## A New Era for Stroke

### Our campaign for a new national stroke strategy

The current National Stroke Strategy for England was published in 2007 with an aim to bring about much needed improvements to stroke services. We campaigned for it to be developed after a National Audit Office report found that too many stroke survivors were not getting the fast and effective treatment they needed.<sup>1</sup>

The 2007 strategy has led to real improvements including a reduction in mortality by 46% from 1990 to 2010 and an increased awareness of stroke thanks to public health campaigns such as ActFAST.<sup>2</sup>

Despite these improvements, clinical audits continue to show serious failings in treatment. Up to 15% of patients are still being denied vital treatment such as thrombolysis, and 52% wait over the hour recommended in clinical guidelines for a brain scan to diagnose their stroke. We also know that care varies significantly, with better outcomes in areas such as London and Manchester where services have been reorganised to ensure that more patients are treated on specialist hyper-acute units. Stroke survivors tell us that care after they leave hospital is even worse, with two-thirds of stroke survivors not receiving a vital six-month review.

It is essential that all stroke survivors get the care and treatment they deserve no matter where they live. This will only be achieved through a national plan which sets the standard for stroke care and treatment. We need a strategy which will:

- Drive forward the reorganisation of stroke services.
- Drive new advances in treatments which reduce disability in stroke patients and save money in social care costs.
- Improve support for stroke survivors when they return home, enabling them to make a fuller recovery and return to a better quality of life.
- Address the unacceptable variations in stroke treatment and care that currently exist across England.

# The scale of stroke

- Stroke occurs approximately 152,000 times a year in the UK.
- There are over 1.2 million stroke survivors in the UK.
- Stroke is the fourth single largest cause of death in the UK.
- 1 in 4 strokes in the UK occur in people under 65 years old.
- Stroke is one of the largest causes of disability – half of all stroke survivors have a disability.
- The average cost of care (acute and rehabilitation) per stroke patient is currently £23,315 a year.<sup>6</sup>

Stroke is a unique condition. It strikes in an instant but its effects can last a lifetime. With the right treatment, care and support stroke survivors can make a good recovery and maintain a good quality of life.

## You can help us drive forward change

by raising these issues in parliament.

Together we can conquer stroke





## 1. Continue the reorganisation of stroke services

The current National Stroke Strategy calls for stroke services to be reorganised through the introduction of Hyper-Acute Stroke Units (HASUs). This involves closing smaller units and bringing resources and qualified staff together into one large unit. This model save lives and money but adoption has been slow, putting lives at risk and losing money for the NHS.

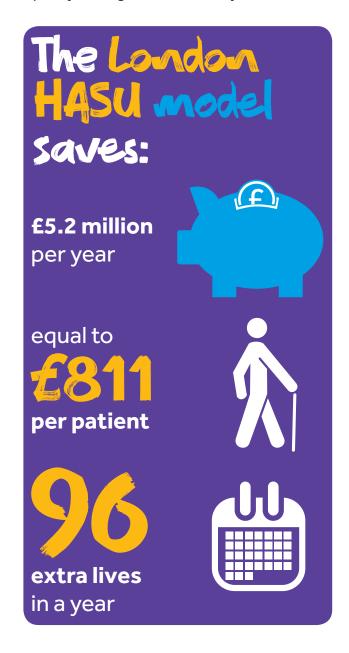
A new National Stroke Strategy is needed to ensure the long term vision for reorganisation continues past 2017. The NHS has changed significantly since the 2007 strategy was published. We need a new strategy to make sure local areas are able to learn from the processes established in London and Manchester to push forward their own reorganisations more quickly, saving lives and money sooner.

"UCL Hospital was exceptional - the A&E department saved my life and the HASU gave my life back to me."

Andrew, 41, stroke survivor

"I'm not sure I would have received such excellent care, treatment and support had I lived in a different part of the country and not been treated in a HASU."

Clive, 51, stroke survivor



### London

Since 2010, anyone having a stroke in London is taken to one of eight 24/7 HASUs rather than the nearest hospital. Patients are assessed immediately by specialised stroke staff equipped to instantly perform brain imaging and give clot-busting treatment where appropriate. No one is more than a 30 minute ambulance ride away from a HASU. 24 Stroke Units provide rehabilitation services after the initial HASU visit.<sup>7</sup>

#### This has saved lives and is cost effective:

 Savings of £5.2 million per year, equal to £811 per patient for the NHS<sup>8</sup>



 Saved 96 extra lives in London in a year 9



 72% of patients received interventions, for example, brain scans within 3 hours <sup>10</sup>



 93% of stroke patients were admitted to a HASU <sup>11</sup>



### **Manchester**

The Manchester HASU model accepts those whose stroke symptoms occurred less than four hours prior to admission. Patients whose symptoms started more than four hours previously are transferred to the stroke ward in Disease Specific Care (DSC). This has reduced costs but has not improved outcomes for stroke patients to the same extent as the London HASU model.

### This has saved money and maintained patient outcomes:

 Length of hospital stays were reduced by 2 days 12



 65% of patients received interventions, for example, brain scans, within 3 hours <sup>13</sup>



 39% of stroke patients were admitted to a HASU<sup>14</sup>



Evidence from the National Audit Office further endorses the move to centralisation. Faster access to tests and specialist treatment, and the associated efficiencies has improved outcomes for stroke patients and helped save the NHS an estimated £456 million between 2007 and 2014.<sup>15</sup>

### 2. Drive new advances in treatment

### **Thrombectomy**

Thrombectomy, the mechanical retrieval of a clot from the brain, is an important innovation in stroke treatment. It is revolutionary because it is for patients who do not normally respond to clot busting drugs. Previously these patients would be left with very severe disabilities, but thrombectomy can reduce these chances.

The only way the England can continue to be a leading player on stroke treatment is through a national strategy which addresses the barriers which are delaying roll out of this vital treatment.

#### Issues with the current roll-out of thrombectomy:

- NICE guidance on thrombectomy (November 2015) says it is safe and effective. However, this guidance is not mandatory and local areas are not required to provide it.<sup>16</sup>
- Adoption in the UK is slow compared to Germany, France and the US.
- At present, there is a huge shortfall in the number of qualified consultants to provide the recommended cover for a 24/7 service. More training places for radiologists are needed to develop this workforce for the future.
- With reconfiguration currently stalled, it is difficult to see how thrombectomy could be provided equitably to make sure people get the scans, assessments and treatments within five hours.

### **Thrombolysis**

Thrombolysis is a clot busting drug. If given within four hours of the onset of symptoms it can improve patient outcomes and reduce disability. One in every ten people who receive it benefit from the treatment. Despite its effectiveness, it is still not available to all who need it. A national strategy is needed to remove the final barriers which are preventing people from receiving this vital drug.

#### Issues with the current rollout of thrombolysis:

- Nationally, up to 15% of patients who are eligible do not receive it because trained staff are not available at the time they have their stroke.<sup>18</sup>
- 100% of eligible patients receive thrombolysis in the best areas, compared to a maximum of 15% in the worst.<sup>19</sup>

£20k

**£0k** 



Year 1

Year 5

# 3. Improve support for people affected by stroke

#### **Our Survey**

The data from this section comes from our survey of 1,424 stroke survivors across England detailing their own personal experiences of stroke care, support and treatment. This was carried out between January-March 2016 via online and paperbased methods.

Stroke survivors tell us that they are not getting the support they need, putting their recoveries at risk. For too many the support comes too late, stops too soon, or they are not offered all types of specialist therapy they need.

This needs to change. A national strategy is vital to improve the quality and availability of care for stroke survivors.

### **Hospital Vs Home**



There is a **big drop** in the care you receive from the time you are in hospital to when you return home.



Over 30% said their

care at home was

poor or very poor.







This is compared to the 78% of survivors who said their care in hospital was good or very good. Stroke survivors in almost half of the UK don't get six-month assessments because the service is not commissioned, despite clear guidance to do so.<sup>21</sup> This means stroke survivors are being denied a vital opportunity for their needs to be assessed and support to be put in place.

### Impact of stroke



**39%** of survivors told us the physical impact of stroke was the hardest to deal with.



21% of survivors said the emotional impact of stroke was hard to deal with.



**27%** told us the therapy received was poor or very poor.



**59%** told us the therapy received was poor or very poor.

The physical effects of stroke are the most difficult to deal with, yet access to rehabilitation and support is poor. Stroke survivors are only getting 77% of the rehabilitation they are entitled to while in hospital.<sup>22</sup> The therapy for the emotional impact of stroke is particularly poor, with a quarter of stroke patients waiting up to 5 months for psychological support.<sup>23</sup>

"After 6 months the doctors and nurses decided I did not need further support which left me feeling as if an 'umbilical cord' had been cut."

Stuart, 61, stroke survivor

# ††††††††



feel abandoned when they leave hospital.

## Stroke survivors are being denied the support they need to help their recovery

## Speech and communication

60% of stroke survivors have problems with speech and communication.

### Physical disability

80% of stroke survivors have a physical disability.

### Hidden effects 87% of stroke

survivors have problems with fatigue and 77% of stroke survivors have problems with memory.

### **Emotional** effects

More than 70% of stroke survivors experience depression or low mood.



This therapy in hospital is particularly bad, survivors get less than half of what they should be according to guidelines.



38% of those who said their disability was severe said that their physiotherapy was poor or very poor.



Nearly 50% of stroke survivors said the support they received for fatigue and memory problems was poor.



25% of stroke survivors are waiting over 5 months for help with mental health issues after they leave hospital.<sup>24</sup>

## Case study

Father of two, Tony McKevitt from Liverpool, had two strokes in 2009, aged 48.

"With lots of therapy I was able to take some steps, providing I had the support of the carers and a wheelchair behind me. I felt there was some hope of getting my mobility back. Unfortunately, after the physiotherapists stopped coming the staff at the [care] home found less and less time to get me standing and walk with me. I felt condemned to a life in a wheelchair."

As a result Tony spent the next four years confined to an electric wheelchair. "I felt trapped in the [care] home, my morale was so low and losing my dignity was one of the hardest things to accept."

A new support worker was horrified Tony was living in a care home at such a young age and put him in touch with the Stroke Association who arranged support. With the support of physiotherapists, Tony stood and managed to take two supported steps, and has gained belief that there is life after stroke.



# 4. Address the unacceptable variations in stroke treatment and care

National statistics show us that the treatment and care stroke survivors receive depends on where they live. Significant variations occur at every stage. This is unacceptable.

The inequalities that exist currently are not being tackled. The only way to reduce these inequalities is through a plan which sets a national standard for the delivery of good quality treatment and rehab to help all stroke survivors make the best recovery possible. Without a national strategy, access to the best treatment and support will continue to depend on where a person lives.





### Access to treatment



### Access to post-acute

There are huge variations in the time it takes to receive a brain scan and to see a specialist stroke consultant. Nationally, consultant waiting time is over 12 hours.<sup>25</sup>

Access to thrombolysis still varies significantly.

Thrombectomy is only currently available in a few locations across England.

The support and therapies people receive following a stroke vary massively across the country.



Only 63% of patients in

North Tees & Hartlepool

receive a brain scan within

12 hours compared to the

national average of 93%.26

These delays can result

in patients missing the window for treatment meaning people suffering

unnecessarily.



82% of patients in Ipswich receive

thrombolysis in a Stroke Unit within four hours. compared to only 15% of those at Wexham Park.27



It is estimated that fewer than 400 patients will receive thrombectomy this year,28 when around 10,000 people could be eliqible.29



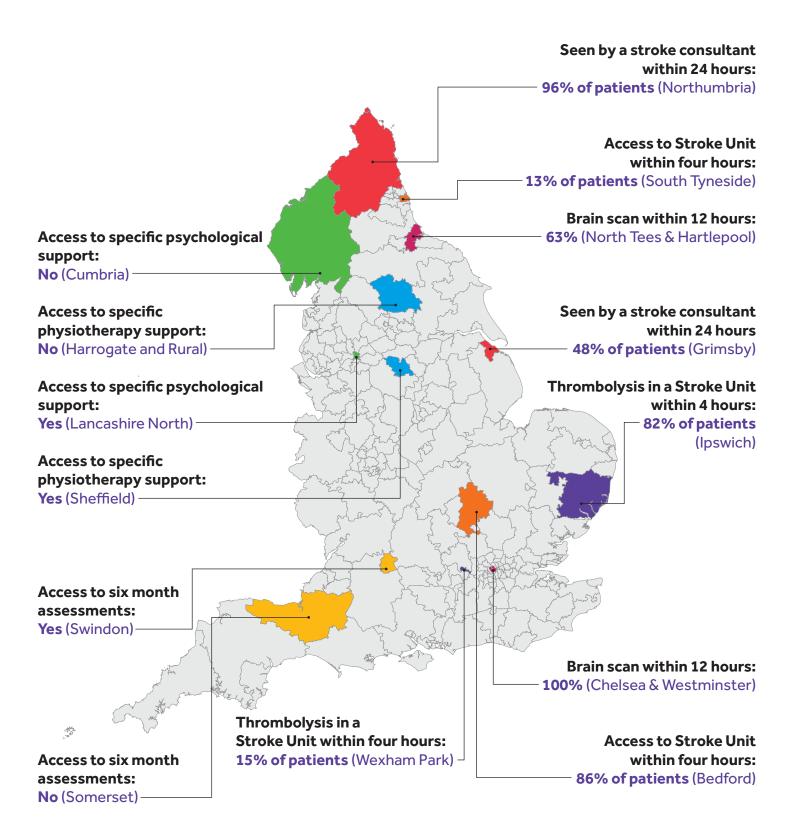
In some parts of the country people wait up to five months for mental health support when the target is 14 days.30

"I had no support. A year on and still waiting to see a psychiatrist."

Zoe, 35, stroke survivor

### **Regional variation**

The statistics on the map below are from the latest SSNAP highlights detailing both acute<sup>31</sup> and post-acute patient care.<sup>32</sup> The data indicate some of the best and worst performing areas for key aspects of care.



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# The Government is still not listening to stroke survivors

### - despite calls from the public to take action

The Government responded to the Stroke Association's petition in July 2016, saying that they have no plans to renew the National Stroke Strategy for England. This is despite calls from stroke survivors, their families and members of the public who want to see a national standard set for stroke care.

The Department of Health says they do not think a new strategy is needed due to the existence of the Cardiovascular Disease Outcomes Strategy and the NHS Five Year Forward View. We do not accept this argument because:

- The Cardiovascular Disease Outcomes Strategy's (CVDOS) aim is to tackle the areas common to all CVD, meaning it focuses most of its attention on common lifestyle risk factors. This means the CVDOS alone cannot wholly meet the needs of stroke patients. Stroke is different to other CVD as it has a wide-range of condition specific impacts from communication problems to physical disability, effects which are not dealt with in the document.
- Further, a new National Stroke Strategy for England would help to deliver the Five Year Forward View by providing the operational mechanisms to deliver on its broad strategic vision. Both are needed as condition specific strategies, such as the cancer and mental health strategies, sit underneath the Five Year Forward View and help to deliver its strategic aims.

You can read our full reply to the Government's response here: stroke.org.uk/NewEraResponse

### Help us take action to create a new era for stroke, you can:



1. Write to the Secretary of State for Health about the need for a new National Stroke Strategy. We can provide a draft letter.



2. Help us secure a debate to drive forward improvements in stroke treatment and care.



**3.** Ask Parliamentary Questions on stroke. We can provide suggested questions to your parliamentary team.



**4.** Visit a local Stroke Association service, stroke club or support group in your constituency. We can arrange this for you.



5. Engage in local media work on the need for a new National Stroke Strategy. We can provide a draft press release specific to your constituency.



- "Department Of Health Reducing Brain Damage: Faster Access To Better Stroke Care National Audit Office (NAO)". National Audit Office. N.p., 2016.
  Web. 11 Sept. 2016.
- Stroke Association. (2016). State of the nation: Stroke statistics. Available: https://www.stroke.org.uk/sites/default/files/stroke\_statistics\_2015.pdf. Last accessed 10 September 2016.
- Royal College of Physicians Sentinel Stroke National Audit Programme (SSNAP). Clinical audit Jan Mar 2016 report prepared by Royal College of Physicians, Clinical Effectiveness and Evaluation Unit on behalf of the Intercollegiate Stroke Working Party.
- <sup>4</sup> Royal College of Physicians Sentinel Stroke National Audit Programme (SSNAP). National report 2015 Phase 2 prepared by Royal College of Physicians, Clinical Effectiveness and Evaluation Unit on behalf of the Intercollegiate Stroke Working Party Accessible: https://www.strokeaudit.org/Documents/Results/National/2015/2015-PAOrgPublicReport.aspx
- Morris, S. (2014). Impact Of Centralising Acute Stroke Services In English Metropolitan Areas On Mortality And Length Of Hospital Stay: Difference-In-Differences Analysis. BMJ 2014;349:g4757.
- Stroke Association. (2016). State of the nation: Stroke statistics. Available: https://www.stroke.org.uk/sites/default/files/stroke\_statistics\_2015.pdf. Last accessed 10 September 2016.
- Morris, S. (2014). Impact Of Centralising Acute Stroke Services In English Metropolitan Areas On Mortality And Length Of Hospital Stay: Difference-In-Differences Analysis. BMJ 2014;349:g4757.
- <sup>8</sup> Hunter, RM. (2013). Impact on Clinical and Cost Outcomes of a Centralized Approach to Acute Stroke Care in London: A Comparative Effectiveness Before and After Model. 2013. Accessible: http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0070420
- Morris, S. (2014). Impact Of Centralising Acute Stroke Services In English Metropolitan Areas On Mortality And Length Of Hospital Stay: Difference-In-Differences Analysis. BMJ 2014;349:q4757.
- Ramsay, AIG et al. (2015). Effects of centralizing acute stroke services on stroke care provision in two large metropolitan areas in England. Stroke, vol 46, no. 8, pp. 2244-2251.
- Ramsay, AIG et al. (2015). Effects of centralizing acute stroke services on stroke care provision in two large metropolitan areas in England. Stroke, vol 46, no. 8, pp. 2244-2251.
- Morris, S. (2014). Impact Of Centralising Acute Stroke Services In English Metropolitan Areas On Mortality And Length Of Hospital Stay: Difference-In-Differences Analysis. BMJ 2014;349:g4757.
- Ramsay, AIG et al. (2015). Effects of centralizing acute stroke services on stroke care provision in two large metropolitan areas in England. Stroke, vol 46, no. 8, pp. 2244-2251.
- Ramsay, AIG et al. (2015). Effects of centralizing acute stroke services on stroke care provision in two large metropolitan areas in England. Stroke, vol 46, no. 8, pp. 2244-2251.
- "Department Of Health Reducing Brain Damage: Faster Access To Better Stroke Care National Audit Office (NAO)". National Audit Office. N.p., 2016.
  Web. 11 Sept. 2016.
- National Institute for Health and Clinical Excellence. Quality Standards Programme. Mechanical clot retrieval for treating acute ischaemic. Web. 10 Sept 2016. Accessible: https://www.nice.org.uk/guidance/ipg548/resources/mechanical-clot-retrieval-for-treating-acute-ischaemic-stroke-3060861609157
- <sup>17</sup> Stroke Association. (2016). State of the nation: Stroke statistics. Available: https://www.stroke.org.uk/sites/default/files/stroke\_statistics\_2015.pdf. Last accessed 10 September 2016.
- Royal College of Physicians Sentinel Stroke National Audit Programme (SSNAP). Clinical audit Jan Mar 2016 report prepared by Royal College of Physicians, Clinical Effectiveness and Evaluation Unit on behalf of the Intercollegiate Stroke Working Party. Accessible: https://www.strokeaudit.org/Documents/Results/National/JanMar2016/JanMar2016-PublicReport.aspx
- Royal College of Physicians Sentinel Stroke National Audit Programme (SSNAP). Clinical audit Jan Mar 2016 report prepared by Royal College of Physicians, Clinical Effectiveness and Evaluation Unit on behalf of the Intercollegiate Stroke Working Party.
- Royal College of Physicians Sentinel Stroke National Audit Programme (SSNAP). Cost of Stroke Portfolio (Health Economics) 2016 prepared by Royal College of Physicians, Clinical Effectiveness and Evaluation Unit on behalf of the Intercollegiate Stroke Working Party.
- Royal College of Physicians Sentinel Stroke National Audit Programme (SSNAP). National report 2015 prepared by Royal College of Physicians, Clinical Effectiveness and Evaluation Unit on behalf of the Intercollegiate Stroke Working Party Accessible: https://www.strokeaudit.org/Documents/Results/National/2015/2015-PAOrgPublicReport.aspx
- Royal College of Physicians Sentinel Stroke National Audit Programme (SSNAP). Clinical audit Jan Mar 2016 report prepared by Royal College of Physicians, Clinical Effectiveness and Evaluation Unit on behalf of the Intercollegiate Stroke Working Party.
- Royal College of Physicians Sentinel Stroke National Audit Programme (SSNAP). National report 2015 Phase 2 prepared by Royal College of Physicians, Clinical Effectiveness and Evaluation Unit on behalf of the Intercollegiate Stroke Working Party Accessible: https://www.strokeaudit.org/Documents/Results/National/2015/2015-PAOrgPublicReport.aspx
- Royal College of Physicians Sentinel Stroke National Audit Programme (SSNAP). National report 2015 Phase 2 prepared by Royal College of Physicians, Clinical Effectiveness and Evaluation Unit on behalf of the Intercollegiate Stroke Working Party Accessible: https://www.strokeaudit.org/Documents/Results/National/2015/2015-PAOrgPublicReport.aspx
- Royal College of Physicians Sentinel Stroke National Audit Programme (SSNAP). Clinical audit Jan Mar 2016 report prepared by Royal College of Physicians, Clinical Effectiveness and Evaluation Unit on behalf of the Intercollegiate Stroke Working Party.
- Royal College of Physicians Sentinel Stroke National Audit Programme (SSNAP). Clinical audit Jan Mar 2016 report prepared by Royal College of Physicians, Clinical Effectiveness and Evaluation Unit on behalf of the Intercollegiate Stroke Working Party.
- 27 Royal College of Physicians Sentinel Stroke National Audit Programme (SSNAP). Clinical audit Jan Mar 2016 report prepared by Royal College of Physicians, Clinical Effectiveness and Evaluation Unit on behalf of the Intercollegiate Stroke Working Party.
- <sup>28</sup> Royal College of Physicians Sentinel Stroke National Audit Programme (SSNAP). Clinical audit Jan Mar 2016 report prepared by Royal College of Physicians, Clinical Effectiveness and Evaluation Unit on behalf of the Intercollegiate Stroke Working Party.
- <sup>29</sup> Chia NH, et al. (2016). Determining the number of ischemic strokes potentially eligible for endovascular thrombectomy. Stroke, vol 47, no. 5, pp. 1377-1380.
- Royal College of Physicians Sentinel Stroke National Audit Programme (SSNAP). National report 2015 Phase 2 prepared by Royal College of Physicians, Clinical Effectiveness and Evaluation Unit on behalf of the Intercollegiate Stroke Working Party Accessible: https://www.strokeaudit.org/Documents/Results/National/2015/2015-PAOrgPublicReport.aspx
- Royal College of Physicians Sentinel Stroke National Audit Programme (SSNAP). Clinical audit Jan Mar 2016 report prepared by Royal College of Physicians, Clinical Effectiveness and Evaluation Unit on behalf of the Intercollegiate Stroke Working Party.
- Royal College of Physicians Sentinel Stroke National Audit Programme (SSNAP). Post-acute Stroke Service Report Phase 2 2015 prepared by Royal College of Physicians, Clinical Effectiveness and Evaluation Unit on behalf of the Intercollegiate Stroke Working Party



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#### 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 here for you. Together we can conquer stroke. If you'd like to know more please get in touch.

**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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### Together we can conquer stroke

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