

SPRING 2012

Stroke
association



Struggling to recover

LIFE AFTER STROKE CAMPAIGN BRIEFING

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'Struggling to recover', the Stroke Association, May 2012

[#lifeafterstroke](#)

www.stroke.org.uk/campaigns

Stroke: the facts

Each year around **150,000** people in the UK have a stroke and approximately **53,000** people die from the disease. Stroke is the UK's third biggest killer after heart disease and cancer.

Over the past **20 years** there has been a growing recognition that stroke is preventable and treatable, rather than simply a consequence of ageing that results in death or severe disability.

Thanks to progress in stroke prevention, research and care, stroke mortality rates are now about a third of what they were 40 years ago. The incidence of stroke is also falling.

Stroke can happen to anyone. **Three-quarters** of strokes happen to people aged **over 65**, but it can affect people of working age, teenagers and even babies in the womb.

Although the impact of stroke varies from person to person, it has a greater disabling impact than any other chronic disease. Stroke is the **single biggest** cause of severe adult disability in the UK.

Half of all stroke survivors are left with a long-term disability, living with a range of physical, communication, cognitive and psychological issues. Managing the effects of stroke can be even more complex if the survivor has other health issues as well.

Over a million people in the UK are living with the effects of stroke and over **300,000** survivors have a moderate to severe disability as a result.

Introduction

Why 'life after stroke' matters

'Struggling to recover' tells the story of eight UK stroke survivors coming out of hospital, and the challenges they face getting on with their lives. Their stories are inspiring and at times sad. Their stories also show the huge barriers that stand in the way of people being able to resume their lives after stroke. We believe these barriers can and must be overcome.

In late 2011, we set up a survey that saw over 2,200 stroke survivors and carers talking about every aspect of their daily lives. The findings are presented throughout this briefing.

In this briefing, you will hear how survivors are not getting assessments of their health and social care needs when they leave hospital, or afterwards. This leaves survivors unable to access help at home or ongoing health support that could make a huge difference. Carers recount how the health and social care systems are hugely complex to navigate and how too many professionals still do not understand the hidden side effects of stroke.

Getting these basic things right could transform the lives of many people and their families. It could also benefit local health and social care economies too. That is why we have launched the Life After Stroke campaign, to bring about changes to help more people make better recoveries after stroke. We hope you will join us in making this happen.

Survivors are also experts in stroke as they live with its impact 24 hours a day. They know what they want to achieve and the help they need. Throughout the briefing you will see mention of the Stroke Survivors Declaration. This is the work of over 120 survivors, setting

out the help they believe they should be able to expect after leaving hospital. All our recommendations for action (aimed particularly at those who plan and provide health and social care) are based on what stroke survivors have told us make the biggest impact on their recovery.*

At the Stroke Association, we are for life after stroke and it runs through everything we do. Our work includes helping people at risk of stroke know how to better prevent it, funding ground breaking research, campaigning for change and providing support to over 35,000 stroke survivors across the UK through our Communication and Information, Advice and Support Services. We believe all stroke survivors should be supported to make their best possible recovery and we will campaign until this has been achieved.

The Life After Stroke campaign is not about new policy or special pleading for stroke survivors – instead it is a call to action for all who care about stroke survivors to deliver on promises already made – and so realise benefits for stroke survivors, their families, and the wider economy. You will find recommendations for action on page 44 of this report.

You can help make this happen by signing up at www.stroke.org.uk/campaigns. Together we can help more people across the UK make better recoveries from stroke.

Jon Barrick
Chief Executive
Stroke Association
MAY 2012

*A full copy of the declaration can be found online at www.stroke.org.uk/campaigns

Kate Allatt's story

Why you should never, ever write off stroke survivors

In February 2010 Kate Allatt had a massive stroke. A working mother of three, 39-year-old Kate had ignored the warning headaches, and by the time her husband got her to hospital, her sight was blurry and her speech slurred. She had a clot, and just a few hours later was given a 50/50 chance of survival.

"When I came out of the coma three days later, I panicked. My body was completely paralysed except for my eyes. My brain was fully functioning and I could see, hear and understand everything going on around me in the Intensive Care Unit, but people assumed I was brain damaged."

Yet nine weeks later, Kate was off the critical list and moved to the rehabilitation ward. Kate's family were told she would never walk or talk again and she should be moved to a nursing home. Communicating initially by blinking, Kate spent days looking at her limbs willing them to move.

"Gradually I regained flickers of movement in my right hand, which I was able to work on with physiotherapy exercises like playing with putty to strengthen my grip. Soon I was able to use a computer and Facebook

and through this was able to communicate with my family and friends. It gave me a lifeline."

With months of physiotherapy, Kate managed to sit up. "I pushed myself hard during my therapy sessions. I would never admit I was tired."

In July that year she spoke her first words and by September she'd made the emotional journey home. "At home I started practicing walking, holding onto the kitchen 'island'; I also began a gym routine. At first I had trouble balancing on the treadmill, but as my confidence grew I was able to let go of the handrail and speed up."

By the end of November Kate had said goodbye to her crutches and promised herself that she would run again. In February 2011, a year to the day after the stroke, she ran her first 20 metres.

"Winston Churchill once said 'success is not final, failure is not fatal: it's the courage to continue that counts'. I keep these words in mind and share them with other stroke survivors."

"...as my confidence grew I was able to let go of the handrail and speed up".

"I pushed myself hard during my therapy sessions. I would never admit I was tired".

What people tell us about life after stroke

In this briefing, stroke survivors across the UK say they want more help to make their best possible recovery. Recovery is a charged and often complex word. For most stroke survivors it's not about going back to how they were before the stroke. Survivors have told us that, for them, recovery means being supported to get on with their lives and achieve the best possible, individual, quality of life. The goals we heard about were huge and diverse. Stroke survivors told us that recovery included wanting to:

- be able to say a daughter's name
- remember how to enter a pin number at the checkout
- pick up the children from school
- walk without someone's help.

Every day we hear stories of the goals survivors set and meet on their recovery from stroke. The Life After Stroke campaign aims to ensure even more stroke survivors are able to achieve their best possible recovery, once they leave hospital.

The Daily Life Survey

During late 2011, the Stroke Association undertook one of the largest ever surveys of stroke survivors and carers in the UK – the Daily Life Survey. Most responses came from England (78% – 1,738 people), Wales (9% – 206 people), Scotland (3% – 72 people) and Northern Ireland (1.5% – 34 people). Half of those responding had experienced their stroke in the past three years.

The survey looked at all elements of what life is like after stroke and reveals the immense barriers people face on their journey to recovery. The purpose of the Daily Life Survey was to better understand this phase. What daily challenges do people face? What support do people receive at home? Does that support meet their needs? What is the experience of caring for someone who has had a stroke?

Throughout this briefing, data are mentioned from the **Daily Life Survey** – data tables are available online at stroke.org.uk/campaigns

Some of the things survivors and carers said make tough reading:

Too many survivors are not being assessed for their health and social care needs beyond hospital – and so are missing out on services that could help them recover

- A single joint assessment aims to assess the ongoing health and social care needs of stroke survivors, making it the gateway to services. Its absence means that many stroke

survivors may miss out on services (physiotherapy, speech therapy, or help with washing and dressing) that could help them maintain their independence at home.

- In England 39% had not been offered an assessment for services, in Northern Ireland it was 24%, while in Scotland and Wales the figures were 45% and 44% respectively.

Of those who had received an assessment of their needs, 7 out of 10 had not received a care plan

- A care plan establishes how an individual stroke survivor will work with (and be supported by) health and social care to best manage their health after leaving hospital.
- All stroke survivors should be getting a care plan, yet in England 60% of people who had received an assessment had not received a care plan. In Northern Ireland, 46% had not received a care plan, while in Scotland and Wales the figures were 71% and 64% respectively.

Ongoing reviews of survivors' health and social care needs are happening all too infrequently

- Best practice in each of the four nations states that stroke survivors should have their health and social care needs regularly reviewed at six weeks after leaving hospital, six months and then annually. This allows them to access the right support.
- In England 47% of respondents who had received a review had only ever had one review, in Northern Ireland this was 40% while in Scotland and Wales the figures were 39% and 54% respectively.

Survivors report access to therapies as too brief to enable best possible recoveries

- Of the 539 people who answered a question about support from the NHS, 43% wanted more support, with physiotherapy (29%) cited as the biggest priority.

Survivors and carers are missing out on vital sources of free support and information

- Survivors and carers are not always being made aware of free sources of information and help. In England, nearly 30% of respondents were not aware, in Northern Ireland this figure was nearly 25%, with Scotland and Wales standing at 33% and 35% respectively.

Survivors and carers want support to stay at home, but often feel very isolated

- Across the UK, being supported to be able to remain at home is highly valued, with 97% of respondents rating it as quite or very important.
- Stroke has a huge impact on people's wellbeing, leaving many feeling lonely and isolated, with 74% reporting they have not been able to get out as much as before.
- 40% of carers said they had not had an assessment of their needs, because they were unaware they had a right to one.

Services stroke survivors rely on are being reduced or withdrawn, with big impacts

- 25% of respondents receiving services in Northern Ireland reported that the services they relied upon had been reduced or withdrawn in the previous 12 months, even though their needs had remained the same or had increased. In England the figure was 18%, Scotland 10% and 18% in Wales.
- Across the UK, the 212 people responding to this question said these changes affected their personal finances (27%), slowed down their rehabilitation (16%) and led to more work for their carer (11%).

Health and social care often fail to join up for the benefit of stroke survivors, causing problems

- Across the UK, 48% of survivors and their carers reported problems caused by either poor or non-existent co-working between health and social care providers.
- 48% of people living in England reported problems due to poor/non-existent joint working. This figure was 59% in Northern Ireland, 51% in Scotland and 50% in Wales.

The barriers faced by stroke survivors and their families are compounded by limited understanding of stroke

- Across the UK, 85% of survey respondents said those they come into contact with do not understand the impact of stroke on their daily lives.

Moving forward

These findings present a challenge to all who plan and deliver health and social care, as well as those who care about stroke survivors, to work together to improve the lives of stroke survivors and their families.

Over the past five years, the health systems across the UK have dramatically improved how stroke is treated, particularly in the acute/hospital phase. Stroke is now almost always treated as a serious medical emergency and more people are surviving as a result. This was made possible by strategies and initiatives from national governments, as well as clinical leadership at a local level. This in turn has led to a reduction in deaths and significant value-for-money savings.

At the Stroke Association we believe it is not new policy or money that is needed, although the passage of many of the biggest improvements in acute care was made significantly easier through ringfenced funding – particularly in England.

In essence what we want to see is better application of what stroke survivors and their carers should already be able to expect – whether it is assessment, a care plan, or support for carers. Crucially these must result in action.

Getting these basics right is better not just for the individual but also local health and social care economies too. The National Audit Office for England cites how Early Supported Discharge (ESD) for stroke survivors from a hospital

ward to home with support “can reduce long-term dependency and admission to institutional care as well as reducing length of bed-stays.” (**Progress in improving stroke care**, NAO, 2010)

The key challenge is for those planning and delivering health and social care at the local level to now turn their attention to the post-hospital recovery phase, and ensure that health and social care services join up as well as possible for the benefit of stroke survivors – enabling more people to make better recoveries.

Ann Frewer's story

Why it is vital to follow through for people who have had a stroke

"Sometimes I hear this called 'care in the community'. The reality is that it's more like sending you to prison. If you are on your own, it's more like solitary confinement."

These are the feelings of former nurse Ann Frewer, 75, on the care she's received since her stroke in November 2011. "When I came out of hospital I was not given any care package. I was told to ask my neighbours for help, and if it had not been for their kindness, I would be sitting at home on my own, starving to death, as I cannot walk more than 150 yards."

Ann, a widow, has vivid memories of the stroke itself, through which she was conscious the whole time. After two months in hospital following the stroke, she was discharged without a care plan or any follow-up appointments at the hospital where she had been treated.

Before her discharge, an occupational therapist and a physiotherapist visited her home so they could assess if it was suitable for her return. They agreed it

was, with a few adaptations, including handrails, a chair lift, and a walk-in shower. When Ann came home she found a handrail at the front door and another upstairs, but none of the other adaptations. Ann has had to pay for a number of adaptations herself, including a stair lift.

Ann has also had no help with her health, though she still has a very severe problem with involuntary movements. The only healthcare she has received has been at her own instigation, and she will soon be attending a Mobility Disorder Clinic on the NHS because she self-referred privately to a neurologist.

While Ann has been provided with access to Dial-a-ride and the blue badge scheme, with help from two social workers, she has had no support with shopping or anything else.

"Luckily I have some savings to pay for the help I need, but there are many other stroke survivors out there who don't, and who are suffering."

"When I came out of hospital I was not given any care package."





Leaving hospital after a stroke

Stroke survivors want support to be able to stay at home

Ann Frewer's story shows that the transition between hospital and home can be traumatic for stroke survivors as they adjust to a life in the community. Many have to learn to live with uncertainty and the feeling that they have lost control over their lives.

It is vital to ensure a smooth transition and particularly continuity of care (across health and social care) to help relieve this stress, and to attempt to plug gaps between the service received in hospital and the services some survivors are able to access once they get home.

Respondents to the Daily Life Survey said that living at home is highly valued, with 97% of respondents rating it as quite or very important. Most of them wanted services to help maintain their independence (86% and 73% rated these as quite or very important respectively), and feel part of the community. The challenge is how to ensure more survivors can be supported to stay at home.

This journey starts with more health and social care services taking the time to understand what a survivor and their family need to lead an independent and dignified life. If we can get this right it will also benefit those planning and providing services, avoiding crisis readmission to hospital or residential care.

"I was given a small amount of one-to-one therapy at home to get myself used to pavements,

hills etc. But there was no positive outcome as it was too short in time and I gained nothing, as I am still unsteady and not confident in walking at all."

(Stroke survivor)

Too many survivors miss out on care plans and assessments

Lynda Guest's story overleaf shows just how crucial it is for those doing the assessment to understand stroke and its impacts. The Daily Life Survey highlights that 85% of respondents thought those they came in to contact with did not understand stroke. The good news is that simple action could make a big difference – see the section on training (page 30), for more ideas.

Good support in the first weeks and months following a stroke enables people to be actively involved in managing their condition, helping them prevent further strokes and achieve their best possible recovery. Health and social care needs assessments are the gateway to stroke survivors getting the right support and services. These assessments should be then turned into a care plan.

Stroke survivors should have an assessment within six weeks of leaving hospital, six months and then annually. This is because people's condition changes, support needs change, and early diagnosis of change is important.

When I go home from hospital I will have specialist support

WHAT STROKE SURVIVORS WANT – FROM THE STROKE SURVIVORS' DECLARATION (POINT 3)

RECOMMENDATION

Care plan: All stroke survivors should be assessed to identify those who need ongoing support in the community and all those who do need such care should receive a care plan, which they should be involved in developing. This plan must result in meaningful action and say who to turn to if things are not working well.

Over a million people in the UK are living with the effects of stroke and over 300,000 survivors have a moderate to severe disability as a result.

Lynda Guest's story

Why better assessments are better for all

"Having a stroke was devastating and life-changing. My life needed a total readjustment."

Lynda Guest, 51, was at home when she had an ischaemic stroke in 2010. She was caring for her disabled husband Nigel at the time. He called 999 and she was rushed to hospital, where she says she received good treatment.

A career professional, Lynda had worked in community development. She was active before her stroke and had no physical problems, but her stroke left her paralysed down one side, and lacking in self-esteem.

Lynda says she received a healthcare assessment but describes it as "difficult to get" and a "very problematic" process. The social worker was casual and unprofessional, she recalls. "He went on about my mental health and undermined me," she says.

After the assessment, Lynda eventually "managed to get a care plan out of him [the social worker]". Initially the care plan did not meet her needs, due in part to its emphasis on her mental health.

"He went on about my mental health and undermined me."

Eventually a care plan that catered more to her physical disabilities was put in place – though it still took more than year for her to get a much-needed stair lift at home.

Lynda has started to regain her life after the stroke, and believes it has changed her life for the better. She's joined the Stroke Association's Positive Pathways course, and is the new secretary of the New Steps' Life After Stroke club in north Wales. **"I'm more determined now than ever before. My survival has made me re-prioritise what matters."**

"I'm more determined now than ever before. My survival has made me re-prioritise what matters."

RECOMMENDATION

Ensure survivors' needs are regularly reviewed: Stroke survivors must be assessed after leaving hospital and then reviewed on an ongoing basis as their health and social care needs may change over time – particularly for survivors whose stroke occurred a long time ago. Commissioners should consider the role the voluntary sector can play in helping with reviews.

I know that my needs will be reassessed after six weeks, then every six and/or 12 months, and as they change

WHAT STROKE SURVIVORS WANT – FROM THE STROKE SURVIVORS' DECLARATION (POINT 5)

"We do not receive any support from the NHS and cannot understand why some people get it while others don't. Unless you find out by word of mouth where to contact anyone, there is no after-support whatsoever." (Respondent to survey)

The Daily Life survey shows that more than a third of all respondents had not been asked if they needed an assessment or review of their needs. In England this figure was 39%, in Northern Ireland it was 24%, in Scotland it was 45%, and in Wales 44%. Of those that had received a review, almost half had had only one review, and only a third had actually received a care plan as a result. A further 28% said they had not received sufficient information and consequently didn't know who to turn to or where to go when they needed support.

One group of survivors needing particular attention are those whose stroke occurred a number of years ago. Their needs can be great – particularly if they are living with other conditions as well as the effects of stroke.

"My family and I had to fight for support, as on meeting me, I appear well. You cannot see the effects of brain damage as I am lucky to be able to speak eloquently and walk, which confused the social services. Social services need more training, education and empathy on not discriminating against invisible disabilities." (Stroke survivor)

Limited access to therapies limits people's recoveries

Without proper assessments, care planning or reviews, stroke survivors are not able to access key services to support them making their best possible recovery.

Our survey revealed that satisfaction levels with services received at home are fairly high. People value home adaptations and care assistants to help with personal care – when they can get them.

The Daily Life Survey highlights that while patients really value the support offered by physiotherapy, occupational therapy and speech therapy, the limited availability of these therapies – often because of rationing at a local level – causes problems and anxiety.

- Across the UK, of those answering a question about NHS support (539), 43% wanted more support, with physiotherapy (29%) cited as the biggest priority.

- This tallies with findings from the Stroke Association's helpline, where information on private physiotherapy is consistently among the top five most requested topics.

In England, 32% of respondents felt they did not get enough support from the NHS, while this figure for Northern Ireland rose to 43%; in Wales it was 35% and in Scotland 35%. (TABLE A9)

"After an initial six-week input of multi-disciplinary services – OT, physio, speech assessment – following discharge from hospital in 2005 I had nothing offered or provided. Left to get on with it!" (Stroke survivor)

The Stroke Association has long campaigned for a greater role for allied health professionals and has funded research into the most effective ways of delivering this care.

Previous work has included highlighting the contribution of physiotherapists (Moving On report), speech and language therapists (Lost without words campaign) and commissioning the Unmet Needs research (2010), which provided an insight into some of the health challenges faced by stroke survivors.

This research showed that more than one in five stroke survivors (21%) receive no after-hospital services such as community-based physiotherapy, or had a delay in getting them (38%). And of the 250,000-300,000 stroke survivors

who have a long-term communication disability as a result of their stroke, only 13% have access to communication support groups. Almost half the people who responded said their needs – in terms of information, mobility, pain management and speaking, among other factors – were not being met.

"Once you have your 12 weeks physio post-hospital, if you reapply for more it takes months to get and you're lucky if someone comes once every two weeks for half an hour. We were basically redirected to a specialist neuro-physio which, naturally, is private and unaffordable." (Respondent to survey)

Our Life After Stroke campaign, of which this briefing is the first part, builds on this work. We argue that the intersection between health and social care planning and provision is where the biggest benefits can be realised – for while hospital treatment is excellent, we believe there needs to be a greater role for allied health professionals, whether employed by primary or social care. The NHS London report, How allied health professionals improve patient care and save the NHS money, provides example of some of the economies that can be realised by greater involvement of allied health professionals working with stroke survivors.

RECOMMENDATION

Involve allied health professionals: Those who plan and deliver services should maximise the involvement of allied health professionals and other services that enable survivors to achieve a life after stroke.

Ruth Just's story

See the person not the symptoms

Ruth Just was 89 when she had a stroke in January 2011. Ruth's daughter Shirley says that although her mother was registered blind and hard of hearing, she was previously mobile and fairly independent.

While in hospital, Shirley was invited to a meeting to discuss arrangements for her mother's return home.

However, when Ruth left hospital, things didn't go according to plan. Somewhere along the journey Ruth fell and had to return to the hospital's A&E department with a gashed leg, cut to the bone on her right shin.

Without her family around her, Ruth was left on her own for six hours without food and unable to communicate because of her stroke. There were problems getting another ambulance, and Ruth was eventually returned home at 9pm with a slip of paper saying that "the patient appeared to be confused".

Shirley said that there was no follow-up for her mother's injury and that she had to contact the GP herself to request a district nurse to come and dress the wound. Shirley said it was a long process

to get a physiotherapist, and felt she had to "fight" for input from social care services.

Added to this, it took six weeks to get a suitable wheelchair for Ruth, and the speech therapy at the hospital was not very successful. Although the family received advice via leaflets, they didn't really feel supported. Shirley feels that had she not kept repeatedly "nagging", her mother would not have received certain aspects of care.

Ruth has since moved to live near her daughter, where she feels the health services are "miles better" – easier to access and much more positive. Ruth now walks with a frame but still uses a wheelchair. She has limited feeling in her right foot and her speech is slurred, but she is having speech therapy.

Somewhere along the journey Ruth fell and had to return to the hospital's A&E department with a gashed leg,

Ruth was left on her own for six hours without food and unable to communicate because of her stroke.



RECOMMENDATION

Get survivors and their families clear, targeted information as soon as possible after the stroke: Health and social care providers must ensure that stroke survivors and carers have access to all the information and advice they need, including how to access services and the help they can get. Planners and providers should consider the online and helpline resources of the voluntary sector, from organisations such as the Stroke Association, as 'at your disposal'.

Information helps people adjust better

Coming out of the relative calm and co-ordination of a hospital acute stroke unit can be a stressful and anxious time for stroke survivors. Providing good information helps people to make better choices. Clear information about stroke, the prospects for recovery, the support available and who to contact when the need arises is vital.

I will be given the information and advice I need, in the format I need, when I need it, to help me understand the effects of stroke and the support that might be available to me

WHAT STROKE SURVIVORS WANT – FROM THE STROKE SURVIVORS' DECLARATION (POINT 6)

Some help is rationed, but we believe that no stroke survivor or carer should be left alone to struggle. Even if they are not eligible for funded ongoing health and social care they should always be made aware, as a matter of course, of the free sources of help and advice available, for example from the Stroke Association helpline or Citizens Advice Bureau.

RECOMMENDATION

Make clear who can access social care: There should be clear and consistent eligibility criteria for social care. If someone is ineligible for support, they must be referred to free sources of help.

"At first I didn't know the effects of a stroke. It would have been good to be told what to expect i.e walking, working, getting about etc. What was life going to be like?"

(Stroke survivor)

Currently this is not happening as well as it should. The Daily Life Survey shows that nearly 30% of respondents in England were unaware of such free sources of help and support, while in Northern Ireland the figure was 25%, with Scotland and Wales standing at 33% and 35% respectively. (TABLE A8)

Ensuring stroke survivors and carers are supported to achieve a life after stroke

People (not system) first

Effective communication between health and social care teams is one of the most important aspects of stroke care. Joined-up working leads to better outcomes, independence and wellbeing for the survivor and their carer.

I can have confidence that my health and social care teams will work effectively together so that my care is seamless and well co-ordinated

WHAT STROKE SURVIVORS WANT – FROM THE STROKE SURVIVORS' DECLARATION (POINT 4)

When health and social care don't work well together, the result is a worse experience and this appears to be the case for at least half of all respondents to our Daily Life Survey. The problems caused by services not working together sufficiently (well or at all) was highest in Northern Ireland at 59%, followed by Scotland at 51%, Wales at 50% and England at 48%.

Through the survey we heard of missed appointments, meetings cancelled at the last minute and administrative errors

resulting in survivors not getting the support they needed. This left them and their families feeling as though they were seen purely as a series of health conditions rather than as people, keen to be supported to make their best possible recovery.

The Life After Stroke campaign calls for all stroke survivors to be able to access a named person to co-ordinate their health and social care needs. Each year, the Stroke Association provides such support to over 35,000 people affected by stroke, through our Communication and Advice, Information and Support services. Survivors have told us that being able to access such a person can make a transformative difference not just to their lives but to the lives of their carers as well.

For while this is the ideal, all too often families and loved ones are forced to act as the lynchpin, co-ordinating, lobbying and cajoling professionals in order to achieve the best possible outcome. This is not to undermine the many brilliant individuals often working within health and social care, more to say that if we are to make life after stroke a reality for all, there need to be systems in place to co-ordinate care around the individual.

RECOMMENDATION

Provide someone to help navigate the complexities of the system: Stroke survivors should have a right to a named person to co-ordinate their health and social care needs so they get met.

Ann and Donald Dunlop's story

The difference carers make

When Ann and Donald Dunlop got married in May 2000, they fully expected to enjoy a retirement full of activity and travel and a busy social life.

However, just eight months later, Donald had his first stroke. This changed everything, especially for Ann as Donald's stroke care needs took over her life. Ann was determined her husband would have the best care possible and through her local Health Trust organised intense home therapy for Donald as well as ongoing support from the community-based stroke team. However, her biggest challenge was yet to come when Donald had his a second stroke in December 2004.

Again, Ann endeavoured to ensure Donald received the best and most appropriate care. However, after the second stroke, Donald suffered a number of mental health problems for which it proved difficult to gain the right support and treatment. Faced with the knowledge that she was no longer able to fully support her husband's needs alone, Ann was persuaded to put him in a local nursing home.

Despite not living at home, Ann is still Donald's main carer, visiting him daily.

As a result, Ann's own health has suffered. With no family close by as her daughters live in Dublin and New York, she'd also given up her hobbies and had to deal with the stress of having to now manage the family finances which Donald had always done.

Despite the fact Donald is not living at home, Ann is still his main carer, visiting him daily, reading to him and keeping his brain stimulated. She ensures the staff keep him mobile and regularly lobbies for specialist equipment to keep him comfortable.

Her ongoing support for Donald has brought significant improvements to his memory, and as a result, his dementia has lessened and he has had some movement return to his hand. Despite the severity of his disability, it is easy to see that Ann brings quality and hope to Donald's life. Ann has also investigated alternative therapies and devotes any spare time she has to promoting improved care generally for stroke survivors.



More people need to recognise carers as partners in care

"My GP has been brilliant for me these past few years. Balancing my blood and monitoring my poor circulation on the left side of my body... I was receiving physical and occupational therapy for over four years."

(Carer responding to the survey)

By widening access to stroke co-ordinators, not only can we achieve better outcomes for individuals but also begin to tackle the lack of understanding among health and social care professionals of stroke and its impact, and the problems this causes (see section 3 for more information).

If I have a carer, they will be informed of their right to an assessment of need

WHAT STROKE SURVIVORS WANT – FROM THE STROKE SURVIVORS' DECLARATION (POINT 5)

While carers like Ann Dunlop do amazing work, many do so to the detriment of their own health and wellbeing. Across the UK, all carers should be made aware of their right to an assessment of their needs as carers. Yet on this issue, local authorities appear to be falling short.

The Daily Life survey shows that 40% of respondents with a carer said their carer had not received an assessment of their needs because they were unaware they had a right to one. In Northern Ireland, this figure was 66%. Although this is only

a very small sample (18 respondents only), this is still not good enough.

In England, Scotland and Wales the figures stood at 37%, 51% and 51% respectively. This shows there is still a huge amount of work to be done ensuring carers are not forced to sacrifice their health and wellbeing when caring for a loved one.

"I feel stressed when at work, hoping my mum is all right at home alone. When I have to get up in the night to help her, I am very tired the next day and cannot concentrate properly. This has a knock-on effect on my job."

(Carer)

Getting the right services and people in place

Ditch outdated assumptions

Assumptions are sometimes made too early about stroke survivors' recovery potential.

The tendency to see people as passive recipients of care – or worse as stroke victims – rather than people with aspirations to get on with their lives is still too pervasive. Survivors have told us that this can lead to a lack of ambition in their care and support, and influence the decisions that those who plan and deliver services make, and threaten key services.

For many recovery is possible. Stories of people feeling abandoned when they lose the emotional and practical support they receive in hospital must become a thing of the past. People make their own best individual recovery when carers, families, friends and talented, dedicated and skilled professionals (across health and social care) and the voluntary sector work together to meet the needs of stroke survivors. For while stroke is traumatic for stroke survivors and their carers (indeed it can turn their world upside down) people are also amazingly resilient.

Others tell us of being excluded from rehabilitation and written off as 'no rehabilitation potential'. Some go into care homes prematurely and consequently have very limited, if any, access to occupational or physiotherapy even though research has shown the difference such therapies can make.

Those of working age who do not receive appropriate support are often denied their potential to return to work.

Cutting services is a false economy

Services stroke survivors rely on are being withdrawn or reduced with huge impacts. 25% of respondents in Northern Ireland receiving services reported that the services they relied upon had either been reduced or withdrawn in the previous 12 months, even though their needs had remained the same or had increased. In England, the figure was 18%, 10% in Scotland and 18% in Wales.

As the cuts have begun to bite, stroke survivors and their carers have been hit hard, with 27% of respondents (212 people) reporting that these changes had negatively impacted their personal finances, 16% saying they had slowed down their rehabilitation, and 11% saying they had led to more work for their carer.

We believe cutting the services that enable stroke survivors to make their best possible recovery is a false economy. The withdrawal of services is likely to put pressure on other parts of health and social care systems. Anecdotally we have heard of an increasing number of carers having to give up work or reduce their hours in order to cope with providing the range of care needed, as well as a rising number of crisis admissions to hospital

Eric Sinclair's story

Why all who plan and deliver care must be ambitious for stroke survivors

Eric Sinclair, 63, ran his own consultancy and training business, enjoyed his work and maintained a healthy diet and active lifestyle.

But in July 2004 he had a stroke during a trip to Norway to visit his son. In hospital in Oslo he was given an immediate scan, and admitted to a specialist stroke unit. After two weeks in hospital with daily physiotherapy and with what he described as "excellent care in a clean, well-run, well-staffed specialist unit", Eric was transferred back to a stroke unit in Scotland where he remained for the next 14 weeks. Eric describes long periods of enforced idleness in a noisy ward with loud televisions. Physiotherapy there was limited to two or three 30-minute sessions per week.

Other than medication, Eric received very little help on leaving hospital, and mentions in particular the lack of a systematic, regular review for stroke patients, despite his repeated requests for NHS physiotherapy. Eric ended up paying for a qualified physiotherapist himself, crediting her with the fact that he is not living his life in a wheelchair.

While he has left-sided weakness and no functional use of his left hand, Eric now lives at home with his wife and continues to improve physically. He started work about a year after his stroke and now works three days a week for his own business, occasionally travelling away from home to run courses for teachers.

"I was – and am – horrified by the lack of ambition shown by the NHS for recovering stroke patients and particularly younger stroke survivors," says Eric. "All stroke survivors should access properly funded and staffed stroke units with specially trained staff. There must be better support and treatment in the community, pro-active post-hospital monitoring and a more positive relationship between the NHS and independent therapists."

"I was – and am – horrified by the lack of ambition shown by the NHS for recovering stroke patients".

RECOMMENDATION

Put survivors at the centre: All who plan and deliver health and social care should recognise that with individualised support, stroke survivors can make better recoveries, which in turn reduces crisis admissions to hospital and care homes and promotes the inclusion of people with disabilities in society. Local health and social care providers should look at how best to promote services that are joined up around the needs of the stroke survivor and their carers. For inspiration on what people have achieve with the right support, see My Stroke Victory (www.stroke.org.uk/mystrokevictory)

or residential care. We will continue to monitor and highlight these issues as they arise.

The Stroke Association is also concerned that in England the move from Primary Care Trusts to Clinical Commissioning Groups could cause an interruption in service planning. The Stroke Association itself provides stroke support services to over 35,000 people a year, 98% of which are up for renewal in 2013. We look for reassurance that continuity of service will be provided to survivors or they may well suffer, their recoveries delayed.

Stroke impact is not understood

85% of those responding to the survey feel that too many people with whom they come into contact do not understand stroke and how it affects their everyday lives. This is particularly difficult as some problems may only become apparent months after a stroke, such as fatigue, depression or dementia. If professionals are not adequately trained to understand these often hidden symptoms, then families can be left to struggle alone, unaware that the change in condition of their loved one may, in fact, be related to their stroke.

A National Audit Office report for England (**Progress in improving stroke care, NAO, 2010**), states that approximately 11,000 stroke survivors are admitted into residential care each year. There is currently no requirement for care home staff to be trained in the communication, mobility and other needs of stroke survivors.

We believe that better understanding leads to better care. Stroke survivors come into contact with a wide range of people – home care workers, social workers, benefit assessors. The more people who can be trained to understand the impact of stroke, the better the advice and support they can offer to survivors and their families and the better outcomes that can be achieved.

Survivors can help design smarter health and social care

At the Stroke Association we are seeing the growth of a more confident and assertive community of stroke survivors who want to use their experience to secure better health and social care for others. One example is a project in England, funded by the Department of Health, called Community Voices. This project aimed to give stroke survivors and their families a chance to meaningfully input into the way stroke services are designed and run.

We believe that by involving stroke survivors, health and social care services will be better designed and avoid many of the pitfalls that are all too familiar to those that use them.

The Stroke Association is also establishing a campaigners’ network across the UK to enable all touched by stroke to have a greater voice and influence over the services they rely on.

Visit stroke.org.uk/campaigns for more details

RECOMMENDATION

Protect and develop key services: Local health and social care commissioners must not only safeguard but also enhance services that stroke survivors rely on, working closely with the voluntary sector.

RECOMMENDATION

Make sure all who come into contact with survivors understand stroke and its impacts: People working with stroke survivors should receive comprehensive training to allow them to understand stroke and meet the needs and aspirations of stroke survivors.

RECOMMENDATION

Involve stroke survivors to develop the best services – they know best what works.



What is happening, and what stroke survivors want to happen

Existing health and social care policy across the UK

ENGLAND

In England, more than 100,000 people a year have a stroke. The care of stroke survivors, from diagnosis and initial management to rehabilitation and long-term management is governed by the Department of Health's ten-year National Stroke Strategy for England, which sets out a framework for delivering effective stroke services. The strategy is delivered through the Stroke Improvement Programme, which supports 28 stroke networks. In 2011, the Department of Health set up the Accelerating Stroke Improvement Initiative in order to speed the work of the Stroke Improvement Programme.

Social care is funded by local authorities, with care offered according to eligibility criteria. If we are to enable more stroke survivors to make better recoveries, the key is now to help health and social care to work more closely together for the benefit of all stroke survivors, no matter what the survivor's age or how long ago they had a stroke.

What can stroke survivors expect?

The National Stroke Strategy for England contains several quality markers for the care and support of people after a stroke:

- **Stroke-specialised rehabilitation** in hospital, immediately after transfer to home or care home, and for as long as it continues to be of benefit.
- People with very severe stroke who are not expected to recover should receive **active end of life care** from an appropriately skilled workforce, whether in hospital or in the community.
- After stroke, people need to be offered a **review** of their health, social care and secondary prevention needs, typically within six weeks of leaving hospital, before six months have passed and then annually. This will ensure that it is possible to access further advice, information and rehabilitation where needed.

In 2010, the National Institute for Health and Clinical Excellence (NICE) produced quality standards that focus on the clinical aspects of stroke care. These include:

- All patients after stroke are screened within six weeks of diagnosis to identify mood disturbance and cognitive impairment.

Over the past 20 years there has been a growing recognition that stroke is **preventable and treatable**, rather than simply a consequence of ageing that results in death or severe disability.

Lafrance Gordon's story

Life after stroke can mean reaching the summit

Former welder, music promoter and fitness enthusiast Lafrance Gordon had a stroke in 2001, aged just 41.

"One night I was feeling unusually tired and decided to sleep on the floor, because of a chronic back condition. Early the next morning, I tried to get up and found I couldn't," recalls Lafrance. "My partner Veresteen told me she thought I had had a stroke and she called the doctor immediately."

For Lafrance, formerly the opening batsman with the Bristol West Indies Cricket Club, recovery has been slow but steady, and he gives full credit to the NHS for the care he received. He had physiotherapy and occupational therapy on discharge, and was given dietary advice, especially about salt.

"When I first got back home it was awful. I felt isolated as I had to be downstairs. I remember creeping out of bed, putting my feet on the ground and trying to walk. I made it to the hallway and looked up the staircase. I knew with sheer determination I could get up there. I had a really

good therapist who worked with me for six months, took me to the gym and on my first walk. I wanted to walk to the cricket ground where I used to play. I practiced every day and would go 10 yards, 20 yards, 30 yards and then stop less each time."

"Through the Stroke Association, I became involved in the Bristol half-marathon and then went on to climb Pen Y Fan in the Brecon Beacons. I fell in love with the mountains and decided that would be my motivation to recover even more. In May 2008, I reached the summit of Snowdon."

Lafrance has since become a volunteer for the Stroke Association, appearing on TV and radio. After a course in journalism, he began working on a radio station and hosted a popular programme. "I also help run a service called Gordon House Project which helps stroke survivors in the Bristol area to understand what stroke is, and offer tips to help them recover."

"I fell in love with the mountains and decided that would be my motivation to recover even more."

ENGLAND CONTINUED...

- All patients discharged from hospital who have residual stroke-related problems are followed up within 72 hours by specialist stroke rehabilitation services for assessment and ongoing management.
- Carers of patients with stroke are provided with a named point of contact for stroke information, written information about the patient's diagnosis and management plan, and sufficient practical training to enable them to provide care.

RECOMMENDATIONS FOR ENGLAND

Recommendations for action in England

- In December 2011, the Department of Health announced a new Cardiovascular Disease Outcomes strategy. The Stroke Association believes this must build on the significant progress made in acute care, through the National Stroke Strategy for England.
- We want to ensure hyper acute stroke care is available for all on a 24/7 basis.
- We hope that the new strategy will emphasise the importance of long-term care beyond hospital, spanning support offered by both health and social care services.
- The strategy must emphasise the role of clinical stroke networks, and fund appropriately.
- We call on Clinical Stroke Networks to work more closely with adult social care – particularly in supporting those whose stroke occurred a long time ago.
- The National Commissioning Board should ensure the National Stroke Strategy for England is incorporated into future guidance on commissioning stroke services.
- NICE stroke standards should be extended to include community-based rehabilitation, longer term support and social care services.

NORTHERN IRELAND

Every year, around 4,000 people in Northern Ireland have a stroke. In response to this, the Northern Ireland Stroke Strategy was launched in July 2008 and since then significant progress has been made.

The Northern Ireland Stroke Strategy has been successful in its implementation in a number of areas. However, the cut in its third year of funding has seen a reduction in the delivery of all of the strategy's 14 recommendations.

The Stroke Association believes that, although the strategy has been unable to deliver on all 14 recommendations, the Northern Ireland Stroke Strategy should continue and develop new ways in which to fulfill all the recommendations.

There needs to be a real emphasis on the development of more rehabilitation and longer term stroke services in order to support stroke survivors, their carers and families on a care pathway to recovery and to avoid social exclusion.

There should be no postcode lottery of stroke services and all services should be available to those affected by stroke.

RECOMMENDATIONS FOR NORTHERN IRELAND

Recommendations for action in Northern Ireland

The Stroke Association Northern Ireland has identified four priority areas for stroke care over the next five years, with the aim of reducing the incidence of stroke, stroke mortality rates, stroke-related disability, and providing a real improvement in the quality of life for stroke survivors.

- Services for stroke survivors must be available to all who need them.
- The stroke community in Northern Ireland must be adequately resourced and work together to prevent stroke and ensure that those who have a stroke receive first class medical and therapeutic interventions which will help them make the best recovery.
- Commissioners must continue to work to improve post-hospital, long-term stroke care.
- We want to see joined-up work between health and social care in order to realise the areas of concern in this briefing, and make life after stroke a reality for more of Northern Ireland's stroke survivors.

SCOTLAND

Stroke is a clinical priority for NHS Scotland, which has had a combined stroke and heart disease strategy since 2002.

A revised plan, the Better Heart Disease and Stroke Care Action Plan, was published in June 2009. This action plan sets out improvement areas for discharge, stroke rehabilitation and some aspects of longer-term support, although this is focused on rehabilitation with only modest reference to ongoing social care support. The action plan also proposes that new clinical standards should be developed around rehabilitation, to complement those agreed for acute care (although these have not been developed as yet).

Implementation of the Stroke Action Plan is supported by a National Advisory Committee for Stroke and NHS Stroke Managed Clinical Networks in each Health Authority area.

The Scottish Stroke Care Audit shows that there is steady progress in improving acute, hospital stroke care as a result of the Scottish Stroke Action Plan and implementation of acute stroke clinical standards, contributing to falling stroke mortality. Unfortunately, these improvements are not consistent across Scotland or all aspects of acute stroke care, and so even more progress needs to be made.

Most stroke survivors will have some level of follow up and review during their first year post-stroke through specialist community stroke teams and/or primary care. In some areas there are also Stroke Liaison Nurses who support transition from hospital and provide ongoing

support – generally for up to one year. Glasgow Health Board has developed a useful online resource to support annual reviews of stroke patients in primary care which has also been adapted for self-assessment. This could be used across Scotland and more widely.

Stroke survivors, their carers and families receive information about stroke, care and support through hospital and primary care staff, and can also get information through government and charity websites and helplines.

Local authority social services have the lead responsibility to commission social care (home care, supported housing and residential care) to meet the needs of their population but this support is provided by a wide range of voluntary and private organisations as well as local authorities. Many stroke survivors rely on this type of support.

New legislation – Self Directed Support – will give service users a much greater say in the social care support they receive. This will also influence and change the way in which these services are planned and provided over the next few years.

The Stroke Action plan is very NHS focused and does not include longer term support issues or the role of social care or supported housing providers, even though they play the key role in supporting life after stroke. It is essential that awareness and engagement in life after stroke issues is strengthened within the social care and supported housing sector.

The Stroke Association and NHS Education Scotland are working with stroke survivors, carers, health and social care professionals and others to establish a new community of organisations and people – Scottish Stroke Knowledge into Action (SSKIA) – to support improvements in stroke care, especially long term support. Once SSKIA is established it will be able to support improvements in life after stroke support across Scotland.

What can stroke survivors expect?

- All stroke survivors should receive accurate, timely and accessible information when they need it through health and social care staff, as well as online and through voluntary groups.
- All stroke survivors should receive an assessment before discharge from hospital to identify the level of continuing care and support they need, including whether they can return home – with or without adaptations – or whether they need to be transferred to a long-stay rehabilitation facility, residential or nursing care.
- Stroke survivors, who need adaptations to their home or supported housing, should receive early help from relevant housing organisations, including local Care and Repair.
- Nursing and personal care (washing and dressing) is currently free in Scotland if this is needed.
- Access to home care and residential care is restricted by eligibility criteria and a person's income and assets. The Scottish government is

introducing new legislation to support people who need social care to play the lead role in identifying their needs and preferences; this is called Self Directed Support. (The Stroke Association has received funding from the Scottish government to help stroke survivors access Self Directed Support.)

- Stroke survivors and their carers should receive ongoing support from their GP and primary care (practice) nurse as needed.
- Voluntary organisations provide a range of support to stroke survivors and their carers, including advocacy, befriending, communication support, community transport, exercise, employment support, housing support, money advice and self-management training. (Whilst this type of support is very beneficial, provision is patchy and dependent on available funding.)

RECOMMENDATIONS FOR SCOTLAND	
Recommendations for action in Scotland	
<ul style="list-style-type: none"> The new integrated Health and Social Care Partnerships and Stroke Managed Clinical Networks should work with the Stroke Association, NHS Scotland's Information Services Division and others, to undertake analysis of current and likely future support needs of stroke survivors and their unpaid carers in each local authority area (population needs assessment). This should include the needs of specific groups such as stroke survivors over 65, those under 65 and from black and minority ethnic communities. The Scottish Stroke Action Plan (currently part of the Better Heart Disease and Stroke Care Action Plan 2009) should be revised to include all key aspects of long-term support for stroke survivors and their unpaid carers. This should preferably be a Stroke only Action Plan. Clinical standards for stroke rehabilitation, including vocational rehabilitation, should be developed to improve the quality of provision. National guidance on life after stroke should be developed to aid improvements to the support provided by health, social care and supported housing providers. Implementation of this guidance 	<p>should be supported by appropriate training for staff.</p> <ul style="list-style-type: none"> GPs and practice nurses should support annual review of all stroke survivors, using the online primary care and self-assessment stroke resource developed in Glasgow. Social care commissioners and providers should work with the Stroke Association and others to help stroke survivors and their carers to maximise access to and benefits from the new Scottish Self Directed Support arrangements. This should include improved access to independent advocacy, self-assessment and self-referral opportunities. The health and social care sectors in Scotland must be adequately resourced and work effectively together to ensure that those who have a stroke receive the help they need to make the best recovery from their stroke. Voluntary organisations that provide life after stroke support should be adequately funded. The Scottish Stroke Knowledge into Action community should be supported and funded so it is able to facilitate improvements to life after stroke support across Scotland.

WALES

Around 11,000 people in Wales have a stroke each year, yet Wales remains the only part of the UK without a dedicated, comprehensive stroke strategy. However, stroke services in Wales have been a ministerial priority since 2008. The introduction of the Intelligent Targets programme has enabled a number of significant improvements, particularly in acute care and early rehabilitation of stroke.

However, published evidence as well as stroke survivors' testimonials conclude that much needs to be improved across the entire stroke care pathway – particularly in relation to the transition from hospital care to longer term support, and rehabilitation at home and in the community.

The **Inquiry into stroke services in Wales in 2010** (published by the National Assembly for Wales Health Committee) and the subsequent inquiry into stroke risk reduction in 2011 have provided important evidence to inform the government on future policy direction for stroke. As a result the Welsh government is publishing, for public consultation, its Five Year Stroke Delivery Plan. This is expected to present a comprehensive approach to stroke, from prevention to life after stroke.

However, since its recently acquired primary legislative powers, Wales is undergoing further change. The main policy framework that will govern the delivery of social care is also being consulted upon (from early 2012). The Social Services Bill will introduce a number of changes to the current approach – primarily it will redefine how local government and its statutory

partners address need and wellbeing at an early stage to deliver family-focused social services.

Critically, this Bill is expected to extend the duty on social services and the NHS to collaborate in the delivery of integrated services and in the use of pooled budgets. The Stroke Association believes this represents an important opportunity for achieving co-ordinated services for stroke survivors across the entire stroke pathway.

RECOMMENDATIONS FOR WALES
Recommendations for action in Wales
<ul style="list-style-type: none"> The Welsh government must continue to prioritise stroke and ensure that the National Stroke Delivery Plan is adequately resourced, led and implemented to achieve meaningful outcomes for people of all ages affected by stroke in Wales. The stroke community in Wales must be adequately resourced and work together to prevent stroke and ensure that those who have a stroke receive first class medical help. It is vital that the NHS and local government come together to work collaboratively with the voluntary sector to ensure that stroke survivors and their carers have access to services that encompass all aspects of life after stroke, including housing, lifelong learning and employment. It is vital that appropriate investment is made to strengthen the stroke research community in Wales

Michael and Christine Bell's story

How the right support makes all the difference

Four years ago while on holiday Michael Bell had a stroke. Today, he says he's enjoying life again. He recalls one physiotherapy session he had at the start of his recovery.

"There was a bloke with two walking sticks just walking across the room, and I said to the physiotherapist 'oh, I'll never be able to do that'," recalls Michael. "She said 'of course you will' – and she was right."

Michael and his wife Christine's philosophical view of life has helped him towards recovery. "To actually see him get out of a wheelchair and walk I think actually made me cry," recalls Christine. "I couldn't believe he could get that far, and that was only the beginning."

According to Christine, every day is a challenge and every day is different. "We just face it as it happens, don't worry about the future, just concentrate on that particular problem there and then," she says.

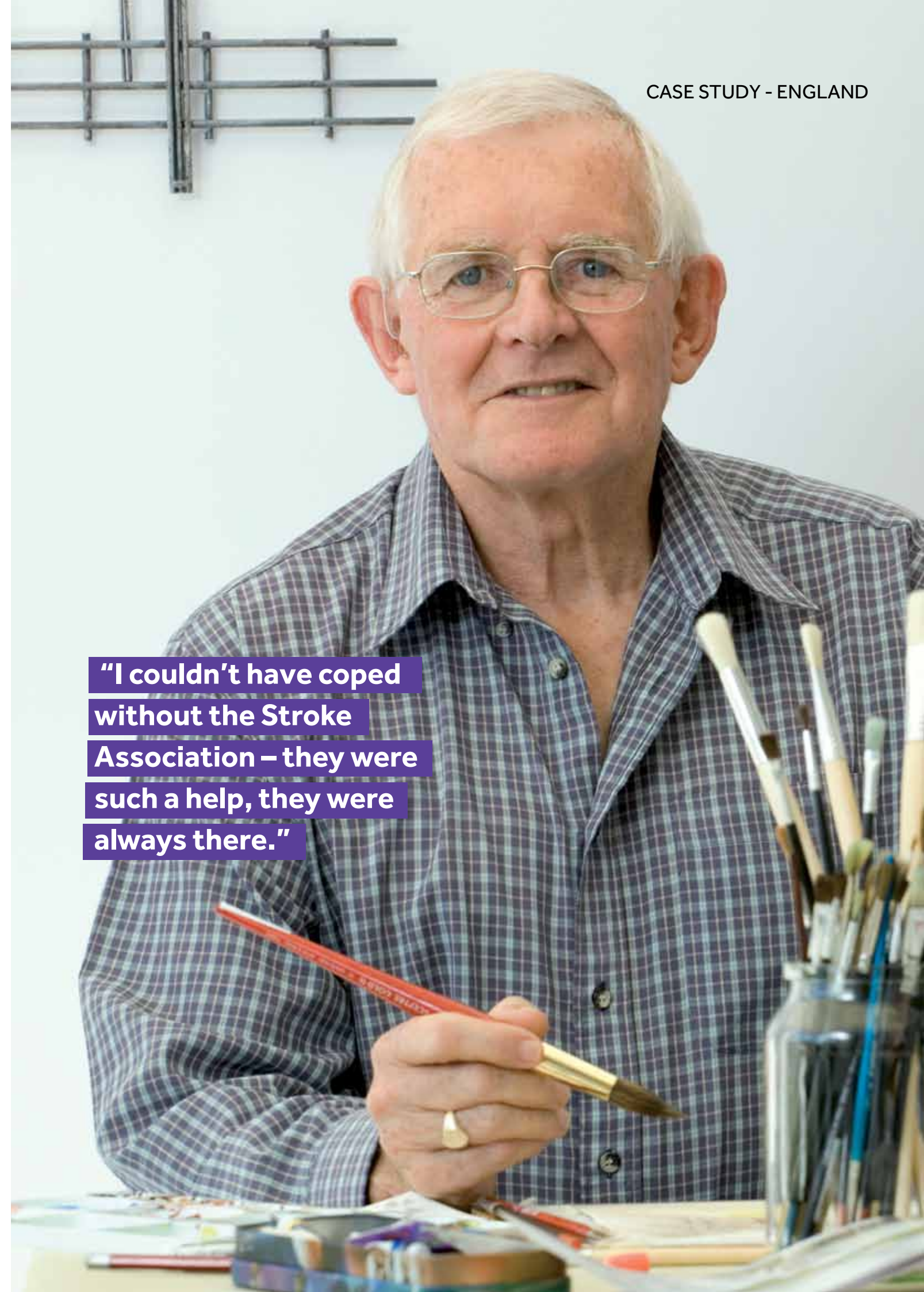
"I couldn't have coped without the Stroke Association – they were such a help, they were always there."

Michael is now well on the road to recovery and still attends Stroke Association meetings. "One of the best pieces of advice I got from anyone was 'never say no'," says Michael. "If somebody says 'will you do this?' I'd say, 'well, I'll try'."

"I've met people I'd never have met before and made friends. I do things now like painting – something I only started because someone at the stroke group suggested it. Now I am enjoying my life again."

"We've come a long, long way and this is quite good enough for us," says Christine. "We're happy with our lot now."

"I couldn't have coped without the Stroke Association – they were such a help, they were always there."



Summary of practical recommendations for those who plan and provide health and social care services

If you are a local planner or provider of health or social care there are some simple actions you can take to improve outcomes for stroke survivors and reduce pressure on other parts of the local health and social care economies.

Put survivors at the centre – All who plan and deliver health and social care should recognise that with individualised support, stroke survivors can make better recoveries, which in turn reduces crisis admissions to hospital and care homes and promotes the inclusion of people with disabilities in society. Local health and social care providers should look at how best to promote services that are joined up around the needs of the stroke survivor and their carers. For inspiration on what people have achieved with the right support see **My Stroke Victory** (www.stroke.org.uk/mystrokevictory)

Provide someone to help navigate the complexities of the system – Stroke survivors should have a right to a named person to co-ordinate their health and social care needs so they get met.

Ensure survivors' needs are regularly reviewed – Stroke survivors must be assessed after leaving hospital and then reviewed on an ongoing basis, because their health and social care needs may change over time – particularly for survivors whose stroke occurred a

long time ago. Service planners should consider how the voluntary sector can help with this.

Care plan – All stroke survivors should be assessed to identify those who need ongoing support in the community. Those that do, should receive a care plan that they should be involved in developing. This plan must result in meaningful action and say who to turn to if things are not working well.

Make clear who can access social care – There should be clear and consistent eligibility criteria for social care. If someone is ineligible for support, they must be referred to free sources of help.

Carers matter – Local authorities must ensure all carers are aware of their right to an assessment of their needs – as set out in law.

Get survivors and their families clear, targeted information as soon as possible after the stroke – Health and social care providers must ensure that stroke survivors and carers have access to all the information and advice they need, including how to access services and the help they can get. Consider the online and helpline resources of the voluntary sector as 'at your disposal'.

Make sure all who come into contact with survivors understand stroke and its impacts – People working with stroke survivors should receive comprehensive training to allow them to understand stroke and meet the needs and aspirations of stroke survivors.

Involve allied health professionals – Those who plan and deliver services should maximise the involvement of allied health professionals and other services that enable survivors to achieve a life after stroke.

Protect and develop key services – Local health and social care commissioners must not only safeguard but also enhance services that stroke survivors rely on, working closely with the voluntary sector.

Involve stroke survivors to develop the best services – they know what works best.

If we all work together - health and social care planners and providers, survivors and carers, the voluntary sector, housing providers and those who provide other services - we can make better recoveries from stroke possible for more people.

Add your support to the campaign today at stroke.org.uk/campaigns

Acknowledgements

Struggling to recover

With huge thanks to all the stroke survivors and families who shared their stories in this briefing

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Throughout the briefing, data is
mentioned from the Daily Life Survey;
data tables mentioned are available
online at stroke.org.uk/campaigns

The Stroke Association. We believe in life after stroke. That's why we campaign to improve stroke care. It's why we support people to make the best recovery they can, but why we believe prevention is better. It's why we fund research to come up with new treatments and ways of preventing stroke. The Stroke Association is a charity. We rely on your support to change lives and prevent stroke. Join us to help more survivors in the UK make better recoveries after a stroke.

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May 2012

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