and identified some key themes for consideration. Some of the issues captured from the questionnaire were from general comments made by stroke patients and their carers.

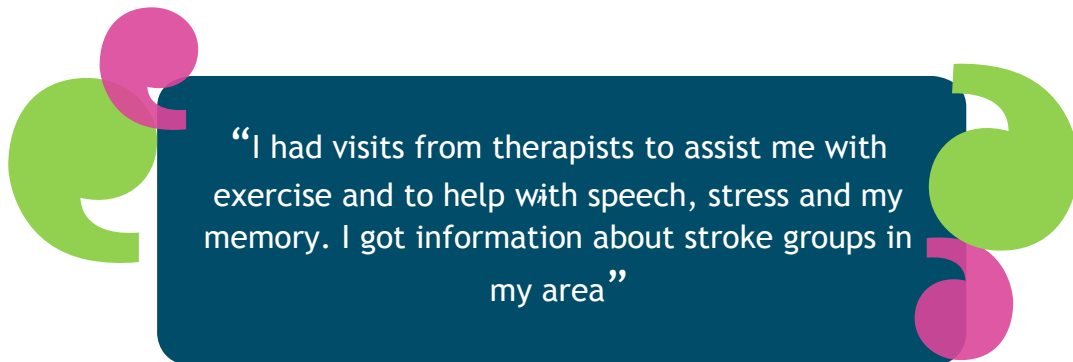
- Most patients told us they were given clear information about their medication when leaving hospital
- Patients who had a TIA (minor stroke) have not received the same information/support as a patient being admitted to hospital.
- There is an element of fear and anxiety for many patients, not being clear about what they can do to prevent future strokes.
- Care planning seems to be an area where there is some confusion and disparity. A high percentage of patients told us they do not have a care plan, however the small number that do have one, are not aware of what is included in the plan.
- Patients are not clear about the range of support which might be available, this includes physical, emotional and financial support. Approximately 46% of patients told us they were not given clear written information on discharge.

- Having timely appointments for therapeutic support and care was identified as problematic for 25% of the patients (29 individuals) who responded to the question.
- The majority of patients told us they felt that that health professionals had listened to them when they discussed their care.
- Most patients said they felt confident managing their health at home.
- Many carers felt they were not given information and advice

The types of support patients valued were, physiotherapy, emotional support & speech therapy.

Some of the things that patients thought were important as part of their recovery and feeling confident back at home were

- Having coping strategies
- Knowing where to go for help, someone to talk to
- Being given useful contacts
- Knowing what to expect
- Support with recovery



Recommendations

Following a review of our findings we would recommend the following actions:

- There needs to be a clear pathway of support for patients who have strokes. This should also include those who suffer from TIA
- All patients should be given a care plan, either on discharge or shortly after they return home. Care plans should be discussed with patient and carers to help them understand what support can be provided. These plans should be person-centred and appropriate for the needs of the individual, we recognise that some will be very simple, but being personalised is so much more useful than just being given a leaflet
- There should be clear and simple literature giving patients, families and carers information about the support available in their locality. This should include emotional/mental wellbeing support as many patients told us they had struggled emotionally to come to terms with the effects the stroke had on their lives
- Patients should be given advice from appropriately trained practitioners about healthy lifestyles and what preventative measures they can introduce into their daily living

Thank you.....

Healthwatch County Durham, North Durham and Durham Dales, Easington and Sedgefield Clinical Commissioning Groups would like to thank those who have contributed to this piece of work, including:

The stroke patients, families and carers who took the time to complete the questionnaires and share their experiences.

Stroke Association

GP practices across County Durham

Appendices

Appendix 1

Healthwatch County Durham
Whitfield House
St Johns Road
Meadowfield Industrial Estate
Durham DH7 8XL
Tel: 0191 378 1037
Email: healthwatch@pcp.uk.net
15 June 2017

Dear Overview and Scrutiny Committee Member

Re: Concerns and recommendations regarding stroke services in Co Durham

Healthwatch County Durham has received 46 letters from stroke survivors, expressing their concerns that the service they currently receive from the Stroke Association is being decommissioned. These concerns include:

- Communication – when contacting CCGs people have been signposted to the website with a response which hasn't answered their concerns. They were frustrated to be signposted to Locate, which they have not found accessible
- Timescales – people wanted to know if the new services will offer them the same level and range of support for the same length of time as they have had previously. In addition they wanted to know if there will be a gap in provision, or a seamless transition
- Process – people are telling us they are quite angry about the way this has been handled and asked if the correct process has been followed
- Engagement – people asked about plans to engage with service users and involve them in the design of new services, to make sure that their needs will be met

Having contacted both CCGs, we met with DDES's Director of Commissioning and received a written response, which was discussed by our Board on 1st June. It was decided that the response did not address the issues raised or outline a plan to deliver meaningful service user engagement. We therefore wish to escalate our concerns to the Overview and Scrutiny Committee and make the following recommendations:

- An extension to the current service of at least three months, until the replacement service is in place that will meet the needs of users
- Meaningful engagement to take place with stroke survivors so that users are at the heart of designing a new service
- A user friendly information pack to be produced, for all patients when they are discharged from hospital, with clear information and signposting to support available in the county
- A user friendly letter to be sent to all stroke survivors with clear information about when the new service will be in place and how to access it

We will attend the Overview and Scrutiny meeting on 7th July and look forward to your consideration of our recommendations.

Yours faithfully,

BJackson

Brian Jackson, Chair, Healthwatch County Durham

Appendix 2

1st September 2017

Dear Patient,

Stroke Services in County Durham

We would like to hear from you, your family or carers who may have been affected by stroke within the last 12 months. Specifically we would like to find out about your experiences of hospital discharge and your follow up care. Hearing your views helps us to improve services for the future.

We have a number of ways for you to share your experiences with us and we would be really grateful if you could take the time to do this.

We have enclosed a questionnaire which can be returned in the freepost envelope by Thursday 12th October 2017.

The questionnaire is also available online <https://www.surveymonkey.co.uk/r/Strokecountydurham>. if you would prefer to complete it electronically

Healthwatch County Durham is an independent organisation that can help you to share your views. We are happy to arrange opportunities for you to give your feedback in whichever way is best for you:

- Freephone: 0800 3047039
- Text: 07756 654218
- Email: healthwatchcountydurham@pcp.uk.net
- Home visits (call, text or email to arrange)

One to one appointment sessions are available, please see list below. You can call, text or email to book an appointment:

- Wednesday 6th September – Barnard Castle
- Thursday 13th September – Stanhope
- Thursday 21st September – Chester le Street
- Wednesday 27th September – Stanley
- Wednesday 4th October – Peterlee
- Tuesday 10th October - Tudhoe

This is a joint piece of work and is being undertaken by NHS Durham Dales, Easington and Sedgefield Clinical Commissioning Group (DDES CCG), NHS North Durham CCG and Healthwatch County Durham.

We very much hope that you are able to give your feedback and views through one of the ways that we have given above.

Yours sincerely



Sarah Burns
Director of Commissioning
On behalf of North Durham/
Durham Dales, Easington
and Sedgefield CCGs



Julia Catherall
Engagement & Signposting Lead
Healthwatch County Durham

Further information

Clinical Commissioning Groups are the NHS organisations that are responsible for planning and paying for the majority of healthcare services. You can read more about the work of these organisations using the links below;

- NHS North Durham (ND) CCG - www.northdurhamccg.nhs.uk
- NHS Durham Dales, Easington and Sedgefield (DDES) CCG - www.durhamdaleseasingtonsegefieldccg.nhs.uk

Healthwatch County Durham is the independent consumer champion created to gather and represent the views of the public and play a role at both a national and local level, making sure that the views of the public and people who use services are taken into account.

You can find more information about them and their work on the following link:

www.healthwatchcountydurham.co.uk/

Appendix 3

Stroke services across County Durham questionnaire

1. Are you completing this survey as:

A stroke patient

A carer of someone who has had a stroke

A family member/relative of someone who has had a stroke

Other _____

2. How long ago did you experience your stroke? Please put a X over your answer

In the past 6 months

6-12 months

1-3 years

Leaving hospital:

3. What support was provided when you left hospital to help you settle in at home? For example: information leaflets, therapy team contact details etc.

4. Did you know where to go for support?

Yes

No

Don't know

5. Were you confident in accessing other types of support groups / activities?

Yes

No

Don't know

6. Were you provided with clear written information about your medications?

Yes

No

Don't know

7. Were you provided with clear written information about your therapies (physical / emotional)?

Yes

No

Don't know

8. What information and support has been provided to carers / friends /family involved in your care?
For example information / advice, appointment details etc

9. What information do you think is the most important to stroke patients when they leave hospital and return home?

Your care plan:

10. Do you have a Health and Social Care plan

Yes No Don't know

11. Do you know what is in the plan?

Yes No Don't know

12. Did someone explain the care plan to you?

Yes No Don't know

If Yes, Who did this?

13. Were you able to ask questions about your care / plan?

Yes No Don't know

14. Who did you go to if you had any questions about your plan?

Support and follow up care

15. Since you left hospital, have you had appointments with the following:

- | | | | | | | |
|--------------------------------|-----|--------------------------|----|--------------------------|------------|--------------------------|
| a. Physiotherapy | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> | Don't know | <input type="checkbox"/> |
| b. Occupational health | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> | Don't know | <input type="checkbox"/> |
| c. Speech and Language Therapy | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> | Don't know | <input type="checkbox"/> |
| d. Dietetics | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> | Don't know | <input type="checkbox"/> |
| e. Podiatry | Yes | <input type="checkbox"/> | No | <input type="checkbox"/> | Don't know | <input type="checkbox"/> |
| f. Any other support _____ | | | | | | |

16. Did you feel that your appointments for the therapies / care listed above were given to you at the right time?

- | | | |
|--------------------------|--------------------------|--------------------------|
| Yes | No | Don't know |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

17. Have you been able to review your care plan?

- | | | |
|--------------------------|--------------------------|--------------------------|
| Yes | No | Don't know |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

18. When did you have a review of your care/treatment?

- 1 month (after returning home)

- 2 – 5 months (after returning home)
- 6 months (after returning home)
- 6-10 months (after returning home)

19. Who was involved in the review with you? Eg: nurse, physiotherapist

20. What did you discuss as part of the review? Eg: treatment, medication

21. Would you have liked to have been able to discuss anything else in the review?

- | | | |
|--------------------------|--------------------------|--------------------------|
| Yes | No | Don't know |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

If yes, what would you have liked to discuss

22. Did the health professional listen to you about your care?

Yes	No	Don't know
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

23. Were there any changes to your support?

Yes	No	Don't know
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If yes, what were the changes?

What has worked for you?

24. What type of support has made a difference to you? For example, physical therapies, emotional support

25. Would you like to access any other type of support?

Yes	No	Don't know
-----	----	------------

25. Would you like access to any other type of support?

Yes

No

Don't know

If yes, what support would you have liked to access?

26. Are you confident in managing your own health / condition at home?

Yes

No

Don't know

27. What could help make you more confident to manage your own health?

EQUALITY MONITORING

As a public sector organisation, it is important that the NHS finds out how different people experience services. These next questions ask for some information about you but, you DO NOT have to answer any questions if you don't want to.

28. Are you
- A woman
 - A man
 - Transgender

- What is your age?
- | | |
|---|--|
| <input type="checkbox"/> 17 years & under | <input type="checkbox"/> 18-29 years |
| <input type="checkbox"/> 30-39 years | <input type="checkbox"/> 40-49 years |
| <input type="checkbox"/> 50-59 years | <input type="checkbox"/> 60-69 years |
| <input type="checkbox"/> 70-79 years | <input type="checkbox"/> 80 years & over |

Do you have any of the following;

- Caring responsibilities for a family member, friend or neighbour
- Children under 16 years of age
- Paid employment

Do you have a physical or mental impairment, which has lasted or will last at least 12 months and affects your ability to carry out normal day-to-day activities?

- Yes No

If Yes, please indicate the nature of the disability; _____

What is your ethnicity

These categories are based on the Census 2011 categories and recommended by the Commission for Racial Equality.

Asian, Asian British, Asian English, White

- | | | | | |
|--------------------------|--------------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | Asian Scottish, or Asian Welsh | British | <input type="checkbox"/> | |
| <input type="checkbox"/> | | Asian / Asian British | English | <input type="checkbox"/> |
| <input type="checkbox"/> | Bangladeshi | Gypsy or Irish Traveller | <input type="checkbox"/> | |
| <input type="checkbox"/> | | Chinese | Irish | <input type="checkbox"/> |
| <input type="checkbox"/> | Indian | Scottish | <input type="checkbox"/> | |
| | Pakistani | Welsh | <input type="checkbox"/> | |

Other Asian background (specify if you wish):

Other White background (specify if you wish):

Black, Black British, Black English, Black Scottish, or Black Welsh

- | | | |
|--------------------------|---|-------------------------|
| <input type="checkbox"/> | African | White and Asian |
| <input type="checkbox"/> | | White and Black African |
| <input type="checkbox"/> | Caribbean | White |
| | Other Black background (specify if you wish): | White |

Mixed

- | | |
|--------------------------|---------------------------|
| <input type="checkbox"/> | White and Black Caribbean |
| <input type="checkbox"/> | White and Chinese |

Other mixed background (specify if you wish):

Other ethnic group

- | | |
|--------------------------|---|
| <input type="checkbox"/> | Arab |
| <input type="checkbox"/> | Other ethnic group (specify if you wish): |

Prefer not to say

What is your religion/belief?

- No religion
- Buddhist
- Muslim
- Christian (including Church of England, Other (specify if you wish):
Catholic, Protestant and all other Christian denominations)
- Hindu
- Jewish
-
-
-
-

Which of these best describes you?

- Heterosexual/straight
- Bi-sexual
- Gay
- Lesbian

In which town or area do you live? _____

- Prefer not to say

Appendix 4



North Durham Clinical Commissioning Group
Durham Dales, Easington and Sedgefield Clinical Commissioning Group

North Durham and Durham Dales, Easington and Sedgefield Clinical Commissioning Groups (CCG's) embarked on engagement with stroke survivors in July 2017; working in partnership with Healthwatch County Durham.

Conversations took place between the provider of the stroke services at County Durham and Darlington Foundation Trust (CDDFT) to agree the best, most sensitive way to approach stroke survivors.

The aim of the engagement was to speak to stroke survivors who had been discharged within the last year to gain feedback and knowledge of what services and care they had received to gather a fuller picture.

The CCGs engagement teams visited stroke groups and contacted other relevant stakeholders across County Durham. Over thirty stroke survivors were engaged in this face to face discussion where they were able to explain their varying experiences after being discharged from hospital.

Due to patient confidentiality information that would have been used to identify stroke survivors was not able to be shared with the CCG. To reach patients who had a stroke in the last year and subsequently been discharged from hospital, we worked with our primary care data team who were able to run a search on each individual General Practice systems for any patient who had a read code (diagnosis code) on their records as having a stroke within that time period.

From here, we were able to provide the different GP practices with the correct number of packs for them to address and send onto the patients and therefore no patient data was shared.

These packs included a letter, the questionnaire (appendix 2) and a free post addressed envelope. This information was put into a plain stamped envelope which the practices agreed to put the patient address on and send out.

The deadline for the survey was October 12th. The questionnaire and the Healthwatch appointment sessions were communicated via the CCGs social media platforms and Healthwatch.

The Engagement Team from the two CCGs visited the following stroke groups:

- Exercise After Stroke Easington – Healthworks on Friday 18th August
- Exercise After Stroke Easington – Healthworks on 11th September
- Durham Stroke Club - Stroke Association on Tuesday 8th August
- County Durham Stroke Club - Stroke Association on Tuesday 15th August

At all of the groups, the Engagement Team based the conversations around the stroke services survey and gathering views about patients' experiences of services after discharge from hospital. The feedback received varied within the different groups. Even though this engagement work was focused around patients who experienced stroke services within the past twelve months, we spoke to people who had experienced a stroke more than two years ago and more. All of the information captured was able to give us a more historical view of the stroke services and patients experiences.

The information gathered from discussions is detailed below:

1. Stroke survivors who experienced a stroke in the past year

When discharged care workers came out from the council but were not found to be suitable and now the family pay for a carer.

The family were informed that a stair lift was required for their home and a downstairs bed. The family put this in place, and did not have any financial support.

Complicated information was provided on finance and benefits which resulted in difficulties.

There is a need for continuity of a social worker.

Health and Social Care plan was provided but there had been no review.

The family found the stroke club by word of mouth. Stroke survivor takes part in Reiki at the club. This is found to be enjoyable.

Speech and Language Therapist (SALT) now comes out to the family home but this had not been put in place until eight months after the stroke and it was felt that this would've been beneficial earlier. No other therapies had been provided.

The family did not have a lot of information on contacts for help.

Carers association support is very good as is the GP.

Felt that at discharge meetings the family were not listened to. Professionals need to take more consideration to personal circumstances – very important for the family.

2. Stroke survivors who experienced a stroke two years ago

No care plan. Received speech therapy for six months and supported by Stroke Association. Leaflets were received on having a stroke.

3. Stroke survivors who experienced a stroke two to three years ago

Physio was received for arm mobility in hospital. Physio was then provided at home. Took part in physio trial for university – a number of months.

A review was provided.

Stroke association came out to the house to support with lifestyle advice – helped stop smoking. – Family not sure if this was the health and social care plan.

No emotional support was received, though the family were advised of potential concerns following a stroke.

4. Stroke survivors who experienced a stroke over four years ago

After discharge a nurse came out for a visit and Stroke Association information was provided by the hospital.

No six month review was been experienced.

Counselling and emotional support was needed and was important.

Transport and finance problems experienced by all.

No physio received, though would've helped. Stroke survivor very reliant on family care.

The stroke club was positive as they find it beneficial to be around others with similar experiences. The hospital informed the patient of the club.

Stroke survivor and family do not know where to get help. No support from stroke support since the stroke was experienced.

Carers come out to the family home.

The GP was helpful when needed.

5. Stroke survivors who experienced a stroke over five years ago

Review was provided after one year.

Stroke survivor experiences epileptic seizures following stroke which has knocked the confidence. Epileptic nurse arranged talking changes, though only six sessions were offered. Family felt that if more emotional support was provided for the confidence then the physical recovery would improve.

Family paid for private physio. Physio was provided in hospital for three months.

No help received from Stroke Association, though a lot of information was provided via post/email.

Carers association provide carers day out but the family carer is not able to uptake this as this would leave the stroke survivor without care – and with lack of confidence if the carers was to have a day out, this would result in stress/worry.

No follow up had taken place apart from for medication purposes. No annual check ups. Family felt that a six month review was not long enough to be signed off as the family are still adjusting and wouldn't know all the needs.

6. Stroke survivors who experienced a stroke over eight years ago

Stroke survivor had speech difficulties.

Physio used at the stroke club. Private physio at home useful.

Discharge – hospital suggested three carers a day and family were able to have input and have the preference of one a carer a day on a morning as partner could support otherwise and stroke survivor did not wish to have carer help on an evening/bedtime.

SALT and physio was provided on and off for one year but was not offered following this.

Accessed NETA (North East Trust for Aphasia) for two years.

Art therapy – Gilesgate - helps as prior to stroke handcrafts was the hobby and now not able due to mobility.

Carer support information provided via word of mouth. Carers enjoys a day out but difficult to have care in place.

Would be useful to have local GP more involved.

Received medication reviews but no stroke specialist.

Stroke club was accessed by Stroke Association. The club was found to be beneficial as it was good to be social and be out and about.

7. Durham Stroke Club feedback

Six people attended who had experienced a stroke in the past four to twelve years.

Many of the group had received no follow up care, one had been offered Occupational Therapy and they attended the patients' home once.

None of the group got a health and social care plan.

One stroke survivor had found that the physio was more focused on walking to push for him to be able to walk before being discharged from hospital, which neglected the physio required on his arm. Now unable to use his arm.

Speech and language therapy was found to be really helpful. For the first year following discharge SALT was provided at home and up to the three years following SALT was accessed at hospital.

Patient refused carer support as they felt the carers were too local and this would infringe on their privacy in the community. At home care was provided by friends and family.

It was generally felt that there needed to be consideration that there were all different types of strokes and all patients are affected and cope differently. Patient confidence is affected and from this in some cases fear is developed.

It was strongly felt that social interaction helped the stroke survivors to recover and was still highly important to date to help them cope with the changes to their everyday life.

None of the stroke survivors had been offered counselling.

It was felt that there was considerable lack of referral to the group which they felt could be valuable to other stroke survivors. Transport issues were raised and the financial impact on stroke survivors for whom the only transport they have the ability to access is a taxi.

Recommendations

We recommend that when the Commissioning Team are looking at procuring stroke services they need to take into consideration:

- Social interaction is highly important to patients and they need information on sign posting to stroke groups for support
- Speech and Language Therapy (SALT) is very valuable to patients
- There was an obvious lack of after-care that was recognised – all patients need a health and social plan and a follow up six months after discharge
- There is a lack of emotional support and this should be something that is offered to patients as part of their after care
- Consideration in professionals of how patients may be affected differently
- Consideration needed in professionals of how patients may cope differently
- There may be financial impact eg: travel costs, this should be highlighted in the sign posting services

- This Stroke club isn't well publicised – as part of signposting, patients should have information on different services which offer non clinical support
- Care needs to be consistent for every patient
- There is a requirement for some level of emotional support to be offered along with treatments such as physiotherapy and speech and language therapy.

Appendix 5

Please find below an excel workbook containing all the summary data used in this report. If you would like to look at the data and have trouble opening the workbook please contact Healthwatch using the details below.



Summary data-
questionnaire Oct 17.:

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