



Support for the mental health and wellbeing of people with long-term conditions

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Acknowledgements

Healthwatch Bradford and District would like to thank all patients, carers, friends and families who shared experiences with us. We appreciated people taking the time to give us their feedback whilst dealing with a long-term condition and often coping with stress and other mental health conditions. We confirm that we will respect their confidentiality. Healthwatch will use this information to ask providers and commissioners of services to make improvements to the service based on patient experiences.



Why we carried out the project

Through our engagement and outreach work with many different groups of people using health and social care services, Healthwatch Bradford was aware that patients sometimes received good care for their physical illness but were not supported with their mental health, which was in many cases affected by their physical problems. We heard how services did not always see “the whole person.” We also heard examples of fragmented services that only dealt with one part of an individual’s different needs, either support for physical health, or mental health but not both at the same time. The way services are organised nationally doesn’t always help, with a range of provider organisations delivering different elements of support - this can be complicated and difficult for the different agencies to plan and co-ordinate. And we heard that this doesn’t work for the patient and carer either.

We decided to look at this issue in more depth and decided to focus on how people with long-term conditions were supported in relation to their emotional wellbeing and mental health. After taking advice we decided to focus on engaging people who had a diagnosis of heart failure as a slowly developing long-term condition and stroke as a sudden onset condition with severe long-term impacts. We ensured that the focus of this project would not overlap with other engagement being done by the CCGs or others and that it would be of value to the NHS.

Extract from report by the Kings Fund and Centre for Mental Health (2012)

People with long-term physical health conditions - the most frequent users of health care services - commonly experience mental health problems such as depression and anxiety, or dementia in the case of older people. As a result of these co-morbid problems, the prognosis for their long-term condition and the quality of life they experience can both deteriorate markedly.

In addition, the costs of providing care to this group of people are increased as a result of less effective self-care and other complicating factors related to poor mental health. Health and social care services in England are not currently organised in a way which supports an integrated response to the dual mental and physical health care needs of patients. The institutional and professional separation of mental and physical health care leads to fragmented approaches in which opportunities to improve quality and efficiency are often missed.



Summary



During the autumn of 2015 and winter of 2015/16, the Healthwatch team gathered feedback from patients with heart failure, stroke, or another long-term condition about their experiences. We asked about the impact of their condition and whether they were offered support for their emotional wellbeing and mental health alongside their physical health. We received feedback directly from individuals, from groups of patients and carers, and through questionnaires.

Key findings

- The majority of people we spoke to were positive about the care they received for their physical conditions.
- The majority of people we spoke to reported that they were not assessed or offered support for their emotional wellbeing and mental health.
- The support provided by healthcare professionals such as physiotherapists, specialist nurses, and speech and language therapists was reported as being important to people's mental health as well as physical recovery.
- Some people felt this support did not last long enough, or was not offered at the right time in their recovery, and nothing was put in place when rehabilitation therapy came to an end - leaving people vulnerable to deterioration of their mental health.
- There was felt to be a general need for more specialist nurses and other professionals providing care in the community following discharge home from hospital.
- Whilst there was support for speech therapy and physiotherapy, some of the other impacts on people (for example, difficulties with reading and understanding information) were not always recognised and supported.
- People told us that peer support groups were invaluable and most people had found their way to this support informally, rather than being signposted by NHS services.
- People relied heavily on friends and family to identify available support and make arrangements for practical things like transport, financial advice, which was often very difficult.
- More information needs to be provided to patients and carers about the support available for both physical and mental health and wellbeing on discharge home.

Our findings



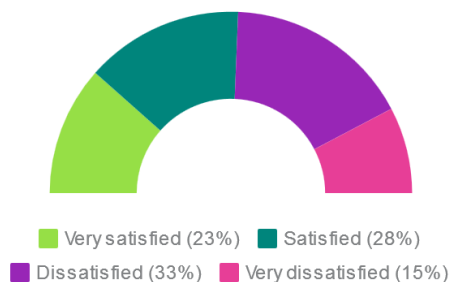
These findings are drawn from discussions we had with 101 people in 6 different support groups and 55 individual responses to our questionnaire. Some of the people who attended groups also completed a questionnaire so there is some overlap between these two figures. More detail of who we spoke to is in Appendix 2.

We also gathered detailed case studies through one to one interviews.

Quotes are given to illustrate the feedback we received; these may be taken directly from questionnaires returned to us or may be taken from notes of Healthwatch staff from focus groups or individual interviews.



Overall satisfaction



We asked people to rate their overall satisfaction with the support they received for their mental health: 39 people answered this question.

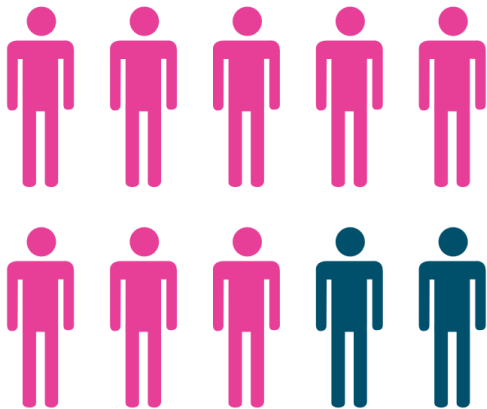
Just over half of people said they were satisfied or very satisfied.

“A lot more needs to be done to support the emotional wellbeing and mental health of stroke survivors!”

“I am dissatisfied with the support from the professionals as I was not told anything or given details of where to go for help. I am very satisfied with the support groups I attend as these help us to deal with our own situations.”

When commenting on their overall experience, some people described the devastating and debilitating effects of their physical illness which in turn had an impact on mental health, in one case resulting in an attempted suicide.

“As a result of having a stroke I wanted to kill myself and was admitted to the hospital. I would not have tried to kill myself if hadn't had a stroke. If I had more support at home things would not have got so bad, I was left unsupported and isolated.”



Eight out of ten people said their long-term condition had either a significant or massive impact on their life.

Our questionnaire asked people to rate the impact of the long-term condition on their daily life, for example doing the things they want to do, exercise, work, volunteering, family life. The responses were:

- No impact on my life 3%
- Some limited impact on my life 5%
- Significant impact on my life 41%
- A massive impact on my life 43%

Survey responses and group discussions illustrated the wide range of impact on people's lives: emotional difficulties, social isolation, impact on work and leisure activities, strain on relationships, financial problems, a loss of work and employment.

“When I had a stroke back in 1991, I was full of anger and rage and didn't understand what has happened to me. I was 35 at the time with two very young children. It had a massive impact on my life.” (*Shipley Stroke Group*).

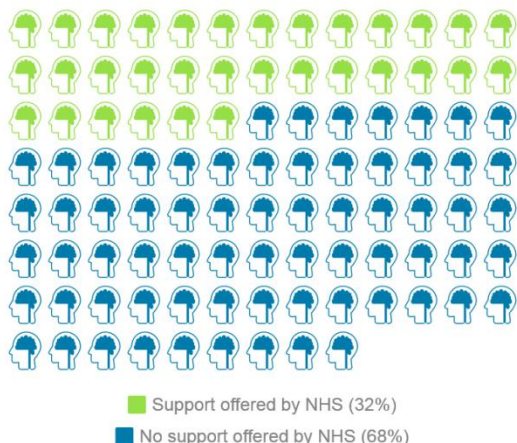
“I was in hospital for 5 weeks; I couldn't speak at all for 6 weeks. I live by myself, sometimes I get depressed but there is nothing there.” (*Keighley Stroke Group*).

“The stroke has left a significant impact on my life, both physically and emotionally. I have difficulties with mobility, speech and I suffer from low moods and depression.” (*Stroke survivor, Khidmat Centre.*)

“There is a huge strain on the family. No-one knows the impact, no one tells you what to expect. I didn't know the impact of stroke on sight or short term memory.”

“My daughter was 14 when I had my stroke. I was in hospital for 5 months, she was so upset, my partner had to try and do everything. Our daughter stopped going to school, but all we got was a visit from the truant officer.”

It became clear, when discussing the issues of mental health and wellbeing, that the majority of those who spoke to Healthwatch felt an overwhelming effect on their lives as a whole - both from a physical *and* mental health viewpoint.



Two-thirds of people told us they had not been offered mental health support from the NHS.

In our survey, 68% (25 people) said they had not been offered support from the NHS.

“I had my stroke in 1991. Your physical care is catered for in hospital but no one really asked how you felt: I suppose they do that now. But I’ve never been asked.”

“I am dissatisfied with the support from the professionals as I was not told anything or given details of where to go for help.”

The group and individual discussions echoed this, with most people saying they did not get any support from the NHS for emotional wellbeing.

“Blood taken every 6 months, physical treatment only, nothing psychological.”
(*Shipleigh Stroke Group, survivor*).

“They asked me ‘is he depressed?’ I said of course he is, his life has been turned upside down, even I can work that out. He was only offered anti-depressants but didn’t want them. Nothing else was suggested like counselling, or even the stroke group.” (Carer)

“I had no emotional help from the NHS. The best help came from Horton Housing Association, who not only arranged accommodation, but also set up a meeting with someone from the Stroke Association. This gave me invaluable support. The Stroke Group also put me in touch with a speech therapy group as I was never offered support with this. My former employer recommended Reiki healing which again has been very beneficial. In short, I was not offered any help emotionally - I had to find it myself or have it recommended by family/friends.” (*Creative Arts Stroke Group*)

“The acute care in hospital is so good. The ongoing rehabilitation is nothing like as good, but it’s every bit as important for the patient’s life. There’s no emotional or psychological support.”



Information - who provided information about support for mental health?

“A specialist Stroke Nurse told me about a local support group.”

Of the 12 survey respondents who got offered support by the NHS, 11 told us where they got the information or help to be referred. The top sources of information were:

- Specialist nurse 4 people
- Hospital doctor 3 people
- GP 2 people

“My GP was very good and told me about an exercise class for heart patients. This was an 8 week course and while I was doing it I was told about this group [Bradford Heart Support Group], and I have been going to the group ever since.”

“I was in hospital for 3 or 4 days but was discharged with no information.”
(*Keighley Stroke Support Group*).

We asked if people got information about support for their emotional or mental health from other sources. In our questionnaire, 37 people responded to this question and over half (19 people) had received information from non-NHS sources:

- 60% got information from local community organisations
- 33% got information from family and friends.

In this small sample, a few people said they got information from the internet, newspaper or media, or local directories. The advice and support role of local community organisations is very clear throughout, and national charities Stroke Association and Pumping Marvellous were also mentioned positively.

Although most people were not offered support from the NHS, many did find that support either for themselves or through other routes.





In the discussion groups people talked about the kinds of support services they had used.

Some people talked about focused mental health support:

- Psychological support
- Psychiatric support
- Anti-depressant medication

Stroke groups or heart/ cardiac groups were most commonly raised and it was clear that the understanding and emotional support from others who had been through the same thing was of great benefit.

Other support services such as physiotherapy and exercise were also mentioned:

*“I feel that any support can aid mental health and wellbeing, especially physio,”
(Shipleigh Stroke Group).*

“Can I go to a gym? It helps mental wellbeing but no one will tell me if it’s ok.”

Religious and cultural issues were also reported as being a factor in emotional wellbeing. One person talked to us about the impact his illness has had on his life, he described how he takes comfort in his religion and this supports him address and overcome low moods.

“Only God can help me and I go to the mosque to pray which helps.”

“It’s good to get away for a few hours, out of the house and among friends and community”

One person, aware of the stress on her carer, noted the importance of respite care (in her case at Thompson Court) to give her partner a break.

In the questionnaire we asked, “If a service to help your emotional wellbeing or mental health was offered but you didn’t use it, please tell us why this is”.

The most common reasons were that it was an unwanted intervention that had been offered, it was judged to be an unhelpful service, or there were concerns about side effects of medication.

“I could not relate personal problems over the telephone to a complete stranger and I felt this was a waste of resources. Inappropriate support.” (Offered telephone befriending service)

“Didn’t use anti-depressants as don’t like taking medication. Instead my counsellor told me to give up work as this was stressful. I did, and felt much better. Unwanted intervention.”

“I didn’t want medication, I wanted to mix with others in a similar situation.”



How quickly people were able to get the service they wanted

We asked people about the time it took for support to be put in place. We had some responses and accounts of support services being put in place quickly:

“Very fast, it was quick; my daughter found out about the group and made the arrangements.” (*Stroke survivor comment about a community support group*).

“Befriending - only had to wait a couple of weeks. Speech therapy - only lasted a short time as the therapist moved jobs and I carried on with my befriender.”

However there were a greater number of comments and responses that indicated people were dissatisfied with the delay in services being put in place.

“We were not offered any services until they were actually required. Got into financial difficulties, became suicidal - the stroke group said they were not surprised it happened.”

“Physiotherapy - would be better to go direct rather than via the GP, 6 weeks after coming out of the loop, then referred back again for another 6 weeks.”

“Approximately 16 weeks after my operation (to access an NHS-run rehabilitation group). *Bradford Heart Support Group*

“Waited many months.” (stroke survivor)

As a result of, on occasions, long waiting times for therapies or time limitations on treatment, people reported deterioration in their mental health and wellbeing as a result of stress and anxiety due to worrying about their condition, or not having appropriate information.





How long did the service last, was it time limited?

In the groups we attended, while speaking positively about the support offered by physio and speech therapists (particularly following a stroke) people often said they felt that this was too limited, and they would have liked rehabilitation support to carry on for longer or later on in recovery.

This was also evident in some survey responses:

“Approximately 4 weeks. I needed something else.”

“Intermittent. not enough, not even adequate”

Others told us that although the support was time-limited, they had felt it was enough for them.

“8 weeks - very informative, adequate.”

“Time limited to a number of sessions. I was ready to be more independent when it finished.”

A small number of people described support being available to them whenever they needed it. Being able to call on support as needed seemed to give people a more positive experience - clearly this depends on the nature of the intervention.

“(As a child) I could access services whenever I wanted and it was not time limited - the professionals visited me at home for hourly sessions. But when I moved from school to college the sessions were limited to 6 weekly programmes.”

“Counsellor visited at home and then came to the exercise class - was always on hand, and I could phone whenever I wanted.”

Some people said that support was not offered at the right time, that they did not feel the need for input until later on in recovery, but by that time nothing was offered.

“Sometimes it’s better to have physio later on - say 12 months later when things have settled and you know where you are.” (Shingley Stroke Group)

“Both physio and speech therapy helped but did not continue for long enough as I needed help and support for longer to regain speech. When my carer asked for another referral to speech therapy this was met with an angry response that we had asked for more input and no one became involved to help.” (Survey)





What was good?

We asked people to tell us what support they had found most helpful:

Many people commented on the valuable impact of help provided by family and friends.

Professional community support was well received; nearly two-thirds of the open text responses in our questionnaire referred to rehabilitation services such as physiotherapy or speech and language therapy as helpful to their emotional wellbeing and mental health.

“The physiotherapists gave me the most emotional support.”

People were very positive about peer support from groups, often run by charities or small community organisations. A third of the questionnaire responses highlighted the continuing need for dedicated support groups where people can meet with others in a similar situation and commented that it was even more informative when the groups were attended by advising professionals .

Many more of those interviewed on a one to one basis or in groups also supported the need for such peer groups, saying they helped alleviate feelings of isolation and anxiety.

“(I attend) two Stroke support groups. I also went to a balance group held at Westwood Community Hospital for 6 weeks which helped me to regain some self-esteem as I was left unable to walk and with slurred speech.”

“Shipley stroke group, being here among friends, activities. The people who run the group are very helpful and caring. It builds your confidence and makes you feel lovely, keeps you going.”

“Befriending gave me the confidence to go out again and to attend a support group for stroke survivors. The support group for heart failure also helps - I gave myself 3 months to attend but still attend after several years.”

“It's all very scary at first you think you are going to die. For me it was being in contact with other heart failure patients and Pumping Marvellous that helped.”

Although peer support groups were seen as invaluable by those who attended them, concerns were expressed at the lack of funding and as a result, possible cessation of these groups.

“I was referred to a stroke group by a physiotherapist. The group [is under] great stress because of the way the CCG cut off funding.”

Respondents were asked to comment on referrals for professional help offered following diagnosis in the form of therapies. Of those who were offered and accepted help, most found it helpful and one response via the online survey commented:

“Counsellor visited at home and then came to the exercise class - was always on hand, and I could phone whenever I wanted.”



What was less good?

We asked people what support had been less effective:

Some of those who replied felt that the referrals to psychological therapy had limited benefit, largely due to the lengthy waiting times for referrals and the limited sessions that could be offered. When therapies were offered people felt they were helpful, but people complained that when therapies came to an end there was nothing else put in place to support them, even though they had not recovered.

“Referral to psychiatrists was a waste of time, waiting 6 -9 months. At one point Bradford council had a social worker in the Airedale stroke ward who could refer you to a clinical psychologist - no longer applies.”

“Psychology service was of limited help. It might have helped if it had continued.”

“I had Speech & Language Therapy but they missed visits. I was told would have twice weekly visits for 6 weeks, but they have two weeks holiday (so missed 4 visits). I asked them to make up these missed visits but they didn't.” (Keighley Stroke Group)

“For six weeks after discharge from hospital got massage, Speech & Language Therapy and 2 weekly visit from psychologist, all good. After that stopped, didn't hand me on to anything else.” (Keighley Stroke Support Group)

“I started moving up hill, but then (after 6 weeks) was left with nothing. Awful being left high and dry - you're just lost and don't know what to do.” (Keighley Stroke Support Group)

Some respondents felt that GPs relied too much on prescribing medication to address people's mental health needs -people said they didn't want anti-depressants but no other options were explored or offered when they approached their doctor about depression. People said they thought that being referred to peer support groups by the NHS would have been more helpful, but this kind of support was not offered or recognised by professionals.

People told us that there was little or no information provided at point of admission, during recovery or on discharge - either about the likely effects of their condition or what support would be available afterwards. This leaves people feeling anxious and frightened about their futures - a feeling of having to “go-it-alone”.



What else would have helped, ideas for improvements?

We asked people to think about what would have improved their experience:

The strongest theme was a need for more information about where to go for help particularly on discharge home.

“It would have helped to have more information on what is available in the area in terms of support groups and self-help groups - my family found out for me but I was not given any information on what was available. I wanted to regain my independence and stay as busy and as active as possible but I didn't know where to go to access anything.”

“Clear information on discharge in the form of a comprehensive pack to include support in the area - such as support or self-help groups or balance groups (such as the one run at Westwood Community Hospital in Cooper Lane) and these should be self-referral schemes rather than needing a formal referral from a GP. An information pack would be a good idea.”

Many people also talked about practical issues where advice and support could have reduced the stress and anxiety experienced by patients and their families, particularly in regard to money and employment.

“I have paid all my life into the National Health Service and got nothing back when I had my stroke. I was working at the time but then couldn't work and got no help or information on benefits and as a result fell into depression. I had to fight for DLA and this wasn't easy when I was not well at the time. There needs to be some way of getting information to people to avoid them worrying about things like financial pressures and how to apply or who to go to get benefits advice as this aspect was really stressful and did not help my mental health at all and I am now on anti-depressants.”

“Some advice about money because I was so worried as alone and unsupported and needed advice to stop me feeling suicidal.”

“I am the sort of person who likes to be out and about and this was difficult as I was left with no mobility until it returned but this was through sheer hard work on my part. I was not given any financial advice despite that I was working full time at the time of my stroke and was unable to support myself financially. My husband could not claim carers allowance as he was too young which meant that I had to rely on savings. I don't feel there is enough support around financial matters when you are left with such disabilities. I was turned down for Disability Living allowance which left me with serious financial problems and for which I received little to no help at all.”

People suggested the need for more specialist nurses working in the community, whose expertise in stroke or heart failure coupled with their knowledge of each individual patient enables them to recognise people's mental health needs and put appropriate support in place.

Several people referred to how helpful it would be if staff who understood the conditions, or volunteers who'd been through similar experiences, could help people understand what to expect following diagnosis. Healthwatch understands that there used to be a scheme where volunteers (who were stroke survivors themselves) visited stroke wards to "buddy" existing patients, and some people we spoke to expressed an interest in visiting wards for this purpose because they felt it would be valuable.

People talked about how important it was for their wellbeing to be able to get out of the house, and how difficult this could be, particularly after a stroke. People are unable to get a 'blue badge' for parking after a stroke because although they often have severe mobility problems, they are not permanently disabled and may recover. It was suggested that consultants should be able to issue temporary badges; this would help in the initial stages for those who are left unable to walk, and the families caring for them.

"I think having an emergency badge scheme would be really beneficial as when you have a stroke some are left with no mobility and even if one could be given for 3 months it would help aid recovery and if able to get out and about easily it would help wellbeing."

"I also think that there should be some help support and advice at the point of discharge - I was given nothing in the way of advice. Some of the support groups are willing to go into hospital wards and help others who are left severely debilitated but this is not funded and really they are doing the job of a professional - such groups should be funded so that they can offer help and support to others - in the longer term this would pay off."





Our recommendations

Based on the feedback we have received from patients, carers and staff, along with the observations made by the Healthwatch team, we have a number of suggestions for improvement. We would like providers and commissioners to respond to these recommendations.

- Support for mental health should be built in to the patient pathways for long-term conditions, so that it is routinely offered to people rather than leaving patients and carers to seek out support for themselves.
- Mental health services such as psychology, psychiatry or counselling should be integrated into the care of people with long-term conditions, both in hospital and in the community.
- Commissioners should consider increasing the level and scope of NHS community rehabilitation services to meet the evident needs of people with long-term conditions, reducing waiting times and ensuring services are delivered for long enough.
- Commissioners from the NHS and the Council should consider how they can provide more funding to community and voluntary sector support groups, as they are clearly providing important services but need more support.
- Better information should be developed about the support available in the community from both statutory and voluntary services for patients and families. This should be consistently provided at discharge from hospital or at the time of diagnosis.
- Sources of advice on money, benefits, employment and other practical matters should be identified, and this information should be routinely offered to patients and carers.
- Services should work with support groups to recruit volunteers with direct experience of living with long-term conditions to operate a “buddy” scheme; this would assist with providing information and practical advice for patients and their families.
- The transport and mobility issues facing people after stroke should be addressed, including looking into how people could obtain a temporary ‘Blue Badge’.
- When addressing the mental health needs of patients with long-term conditions, professionals should take a holistic approach and recognise the benefit of social activity and peer support alongside talking therapies and medication.

Healthwatch Bradford and District will continue to listen to people’s experiences of care and support for both mental and physical health when living with long-term conditions. We’ll continue to work positively with local commissioners and providers to help ensure these views can influence the way services are planned and provided.

Case study 1

Mrs B talked to Healthwatch about the experience of her husband, who had a stroke last year aged 57. She described how the stroke had a huge impact on her husband, and the whole family.

"The mental health impact of stroke is huge - my husband has gone from a fit, active, working man to being incredibly disabled overnight."

Her husband was young when he had the stroke, and it was difficult to come to terms with his sudden illness.

Mr B was treated initially at the Hyper Acute Stroke Unit at Bradford Royal Infirmary, and then at St Luke's, on a combined ward which cared for a mixture of stroke patients, neurology patients, and elderly care patients.

Mrs B says that most other patients on the ward were much older than her husband, and many were suffering from dementia. Being cared for in this environment had a strong negative impact on her husband and how he felt; it was hard for him to envisage recovery and he would have benefitted from being among other patients 'who were more like him'. She feels that the hospital combining stroke, neuro and elderly care wards was a bad idea and that it doesn't enable staff to meet the needs of each patient group properly.

She feels that the ongoing psychological support for stroke patients is very poor.

"The acute care in hospital is so good. The ongoing rehabilitation is nothing like as good, but it's every bit as important for the patient's life. There's no emotional or psychological support.

"Even the self-help groups like the Stroke Association have lost their funding, so there's nothing local to me where we can go for help and advice - just what I can find online."

Mr B was discharged back to the care of his GP after he left hospital. Mrs B was very concerned about her husband's low mood, and encouraged him to ask his GP about psychological support. The GP was dismissive and told him that it was 'all about positive thinking' and 'recovery comes from the heart'. This discouraged her husband from seeking further help or talking about his feelings. Eventually her husband was prescribed anti-depressants but she says this feels very difficult for her husband to accept as he's 'not the kind of man to admit to struggling'.

Mrs B feels strongly that stroke patients should see a trained psychologist who understands the impact of stroke, and that this should be a routine part of rehabilitation so that patients don't feel the stigma of asking for help.

"Mental health is simply not commissioned for stroke patients. There should be specific, specialist psychological support in place as part of rehabilitation.

"I feel like once they've got you out of hospital, that stroke is not important; it's a forgotten condition. But stroke is such a common occurrence, and more must be done to help people, especially younger people who have lots of their lives left ahead of them, to recover mentally as well as physically."

Case study 2

Mrs S had a stroke in 2012. She worked full time as a nurse in a GP surgery, her stroke left her unable to walk and with speech difficulties. She quickly ran out of sick leave and had to leave her employment as she was unable to work.

Mrs S was cared for on Ward 9 at Bradford Royal Infirmary; she describes generally good treatment in hospital. However some aspects of care were lacking and contributed to her feeling very low, for example during her stay in hospital Mrs S was offered only one shower in 6 weeks and this was just prior to discharge. She said it felt amazing to have a shower after so long, and she feels it would have helped improve her wellbeing if she'd been supported to have a shower sooner.

When Mrs S was discharged from hospital, she felt in a daze and was frequently tearful. No professionals picked up on this and she did not feel able to do anything about it; not knowing if how she felt was depression or connected to the stroke.

Following discharge she received one visit from the Stroke Specialist Nurse who told her about a stroke group in Wibsey, but it was too difficult for her to travel because she couldn't walk and needed to use a wheelchair after her stroke.

Mrs S was also told that there was a monthly meeting in the physio department at the hospital, however when she turned up at the hospital she couldn't find the group. She went onto the stroke ward to ask where it was, but no one knew anything about it, so she had a wasted trip and went home without finding the support group. Mrs S found out afterwards that it was downstairs in the building, but no one on the stroke ward knew it existed.

Mrs S later attended Whetley Hill Resource Centre on a 'back to life' course which was a 6 week course covering diet, computers and exercises. She found this useful, but doesn't think this service is available any more. The group enabled her to meet others in a similar situation and this helped her deal with what had happened to her. It was here that she found out about a local support group in Bradford, which she now attends.

Mrs S feels that one thing which could make a real difference is better advice about money and benefits.

"Trying to find out about benefits is a minefield, I found it very frustrating. I was very worried about money and anxious about my family's future."

Mrs S couldn't get access to her pension as the age limit had just changed, and her husband was unable to get carers allowance as he was too young. It took her nine months to get any benefits even though she was significantly disabled by the stroke.

Mrs S described her frustrations at not being able to get a blue badge. She was refused because she 'might get better' and was not permanently disabled. She says that if she could have had a badge only for a few months this would have helped. Being able to get out and about more easily would have made a real difference to her emotional wellbeing and recovery.

Case study 3

Mrs A was diagnosed with Atrial Fibrillation in 2009, and in June 2013 had a stroke.

“The impact on my life has been limited because I make sure that I am as active as possible and go out nearly every day. I also attend two groups - one for AF and one group for stroke, both in the Keighley area.

“The support from the NHS for my mental health and wellbeing was non-existent after both the AF diagnosis and my stroke. My family found out about the support group, telephone helplines and I recall having some input on financial matters but cannot recall from whom. All support was found through my family.

“I was in touch with a “befriender” who visited me several times over a number of weeks to help me go out, and also took me to the first meeting of the local stroke group. I felt I couldn’t go to this alone as I was worried I would feel uncomfortable.”

After the first visit I felt fine to attend and the help provided was really useful.

Mrs A’s family sought out the befriending support service, and made all the arrangements soon after she was discharged. She says it was a shame that they could only offer a limited number of visits but that as a result of the support she felt ready to be more independent.

Mrs A finds the difficulty she has with written information still has a significant impact on her life, and she has not been given any support with this from the NHS.

“Having my stroke left me with difficulties in reading and understanding what was written, both on paper and on my computer. I couldn’t make sense of the words in front of me. This creates problems for me when reading household bills and other things. I couldn’t find any real support to help me with suddenly losing the ability to read and feel that any assistance with this would have helped tremendously.

“My befriender tried to help me to regain my ability to read and understand what was written down but there was no formal help offered with this and it was so unexpected.”

Mrs A felt that the clinical care whilst on Ward 5 at Airedale Hospital in 2013 was excellent but she would have preferred to have more information about what the effects of stroke might be, and what to do if she experienced symptoms in the future.

“Recently, I had the feeling that I might be having another stroke. I was alone, I didn’t know what to do, and I was worried. As it was a Friday I knew that my GP would close over the weekend, so I waited and visited on Monday. My GP didn’t know what to do either so I was asked to go home and my GP said she would contact me later when she had checked out what to do. She rang me back a couple of hours later and asked me to go to Airedale hospital. I didn’t think I had any obvious symptoms but kept walking into walls and feeling odd. When I was seen at hospital I was told I had had another stroke and sent home.”

Appendix 1:

Our way of working and who we spoke to

Healthwatch visited six support groups for the two conditions mentioned, carrying out group discussions with a total of 101 people. At these groups, some people also completed individual questionnaires - so there may be some overlap between comments made as part of group discussions and those given individually.

Healthwatch staff also carried out in-depth interviews with ten people to talk on a one to one basis. These were people whose mental health had been deeply affected, or who wanted to share detailed personal stories, or who had specific cultural perspectives which we wanted to understand.

We set up an online survey via Survey Monkey; this was featured on our website and sent out via e-bulletins and social media. Respondents could fill this survey in independently or with assistance from Healthwatch staff.

Healthwatch visits to groups:

● **ShIPLEY Stroke Group:** 1 October 2015

14 men, 15 women, including both carers and stroke survivors. Three small discussion groups followed by one to one questionnaires.

● **Keighley Wellness Group:** 19 October 2015

28 women and 11 men attended this group. They were given overview of project by Healthwatch staff, and given individual surveys to complete.

● **Creative Arts Stroke Group:** 20 October 2015

2 women and 3 men took part in a group discussion and completion of questionnaires with support from Healthwatch staff.

● **Khidmat Centre:** 2 December 2015.

4 South Asian men, individual stories, two of whom had experienced a stroke, one had a diagnosis of heart failure and one had another long-term condition that had affected his mental wellbeing.

● **Bradford Heart Support Group,** 5 January 2016

9 women and 4 men attended this group.

● **Keighley Stroke Group,** 13 January 2016

11 people attended, 7 women and 4 men; these were nearly all people who had strokes but with one or possibly two carers.

Healthwatch staff carried out 10 one to one interviews.

Survey respondents:

There were 55 responses to our questionnaire, not all complete. 33 people told us about their condition or caring situation:

- Heart failure 27% (9 people)
- Stroke 73% (24 people)
- Carer of person with heart failure 6% (2 people)
- Carer of person with stroke 9% (3 people)

The year of the stroke or diagnosis of heart failure varied from 1991 to 2014. One person had a stroke at birth in 1995. Another person said they had a heart attack as a result of chemotherapy. The majority simply provided the date.

Our questionnaire asked if people had an additional long-term condition:

- 7 people also had diabetes
- 4 also had asthma
- 4 had orthopaedic conditions or arthritis
- 2 also had cancer

Appendix 2:

Extract from a report by Kings Fund & Centre for Mental Health (February 2012)

Long-term conditions and mental health - the cost of co-morbidities

Chris Naylor, Michael Parsonage, David McDaid, Martin Knapp, Matt Fossey, Amy Galea,

Key messages

- Many people with long-term physical health conditions also have mental health problems. These can lead to significantly poorer health outcomes and reduced quality of life.
- Costs to the health care system are also significant - by interacting with and exacerbating physical illness, co-morbid mental health problems raise total health care costs by at least 45 per cent for each person with a long-term condition and co-morbid mental health problem.
- This suggests that between 12 per cent and 18 per cent of all NHS expenditure on long-term conditions is linked to poor mental health and wellbeing - between £8 billion and £13 billion in England each year. The more conservative of these figures equates to around £1 in every £8 spent on long-term conditions.
- People with long-term conditions and co-morbid mental health problems disproportionately live in deprived areas and have access to fewer resources of all kinds. The interaction between co-morbidities and deprivation makes a significant contribution to generating and maintaining inequalities.
- Care for large numbers of people with long-term conditions could be improved by better integrating mental health support with primary care and chronic disease management programmes, with closer working between mental health specialists and other professionals.
- Collaborative care arrangements between primary care and mental health specialists can improve outcomes with no or limited additional net costs.
- Innovative forms of liaison psychiatry demonstrate that providing better support for co-morbid mental health needs can reduce physical health care costs in acute hospitals.
- Clinical commissioning groups should prioritise integrating mental and physical health care more closely as a key part of their strategies to improve quality and productivity in health care.
- Improved support for the emotional, behavioural and mental health aspects of physical illness could play an important role in helping the NHS to meet the Quality, Innovation, Productivity and Prevention (QIPP) challenge. This will require removal of policy barriers to integration, for example, through redesign of payment mechanisms.



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