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Stroke
association



Together we can conquer stroke

Stroke Association Strategy 2015 to 2018

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Introduction

Until recently the received wisdom was that there was nothing that could be done about stroke, unpreventable, untreatable, if it didn't kill, it shattered lives. But over the last two decades things have changed dramatically. New research, changes to the way stroke is treated in hospital and active support in the community have all shown that stroke is preventable and treatable and that more and more people can make amazing recoveries from stroke.

There has been a big reduction in the numbers of people having strokes and a significant drop in the proportion of people killed by stroke. Thousands more people are recovering from their stroke. Our greater understanding of their long term needs has led to more and more people achieving levels of independence and quality of life that would have been unthinkable just two decades ago.

The Stroke Association has been at the forefront of this progress. We are proud of the role we have played in these advances but we also recognise that there is still so much to do. It is still the second biggest killer in the world and the number one cause of complex disability. This strategy sets out the priority areas for our work over the next three years:

- We will be working to reduce the number of people who are having strokes that could have been avoided.
- We will defend the great progress made in acute stroke care provision, and will work to make sure everyone has access to the best possible care in hospital and beyond, wherever they live, whatever their levels of deprivation ethnicity or age.

- We know the huge difference our services and support make, so we will be working to increase our reach, to support self-management for stroke survivors and to build a strong and vibrant stroke community.
- Our research funding will target the most urgent issues in stroke and those that have been neglected in the past. We will campaign to tackle the chronic underfunding of stroke research and the need to develop more research capacity in the UK.
- We will work to ensure that we have a highly skilled and properly resourced health and social care workforce, and that everyone in health and social care services who works with stroke survivors gets the high quality training they need.

Everyday many thousands of stroke survivors take another step in conquering stroke. Dedicated stroke professionals provide treatments and support that help to conquer stroke. Stroke researchers seek the breakthroughs that help to conquer stroke. This strategy sets out the steps the Stroke Association, and the whole stroke community, will take over the next three years to get closer to that goal. Together we can conquer stroke.

Context

Over the last 20 years there has been steady improvement in adult stroke care which accelerated with the advent of the National Stroke Strategy in England and equivalent plans and strategies in Northern Ireland, Scotland and Wales. Some of the headlines include:

- Stroke mortality has almost halved in the UK over the last 20 years. Most of this improvement has occurred in acute care – 30 day mortality from stroke is now below 13 – 13.5%.
- Today most areas have a hospital with a dedicated stroke unit which can vastly improve people's outcomes. Only 58% of patients are admitted directly to a stroke unit within four hours.
- Thrombolysis – a drug that breaks down blood clots and dramatically improves recovery from stroke if administered in time, is now used for 12% of stroke patients in England and Wales, up from just 1.8% in 2008.
- The FAST campaign (2009 to 2013) resulted in a 54% rise in stroke related 999 calls leading to over 4,337 fewer people being left disabled and saving the taxpayer over £332.9m.
- The proportion of patients receiving brain imaging within an hour of admission has increased from 40% to 44.1% within the same period. Around 65% (45% 2004) of the population now know what a stroke is.
- Stroke Association Life after Stroke Services are available to 50% (27% 2004) of stroke survivors and their families through referral from the NHS and our national stroke helpline offers personalised support to anyone affected by stroke.

At the heart of this progress has been work by dedicated stroke researchers, the community of stroke professionals and the Stroke Association. Twenty years ago, stroke research was largely neglected by most funding agencies. Through the Stroke Association's early and continued investment, we have funded pioneering research and established a community of stroke researchers. The UK is now a world-leader in the field, second only to the USA.

Research has provided the evidence base for practical interventions. But without the Stroke Association's campaigning and influencing, and the role it plays in bringing together stroke professionals, progress in translating research into better service provision would have been much more slow and patchy. For example, the Stroke Association's Stroke Manifesto and its Stroke Is A Medical Emergency campaign (both 2005) set the policy context within political and civil service circles and built an unstoppable momentum leading to the formation of the national Stroke Strategy.

Incidence levels of stroke in the UK have dropped, largely because of more effective prevention mechanisms such as medication to control blood pressure and cholesterol levels; further restrictions on smoking and awareness raising campaigns around the issue of salt, fat, alcohol and exercise.

Yet despite all these improvements, the work of the Stroke Association is not done. There has been a worldwide increase in stroke incidence in the last 25 years (68%) particularly among younger adults (25%) while the global burden of stroke is expected to more than double by 2030. With more people surviving after a stroke the numbers of stroke survivors in the population, and the number of families dealing with the consequences has increased.

- Stroke is the second biggest killer worldwide, In the UK one in four people who have a stroke will die within a year.
- 1 in 5 adults admitted to hospital with a stroke are still being treated on general medical wards when they should be in a specialist stroke unit.
- Stroke is the largest cause of complex adult disability.
- People in socially deprived areas are twice as likely to have a stroke and three times as likely to die as those from the least deprived areas. Stroke is markedly higher amongst people in routine employment than those in managerial or professional roles.
- Black and Asian people are more likely to have a stroke, at a younger age, and to die than white people.
- Where you come from, where you live and how much money you have make an enormous difference to who has a stroke, who survives and thrives after stroke in the UK.
- Stroke in adults is a major issue economically and costs the economy £9 billion a year. The economic effects of childhood stroke on survivors and their families which will be over many years are currently unknown.
- Approximately 10,000 strokes could be prevented each year in the UK if all Transient Ischaemic Attacks and minor strokes were treated urgently.
- Most stroke are preventable by taking simple steps to lower your risk of stroke.

- Despite being the primary cause of complex disability and the second biggest killer worldwide, the amount of money going into stroke research is still dwarfed by the amount going into research on other conditions. Only £56m is spent on stroke research each year in the UK, compared with £544m in cancer and £166m in heart disease.

With health and social care systems in transformation, we must ensure that the progress made so far is defended and built on. Politicians and senior NHS decision makers, pressed by competing priorities and austerity, have suggested concentrating on issues other than stroke.

We know from the Sentinel Stroke National Audit Program (SSNAP) that although stroke healthcare has steadily improved overall, there are several hospitals not only under-performing, but performing worse now than they were last year. And the evidence shows that many elements of stroke care are not being done adequately. For example:

- in some areas cut-down versions of Early Supported Discharge have been introduced which are less effective;
- the pioneering work done in stroke care to champion seven day working on stroke units is in danger of being undermined, ignoring staff to patient ratios in favour of spreading existing staff across the seven day week, leading to greater mortality and poorer recoveries;
- less than 16.5% of stroke survivors get a 6 month review;
- psychological support is still under-resourced and inadequate in most areas.

With the cutting of the Stroke Improvement Programme and the transformation of the 29 Stroke Clinical Networks into 10 networks with a much wider remit, much of the critical day to day supportive activities for improvement in England have been lost or are in the process of being re-invented. It is clear that the priority and drive to improve stroke provision has lost momentum within the NHS.

People affected by stroke lack adequate support in the community. Many tell us that when they leave hospital it can feel like 'falling off a cliff'. People can struggle to find and access the support they need and particularly where their needs are complex. Where services do exist, access may be limited, due to timing, funding, or eligibility criteria. Too often family and friends are left to provide or coordinate a loved one's care. For people without adequate support networks, isolation and social exclusion may contribute to relationship problems and depression.

The post-acute stroke pathway is very variable with people receiving intermediate or short term rehabilitation when discharged back to the community and then sometimes only for short intervals of time with little or no support thereafter. SNNAP confirms that stroke care continues to show "unacceptable variation". The most public example of the inadequacy of rehabilitation was highlighted by Andrew Marr last year, who was only offered one session of physiotherapy per week after discharge from hospital and elected to pay privately for daily sessions, which have continued for over a year. Access to timely, consistent support following discharge from hospital is critically important for stroke survivors, but progress in this area seems to have stalled.

The evidence gathered by the Stroke Association shows that a wide range of needs identified by stroke survivors are not being met. Support in accessing benefits, financial advice, emotional support and help in navigating the complexities of the health, social and welfare systems are all vital, but too often absent or too inflexible.

Most importantly for stroke survivors, support should be available over the longer term. Stroke Association services have sought to fill this gap and during the period 2009 to 2011 we saw a rapid expansion, partly driven by the ring fenced funding for community support from the department of Health as part of the National Stroke Strategy. This was cut by the coalition Government, and now there are concerns that the particular and specialist support that stroke families need is falling prey to the austerity and "generic" provision agenda. The commissioning environment has changed dramatically alongside the squeeze in public sector finances which will continue over the coming years. We can expect to see pressures on the level of services commissioned from specialist providers.

There are around 1.2 million stroke survivors in the UK. Each year we provide services to more than 60,000 people affected by stroke. Although we have 357 services funded by the NHS and social care across the UK, there are still too many areas where we do not provide services or they are under resourced or very time limited. Our review of local data has indicated higher levels of readmissions where we do not provide services, compared to areas where we have a service presence. And in our Stakeholder Survey (2014) 43% of respondents said that their top priority was the provision of long term support to help people make the best possible recovery after a stroke.

When we look at the impact of stroke, there is an established relationship between anxiety, depression and stroke. The Stroke Association Survey carried out in 2012 showed that 67% of respondents experienced anxiety and 59% felt depressed with 79% of carers reporting anxiety and 56% depression. Health care costs for patients with long term conditions who also have depression are typically 45% higher (Kings Fund (2012) - Long term conditions and mental health: the cost of comorbidities). Stroke survivors and carers often report losing their existing support networks whether based around their family role, friendship groups, hobbies and/or employment. Provided at the right time in the right environment, the opportunity to access a new support network made up of others similarly affected is, for about a third of stroke survivors, a motivation to get back their life after stroke.

The number of specific Stroke Peer and social support groups has grown over the last ten years, largely because of the additional 110 long term support groups formed by the Stroke Association. There are around 520 stroke clubs (320 being affiliated to us), around 60 Different Strokes groups and around 80 Speakability groups. These can provide a lifeline to coping with feelings of isolation following stroke.

A professional workforce of sufficient strength and depth to provide the best care and confidently drive forward improvement is a prerequisite of good stroke care. In 2011 the British Association of Stroke Professionals estimated a shortfall of 163 stroke specialist posts. In research, some senior academics talk of an impending crisis, with an insufficient number of mid-senior level academics in place to become the next generation of research leaders. In addition, although there is a well-established specialism for stroke in medicine and nursing, there is no stroke specialism in the allied health professions. There is also an urgent need to improve the knowledge and understanding of stroke among care assistants, non-stroke specific health workers, social care and residential care staff.

Over the last 10 years the degree of collaboration across countries and continents on stroke has grown enormously, initially led by the stroke research and medical fraternity. There is now more collaboration between governments about stroke and active engagement through the UN and the WHO because of its significance worldwide. The World Stroke organisation has grown in importance matched by a growth in the number of stroke support organisations in many different countries. This activity is leading to more global opportunities to learn, share, and improve the lives of everyone touched by stroke worldwide. The Stroke Association has earned a high reputation within the international community for our work to foster greater collaboration and international initiatives to tackle all aspects of stroke.

Ambition One: Preventing avoidable strokes

Why is this important?

Strokes are preventable and treatable. The best way to conquer stroke is to prevent them from happening.

There is clear evidence that at least 4,500 strokes a year could be avoided if atrial fibrillation (AF) was identified and those people with AF who are at risk of stroke were treated with anti-coagulation medicine. Despite new NICE guidelines, more than 60% of people who enter hospital with an AF related stroke are not on anti-coagulation or have only been prescribed aspirin, which does nothing to reduce their risk. This must change - AF related strokes can and must be avoided.

There is also strong evidence showing that quick intervention after a transient ischaemic attack (TIA) could prevent at least 5,000 people going on to have a major stroke. Too many people dismiss short-lived stroke symptoms as just a funny turn and delays in seeking treatment can be compounded if they get inappropriate advice from their GP. Once identified, it is vital that people who have had a TIA get quick access to a specialist for proper diagnosis and treatment.

People who have had a stroke are at higher risk of having another one. That is why "secondary prevention" is so important. Everyone who has a stroke should get as much advice and support as they need to help them to lower their risk of having a second stroke.

High blood pressure is the single biggest risk factor for strokes, accounting for half of the 152,000 strokes that occur every year. Raising awareness of this and encouraging people to know their blood pressure is a vital first step to people controlling their blood pressure through behavioural changes and/or medication.

The FAST campaign, which we initiated in 2005, has been the catalyst for raising awareness and the priority given to stroke, ensured fast treatment for people who have a stroke and, most importantly, it has driven improvement in acute stroke care and outcomes for stroke patients. Public Health England continues to fund some limited national FAST advertising but more needs to be done to prevent awareness slipping away.

Why should the Stroke Association act?

There are many organisations doing important work to help people reduce their risk of vascular disease, but it is only the Stroke Association that can focus on those risk factors that are unique, or closely linked, to stroke. We know that our strong reputation for being expert puts us in the ideal position to raise awareness and seek to change behaviours. Every week we hear from stroke survivors whose stroke could have been avoided had they known about, and been treated for their high blood pressure or atrial fibrillation. And people who have had a stroke or a TIA seek our advice and support to help them reduce their risk of having a second stroke.

We have a strong track record of raising awareness of the risk factors for stroke. Our long-running Know Your Blood Pressure campaign has grown year on year: in 2014 we tested 60,000 people's blood pressure at over 1000 events.

We have campaigned consistently on atrial fibrillation, raising awareness of the condition and its link to stroke through a range of initiatives aimed at the public and primary care staff and worked in a wide variety of coalitions to improve detection of AF and rates of anti-coagulation.

And we work in partnerships with Government bodies, such as Public Health England, other charities, and coalitions to raise awareness of stroke symptoms and to tackle the risks factors that contribute to vascular disease. Having developed the FAST campaign in 2005 we are in a unique position to work with Public Health England and local public health bodies to keep the FAST message relevant and high profile.

Our priorities are:

- For everyone who has had a stroke or TIA to get the advice and support they need to reduce their risk of having another stroke.
- Continue our campaigning on atrial fibrillation to make sure that all those at risk of stroke get the appropriate anti-coagulation treatment.
- Continue our media and campaigning work to: help reduce the number of strokes related to modifiable risk factors, especially high blood pressure; to promote FAST; and to highlight prevention research findings.
- Work in coalitions and partnerships: to raise awareness to help people reduce their risk of vascular disease.

Specifically, we will:

- Build our campaigning on atrial fibrillation – developing our online toolkit for GPs and others working in primary care; raising awareness of atrial fibrillation and its link to stroke; monitoring and highlighting the number of people who have AF related strokes who are not been treated.
- Build on our Not Just a Funny Turn campaign to make sure that Public Health England's FAST advertising campaign specifically includes reference to symptoms of short duration; monitor and highlight TIA provision across the UK; and work to promote good practice in recognition and referral of TIA in primary care.
- Grow our Know your Blood pressure events - seeking more partners to roll out more events across the UK; generating more national and regional media coverage for the campaign; and measuring people's knowledge of the link between high blood pressure and stroke.
- Provide advice and support to service users, growing the prevention elements of our core services in line with the development of our new recovery model for service provision.
- Provide a range of information and resources about stroke prevention and develop new online tools to help people to tackle the risk factors for stroke they may be facing.
- We will continue to work closely with PHE to promote FAST and will also explore new ways of keeping FAST in the public mind.
- Work with Government and public health bodies to promote the NHS health checks and support Change4Life.
- Seek partnerships to develop local stroke risk reduction marketing programs and campaigns.
- Highlight and promote prevention research findings.

Ambition Two: Making sure there is best stroke support and care

Why is this important?

The great progress in stroke support we have won over the last decade needs to be defended: adult stroke mortality has almost halved in the UK over the last 20 years; only 58% of patients are admitted directly to a stroke unit within four hours.; the proportion of adult patients receiving brain imaging within an hour of admission has increased from 40% to 44.1%; the FAST campaign (2009 to 2013) resulted in a 69% rise in stroke related 999 calls leading to over 4,337 fewer adults being left disabled and saving the taxpayer over £332.9m and 65% (45% 2004) of the population now know what a stroke is.

But the work of improving stroke care is not complete. There is clear evidence to show that getting immediate treatment in a high quality stroke unit depends on where you live, and what time of day or day of the week you have your stroke.

And the progress seen in acute care for stroke has not been matched by support in the community. The Prime Minister agrees: *“But what is now required is more effort really to look at how we can make someone who has had a stroke have a better quality of life.” (29th October 2014, Hansard).*

Provision of rehabilitation therapies in the community is still far from adequate, in terms of intensity and duration; and access to long term support for stroke survivors is determined more by your postcode than by your needs.

Our ambition, in partnership with the whole stroke community, is to make sure that stroke survivors should have the chance to make the best possible recovery. To conquer stroke, everyone needs the best care and support.

Why should the Stroke Association act?

For more than a decade the Stroke Association has been at the forefront of campaigns to improve stroke provision across the UK: whether it was the development of the English National Stroke Strategy and equivalents in Scotland, Northern Ireland and Wales; the ground-breaking re-configuration of acute stroke services in London; or the development of the FAST campaign, we have been at the heart of stroke improvement, effectively influencing at national, regional and local levels.

We are experts in all aspects of stroke and drawing on the testimony of tens of thousands of stroke survivors we provide a unique, evidence based and in depth insight into the needs of stroke survivors and the improvements in care they require. We understand the NHS and social care stroke care pathway, but, crucially we also understand the stroke journey that people who have had a stroke have to embark on.

Our proud history of service provision provides a practical demonstration of the difference that can be made and of best practise in meeting the needs of stroke survivors and their care givers.

Our passion is to make sure that every stroke survivor has the best possible chance of recovery, backed by our history of funding ground breaking research and innovative service provision and by the voices of stroke survivors across the country.

Our priorities are:

- Keep up the pressure for better stroke care so that every adult gets direct access to a specialised stroke unit, 24 hours a day, 7 days a week; everyone should get specialist support and intensive rehabilitation when they leave hospital; and that everyone gets a review of their needs every 6 weeks, 6 months and annually.
- Highlight and work to address the social, health, ethnic and geographical inequalities that lead to greater prevalence of stroke and worse outcomes
- Reach out to more stroke survivors, their families and carers of all ages, and the bereaved, so we can provide information and support to them

- Advocate and work in partnership to build research funding capacity in stroke to more appropriate levels and make sure we have a well-trained stroke and health and social care work force, now and in the future.
- Continue to bring together and forge a strong stroke community through the UK Stroke Forum, the UK Stroke Assembly, stroke club and long term group work; supporting children and their parents with stroke, and by acting as a catalyst for international collaboration.
- Continue to develop the website and other digital offerings to meet the information needs of stroke survivors and their loved ones and to help build a stronger stroke community.
- Continue to develop our website as an information and knowledge hub for specific audiences including stroke survivors, stroke professionals and stroke researchers.
- Continue to develop and grow our Supporters Network, so that more and more people can engage with our cause and become part of the stroke community engaged in campaigning for, donating, volunteering, supporting stroke related activity.

Specifically, we will:

- Use the growing evidence base provided by the Stroke Sentinel National Audit Program (SSNAP) to highlight the areas of stroke care that need more improvement and to advocate for change.
- Support the position that Children and young people should have access to specialist tertiary level stroke support at the time of diagnosis and specialist support and rehabilitation when they leave hospital.
- Commission a landmark study to make the economic case for conquering stroke.
- Publish data and analysis on variations in stroke care across the four UK countries.
- Develop relationships with key decision makers within Government, health and social care in order to influence the case for continuous improvement in stroke provision.
- Advocate for Early Supported Discharge to be available in every area.
- Continue to exert pressure so that everyone who has a stroke is followed up at six weeks, six months and then annually, as outlined in the National Stroke Strategy.
- Launch a campaign to call for more intensive and longer lasting stroke rehabilitation after people leave hospital using evidence to show that better recoveries and ultimately costs savings to the NHS would result.
- Continue to highlight the impact of health inequalities on outcomes.
- Enhance our awareness raising and marketing to reach out to more stroke survivors in order to offer them information and support and develop a program of engagement with stroke units to ensure that as many stroke survivors and their carers as possible can access our information and support.
- Continue to produce high quality, accredited and accessible information materials, films and other tools to support stroke survivors and their loved ones.
- Continue to raise awareness of all aspects of stroke through our media and social media activity using our limited resources wisely to focus on key identified audiences.
- Develop our brand and use our brand to support our fundraising, service provision and outreach.
- Develop campaigns in support of a step change in the annual amounts invested in stroke research in the UK
- Highlight the current shortage in qualified stroke specialist consultant and nurses and the pressing need to head off a potential stroke workforce crisis.
- Continue to support the development of a strong and vibrant stroke community through our work to support Stroke Association Voluntary Groups, Stroke Clubs, the UK Stroke assembly, the Stroke Clubs Conference and the UK Stroke Forum
- Continue to highlight the issues facing children and young people who have a stroke, the impact on them and their families and the services and support they need. Make sure that a new set of Childhood Stroke clinical guidelines is produced.

Ambition Three: Expanding the network of services and long term support across the UK

Why is this important?

Considerable progress has been made in the provision of acute stroke care, which has led to a reduction in mortality and hospital bed days. However the post-acute stroke pathway is very variable with people receiving intermediate or short term support, when discharged back to the community and then sometimes only for short intervals of time and little or no long term support thereafter. The national stroke audit (SSNAP) confirms that stroke care continues to show “unacceptable variation”. Less than a sixth of patients in England and Wales receive the mandated assessment six months after having a stroke. (Ref:-Article in the BMJ- 2014. 349. 18/8/14). The data for children and young people affected by stroke is unknown.

Access to timely consistent support following discharge from hospital is critically important for stroke survivors. Navigation of services, recovery and rehabilitation services should be available and provided flexibly. Most importantly support should be available over the long term.

Peer and social support can provide the lifeline to coping with feelings of isolation following stroke. Stroke survivors and carers often report having lost their existing support networks whether through their family role, friendship groups and employment. Provided at the right time in the right environment, the opportunity to access a new support network made up of others similarly affected can be the motivation to get back their life after stroke.

Why should the Stroke Association act?

There are around 1.2 million stroke survivors in the UK. Each year we provide services to approximately 60,000 people affected by stroke. Although we have 357 services across the UK, there are still many areas where we do not provide services or they are under resourced or very time limited. Review of local statistics on hospital admissions and readmissions has indicated higher levels of readmissions where we do not provide services, compared to areas where we have a service presence. (Stroke Association: NW London review of stroke services).

The commissioning environment is rapidly changing and alongside public sector efficiencies, which will continue to be required over the coming years, we have already seen the beginning of an erosion of services commissioned at a local level. Our Stakeholder Survey (2014) showed that 43% of respondents said that their top priority was the provision of long term support to help people make the best possible recovery after a stroke.

Our priorities are to:

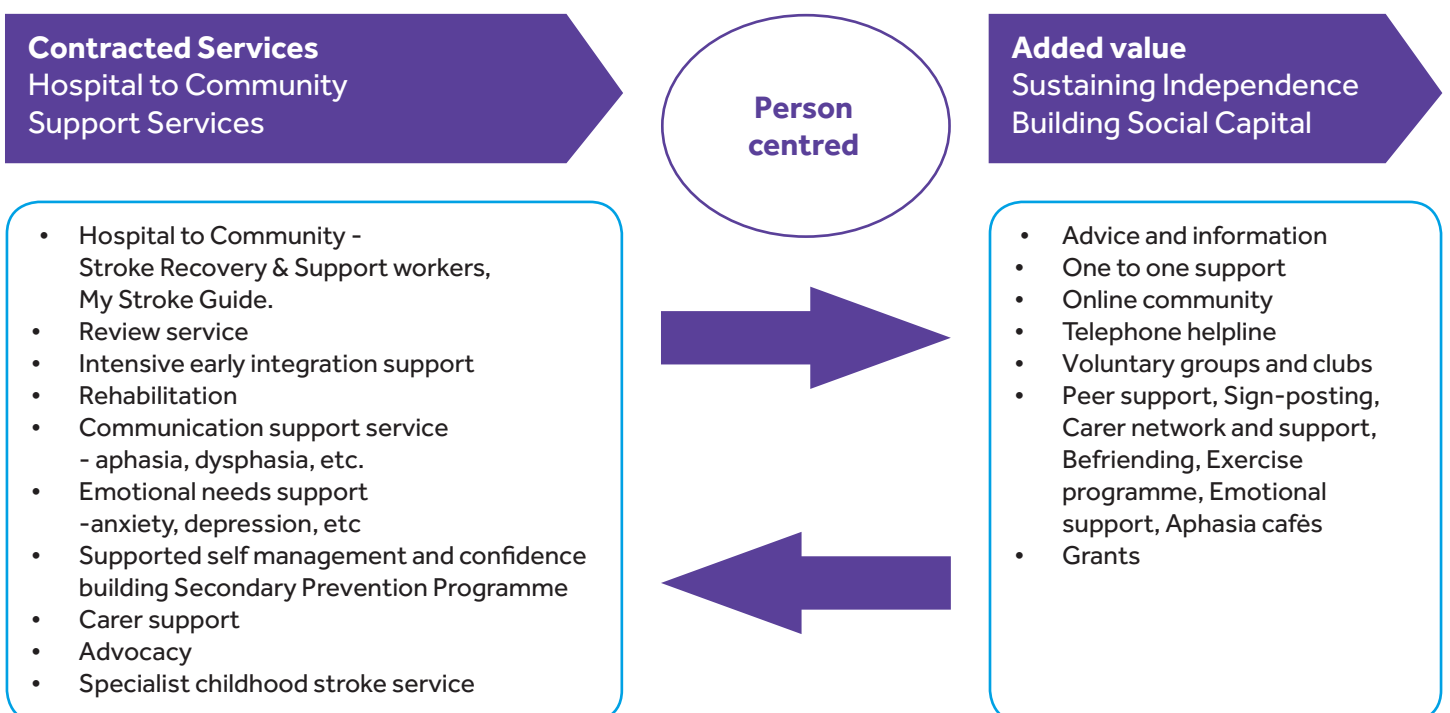
- Work to secure a diversity of income streams (including statutory funding, personal budgets and self-funders) and achieve more services, challenging when we know services of value are threatened and continuing to offer services based on voluntary income in every community of the UK.
- Commit to continuous improvement, innovation and early adoption of best practice, working in co-production with service users, developing our Stroke Association Outcomes Framework to show the difference we make.
- We will commission and publish independent evaluation of our Stroke Association Services to enable continued improvement and development of best practices.
- Support people in self – management of their stroke through promoting and rolling out My Stroke Guide.
- Support the maintenance and growth of long term stroke support groups.
- Grow new services that provide therapies to aid recovery and quality of life.
- Reach out to more stroke survivors, their families, carers and the bereaved, so we can provide continuing information and support to them, aiming to build positive long term relationships.

Specifically, we will:

- Facilitate dialogue and planning about the best form of pathway and services post hospital discharge.
- Expand and build on our service base in *England/Wales/Scotland/Northern Ireland* through funding opportunities and by charitable means by: Assessing opportunities and building the Stroke Association presence in countries.

- Introducing a new model of services: the Recovery model, which will ensure better quality of care, is delivered to people affected by Stroke, through co-production, piloting and continuous evaluation.
- Develop a Stroke Association Outcome Framework, which will respond to the needs of Service Commissioners and effectively demonstrate how our services are making a difference to people affected by stroke.
- Position services to respond to the self-funding and Integrated Personal Health and Social Services budget by creating new services for the self-funding and the Personal Budget market commencing with tailored exercise and Secondary Prevention Programs and partnering with Later Life Training.
- Promote reviews of clients at 6 week/ 6 month and annually and use available data to demonstrate unmet need
- Roll out the introduction of My Stroke Guide as part of a wider approach to promoting self-management through services.
- Continuing to grow and develop our network of Voluntary Groups to ensure those affected by stroke can access long term peer and social support that meets their needs.
- Increasing our support of people affected by stroke in their community, including building on our befriending schemes, exercise and activity groups, emotional support activities and carer respite.
- Continuing to support independent Stroke Clubs through an affiliation scheme to ensure the highest quality of local peer and social support.
- Continue with and develop new digital, print and online resources to complement all our services including contracted services, the National Helpline and our long term support groups.
- Build our volunteer support capacity by expanding roles available to volunteers and coordinating training and support alongside the introduction of the new Recovery model of services. We will increase in volunteer numbers and volunteer hours, and the number of Stroke Association Voluntary Groups.
- Ensure the continuation of the current NHS/ Stroke Association child stroke support project at the Evelina London Childrens Hospital.
- Consider the demand for the viability of Family Support Days or weekends for families affected by childhood and young peoples strokes.

Stroke Recovery Service Intergrated Service Solution



Ambition Four: Building Research and promoting stroke knowledge to improve stroke care

Why is this important?

Research is vital if we are to conquer stroke. Combined with the insight and experiences of stroke survivors and carers, it helps define how best to prevent strokes, reduce deaths, treat people in hospital and support them in their rehabilitation and physical, psychological and emotional journey after a stroke.

There is compelling evidence of a strong return on investment from medical research. Twenty years ago, stroke research was largely neglected by other funding agencies but since then much has been achieved in the UK, based on very modest investment. Recent research shows that the level of resource dedicated to stroke research is low relative to its disease burden and to comparable conditions. We want to accelerate improvement and increase that investment. We want to ensure that quality research is not held back by lack of funding or barriers that can be removed.

Building new knowledge is not enough. We must also apply it, creating knowledge exchange across disciplines, sectors and countries, developing evidence-based resources for people affected by stroke, and turning the results of all of our research into compelling messages and cases for change. Research and information about stroke will help everyone across health, social care and government to understand stroke better and the role they can play in conquering stroke.

And where evidence does not exist we must innovate to find new ways to support life after stroke, generating new evidence of the innovations that work and then scaling them up.

Why should the Stroke Association act?

We are the only UK charity solely focused on stroke research. Over the last twenty two years, we have awarded more than £40 million through 400 research grants, leading to many advances in stroke care.

We occupy a leading position as a funder, specialising in the development of new ideas and focus, and early phase work. Many successful large clinical trials began as feasibility studies funded by the Stroke Association. We have forged successful collaborations with other funders to raise awareness of stroke and to increase the annual spend on stroke research.

We recognise the value that people affected by stroke bring to research and are proud of our commitment to ensure that the views of stroke survivors shape our work.

In 2013 we made new investments in research communications and knowledge management to use the evidence to challenge the status quo, build new consensus, and influence health and social care policy and practice, research funders and public understanding.

Our priorities are to:

- Fund Priority stroke related research in areas of neglect and under-funding, reflecting expert opinion and the views of people affected by stroke.
- Build capacity, training opportunities and expertise in stroke research; influence to remove the barriers to stroke research and support its translation into practice.
- Disseminate knowledge so that it leads to better outcomes.
- Put stroke survivors and their caregivers at the heart of self-management of stroke by collecting and utilising their knowledge in the My Stroke Guide portal, and our other Services.
- Advocate for an increase in the UK spend on stroke research in line with comparable conditions.
- Continue to support the UK Stroke Forum.

Specifically, we will:

- Publish new evidence on the UK spend on stroke research, and make the case for a higher spend.
- Fund Priority Research Awards in haemorrhagic stroke, the psychological impacts of stroke and vascular dementia.
- Gain greater funding for stroke research through the EU's Horizon 2020 Programme by stimulating new partnerships and ideas development.
- Cultivate the next generation of research leaders through our Lectureship programme and Fellowships. We will co-fund 15 posts and leverage £3m of new funds from UK universities.
- Create knowledge exchange opportunities between key groups through our roundtable series and disseminate well-evidenced publications about how to improve stroke care.
- Leverage new resources for stroke through matched funding partnerships and fundraising.
- Publish findings of multicentre study of unmet needs of young people and families after stroke in childhood/
- To improve children and young people with stroke care by updating and disseminating guidelines best practice, and thereby influencing positively clinical and social care.

Ambition Five: Ensuring a well-trained and resourced health and social care stroke workforce

Why is this important?

We must ensure that stroke survivors receive the best treatment and care to maximise their recovery potential. A strong evidence base of what works is not enough; we also need a workforce of sufficient strength and depth to provide the best care and confidently drive forward improvement.

We are heading towards a crisis point where there won't be enough stroke specific clinicians to staff the vital stroke wards and services we know save lives. The picture is even worse in social care, where there are no mandatory stroke training requirements for the social care staff supporting the 500,000 stroke survivors who need support to carry out everyday tasks. Recommendations have been made for the need of NHS stroke specific education, but this is no longer top of the policy agenda. We must ensure these recommendations are met, and work with others to set standards in social care.

Why should the Stroke Association act?

We are the largest UK provider of stroke specific training covering the whole stroke pathway, and the largest provider of stroke specific qualifications under the Qualifications Credit Framework (QCF). Our training has been endorsed by Skills for Health and the Stroke Specific Education Framework (SSEF), and recent market research for the Stroke Association found that we have many opportunities for market growth.

We have resources for professionals and are currently developing an organisational knowledge centre that, in time, we may wish to make available to health and social care professionals. We host the UK Stroke Forum – the principal scientific, education and training conference - and have strong links with stroke professional bodies including regular email contact with 2,000 professionals about education and training opportunities.

We were involved in the development of the SSEF and have promoted the tool ever since.

Our priorities are to:

- Ensure that stroke survivors receive high quality evidence-based care through a well skilled health and social care workforce across the stroke pathway.
- Change the perception, where it exists, that stroke training isn't needed.
- Support the work of professional bodies to build sufficient capacity in their workforce.
- Form an alliance with BASP and other Stroke Professional care organisations to influence to create an appropriately skilled and resourced workforce for the medium term and long-term future.
- Support the growth of Stroke support organisations to advocate for skilled stroke workforce provision outside the UK.
- Ensure that workforce planning is driven by appropriate stroke specific frameworks.

Specifically, we will:

- Explore the possibility of creating a stroke specific interest group with the Royal College of Paediatrics and Child Health, and/or the British Paediatric Neurology Association. With a view to improve knowledge and workforce planning around childhood stroke.
- Campaign for stroke specific education and training across the pathway.
- Develop a campaign to call for stroke workforce planning in health and social care to be driven by appropriate frameworks.
- Shape education and training opportunities available through the UKSF.
- Publish evidence making the case for stroke standards and training and changing the perception that stroke training isn't needed for care staff.
- Provide a comprehensive range of stroke training and support the work of professional bodies to build sufficient capacity in their workforce.
- Promote our education and training programmes throughout the UK to Health Education England, NHS Education Scotland, NHS Wales, Northern Ireland Trusts and Deaneries and Skills for Care.
- Pilot a Stroke Association Care home training award scheme to influence stroke care standards.
- Target key groups of professionals currently receiving limited or no stroke training.
- Target care companies who provide domiciliary care and Personal Assistants, ensuring they have access to our stroke training programme and QCF stroke qualifications.
- Provide a comprehensive range of resources for professionals that support best practice and learning.

INTERNAL AMBITION

Ambition Six: Operating as a world class organisation

Why is this important?

Over the last ten years our people have led and championed the cause of stroke. Working with stroke survivors, their families and carers, with professionals, with volunteers, decision makers and our supporters we've made a real difference to the lives of everyone affected by stroke. Now we want to build on that success. Our strategy requires a step change so that we can support even more people and dramatically increase the resources going into stroke research. This means we will have to change how we work and organise ourselves so that we can be as efficient and effective as possible and create the right platform for long-term sustainability and growth.

Our goal

To operate at a very high level in terms of quality, professionalism, and effectiveness, showing and being recognised as a world-class organisation in delivering our strategy, driving growth, better meeting the needs of people we work with and creating a platform for long-term sustainability.

Our priorities:

1. We will align our resources and organisation to deliver our new strategy and enable growth
2. We will transform how we raise income and increase resources to enable delivery of our strategy ambitions.
3. We will operate as effectively and efficiently as possible through a focused approach to organization development and risk management
4. We will nurture creativity and innovation to grow income and improve performance
5. We will act on evidence and insight to direct our resources where they can have maximum impact
6. We will grow our understanding of key customer/stakeholders, be clear about our prioritized audiences, and join-up our work with them to support our strategic goals, enable customer retention and increase lifetime value
7. We will unleash the talent of our people through a new People Strategy.

Specifically, we will:

- **Structure review.** We will undertake a role and structure review to ensure we have the right structures and the right people and capabilities in place to deliver our strategy.
- **Supporter Strategy.** We will grow our income and numbers of people who support us through focusing on identifying people who are likely to support our cause and retaining their support. Our new strategy will use data and market insight to improve product performance, develop new products and increase awareness of the Stroke Association as a charity in need of funds.
- **Organisation development.** We will develop a new approach to Organisation Development to ensure we have the best culture; planning and performance oversight; processes and quality systems to meet the requirements of a growing and increasingly mature charity.
- **People Strategy.** We will develop a new People Strategy with a view to having the best and most motivated workforce possible to deliver our strategy and maximise future success.
- **Maximising financial performance.** We will review our finance system and invest in a significant upgrade so that we can integrate procurement and finance and provide more detailed business intelligence to internal teams.
- **Strategic Facilities Plan.** We will undertake a strategic review of our buildings to ensure we are based in the right locations with the right facilities so that we are using our resources as effectively as possible.
- **Using technology to improve efficiency.** We will take a strategic approach to technology and IT ensuring our systems are fit for purpose and future proofed.
- **Strategic Marketing Approach.** We will develop a strategic approach to audiences and product development so that we maximise engagement people who engage with us have a seamless experience of the charity in terms of our communications and services.
- **Build on our brand.** We will continue to build on and develop our brand so that the Stroke Association continues to grow in relevance and encourages conversion/action amongst key audiences.

The Stroke Association Council and Directors Management Team 10 March 2015

We are the Stroke Association

We believe in life after stroke. That's why we support stroke survivors to make the best recovery they can. It's why we campaign for better stroke care. And it's why we fund research to develop new treatments and ways of preventing stroke.

**We're with you every step of the way,
together we can conquer stroke.**

Stroke Helpline: 0303 3033 100

Website: stroke.org.uk

Email: info@stroke.org.uk

From a textphone: 18001 0303 3033 100

We are a charity and we rely on your support to change the lives of people affected by stroke and reduce the number of people who are struck down by this devastating condition.

Please help us to make a difference today.



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Twitter @TheStrokeAssoc

Together we can conquer stroke

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