Reshaping stroke services in Northern Ireland

For better recovery and more lives saved
This booklet is a shortened version of a more detailed document.

This booklet gives you information about stroke. It explains some of the words used to talk about stroke.

This booklet will give you information about current services for stroke survivors. It tells you where the services are doing well.

This booklet informs you about changes that would help to improve services and support for stroke survivors and families.

This booklet lists 7 ideas for changing stroke services. It gives you information to explain each idea.

This booklet also invites you to give us your comments.

When we say “we” or “us” in this booklet, we mean Health and Social Care.

The information in this booklet has been created by Health and Social Care organisations in Northern Ireland. This information has been put into an easy read format by the Stroke Association.

You might like to have someone to support you when you look at this booklet.
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Useful words and phrases

This is an explanation of some of the words used to talk about stroke and stroke services in this booklet.

**Acute Stroke Unit**

Hospital wards especially for stroke patients. Acute Stroke Units give stroke patients care and rehabilitation until they are ready to go home. Acute Stroke Units are run by doctors, nurses and therapists who have special training.

**Allied Health Professionals**

Physiotherapists, occupational therapists, speech and language therapists, and other health professionals who work as a team to help people recover after a stroke.

**Early Supported Discharge**

A service given by Community Stroke Teams. These teams provide rehabilitation and support to stroke survivors in their own homes after they leave hospital. The therapy they give should be at the same level as it would be provided in hospital.
<table>
<thead>
<tr>
<th><strong>Hyperacute Stroke Unit</strong></th>
<th>A special stroke unit that looks after a stroke patient for the <em>first 3 days</em> in hospital.</th>
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<tr>
<td><strong>Mini-stroke or Transient Ischemic Attack or TIA</strong></td>
<td>A <em>mini-stroke</em> is also known as a <em>Transient Ischemic Attack</em> or <em>TIA</em>. A mini-stroke happens when the brain’s blood supply is interrupted for a very short time. A mini-stroke is an emergency. You should not wait to see if symptoms get better. You should call an ambulance straight away.</td>
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<td><strong>NICE</strong></td>
<td>NICE stands for the <em>National Institute for Health and Care Excellence</em>. NICE provides national guidance and advice to improve health and social care.</td>
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<td><strong>Rehabilitation</strong></td>
<td>Help with <em>mobility</em> and <em>communication</em>. Rehabilitation helps stroke survivors to lead as full a life as possible.</td>
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<tr>
<td><strong>Scan</strong></td>
<td>A test to look at a problem in someone’s brain or body.</td>
</tr>
<tr>
<td><strong>Specialist Stroke Team</strong></td>
<td>Teams of health care staff that look after stroke patients in hospital or at home. Specialist Stroke Teams have some specialist training. They also have experience of stroke treatment.</td>
</tr>
</tbody>
</table>
A stroke occurs when the blood supply to part of the brain is cut off. This could be due to a **blood clot** or a **brain bleed**.

**Thrombolysis**
Treatment with a drug that breaks down blood clots.

**Thrombectomy**
A procedure to take out a blood clot in the brain.
Introduction

Health and social care organisations want to improve stroke services and care.

We have worked with stroke experts to develop some ideas to improve care after stroke. This booklet is to tell you about these ideas. We want to find out what you think of our ideas. We will begin the discussion about these ideas on 13 June until 12 September.

The booklet focuses on why stroke services need to change and how to improve the care people receive. We will listen to your views about these improvements. We will use what we learn to work with key people to develop a more detailed plan about the future of stroke care.

After this, health and social care organisations will start a wider conversation with the public about their ideas.

“Having a stroke is like an emotional roller-coaster. Young stroke survivors like me need more practical and emotional support to make the best recovery. Stroke services in Northern Ireland are lagging behind the rest of the UK. We need to do better. Share your views and help create better stroke services.”

Helen, from Armagh
A stroke is a **brain attack**. A stroke is a **medical emergency**. It is very **important** that someone who has a stroke gets the right **treatment** very **quickly**.

Getting help **quickly** can help the person who has had a stroke to **get better sooner**.

Stroke affects people differently. Some of the effects include **movement**, **speech**, **vision**, **thought processes** and **feelings**.
About **1000 people die** from stroke in **Northern Ireland** every year.

Every year about **2700 people** in **Northern Ireland** are taken to hospital after having a stroke.

There are **36,000 stroke survivors** living in **Northern Ireland**. More than **half** of these stroke survivors have a long term **disability**.

This **number of stroke survivors** is likely to **go up** as the **population gets older**.
Information about stroke

People who have a stroke need to:

- Go to hospital very quickly
- See a stroke doctor very quickly
- Have the right scans very quickly
- Get the right treatment very quickly
- Get the care they need in a stroke unit

A Transient Ischaemic Attack (TIA) is sometimes called a mini-stroke.

People who have a TIA need to:

- Get a doctor’s opinion
- Have the right scans
- Get the right treatment
- Get advice about healthier lifestyles
For better recovery and more lives saved

What is happening now?

What stroke services are available now? Why do they need to change?

There have been lots of improvements to stroke services in Northern Ireland recently.

- Medicine to break up clots, known as thrombolysis, is available across Northern Ireland.
- Thrombectomy, a clot removal treatment, is available at the Royal Victoria Hospital.
- Community stroke rehabilitation is available across Northern Ireland.

“I was just 47 when I had a stroke. I spent 6 months in hospital but the real recovery started when I got home. I wish there had been more physiotherapy and speech therapy to help me recover faster. Please share your ideas so we can make stroke services better for everyone.”

Ian, from Bangor
Reshaping stroke services in Northern Ireland

But, it’s not enough.

In Northern Ireland, many stroke survivors don’t receive the care, treatment or long-term support they should be offered.

The way stroke services are currently set up makes it difficult for stroke patients to get the best care.

With better access to treatment and services, more stroke-related deaths and disabilities could be prevented. Improved stroke services could also help lower the number of people admitted to hospital or nursing homes because of stroke.

Recent reports about stroke care have shown that there are lots of ways that stroke services can be improved.

Stroke care in Northern Ireland was also recently reviewed. The review found that there isn’t a clear regional plan for stroke care. The number of hospitals providing stroke care is also unsustainable.

One idea is to change stroke services to make sure hospital treatment joins up with community care and continued support when patients get home.

“When my husband had a stroke, it was a big shock for our whole family. We did the FAST test and thankfully he got to hospital quickly. His recovery has been slow and frustrating but we’re getting there. Everyone should have their say on the future of stroke services – you never know when your family will need these life-saving services.”

Hazel, a carer from Newtownabbey
Key themes for the future

We’ve chosen 5 key themes we think are important to stroke care:

1. Prevention
2. Emergency
3. Stroke units
4. Rehabilitation
5. Continuing support

We’ve looked at the current situation in Northern Ireland.

We’ve developed some ideas to improve services.
Idea for improving stroke services

Health and social care organisations have made 7 ideas for improving stroke services in Northern Ireland.

Please read the 7 ideas carefully. Then fill out the ‘Have your say’ questionnaire on page 23.

It’s important you ‘Have your say’, so we can improve stroke services in Northern Ireland.

“Many of us, who have had strokes, are very grateful for the excellent acute care we received. Just as important for some of us, together with our carers and families, is community based care. We wish to ensure that it is available and sustained when required.”

Professor Philip Reilly, stroke survivor from Newcastle
Idea 1
Give people who are thought to be having a TIA access to treatment at stroke units 7 days a week.

There are factors which can increase your risk of stroke. Risk factors include some lifestyle choices such as smoking, poor diet and not enough exercise. Health issues including high blood pressure, irregular heart beat and diabetes can also contribute to stroke. People need to be made aware of the risk factors of stroke so health issues can be managed and lifestyle changes made. People who have a TIA need to be treated quickly as they are at a greater risk of experiencing a stroke.

The 11 TIA assessment clinics in Northern Ireland currently only receive referrals 5 days a week. Delays are likely to lead to avoidable strokes.

What would this idea mean?

- Patients with stroke symptoms will be able to access stroke units 7 days a week.
- These units will be in hospitals with 7 day Acute Stroke Units with stroke trained staff.
- Patients may have to travel further but would be checked for stroke symptoms within 24 hours. This is in line with standards set by NICE.
Idea 2
Assess people for the clot-busting treatment thrombolysis at an appropriate number of hospitals.

People thought to have had a stroke must be taken to hospital by ambulance as quickly as possible.

It is important that people who’ve had a stroke are assessed so they can get the best treatment. A third of people who get the right blood clot-busting drugs within 3 hours make a better recovery. The treatment can only be given within 4.5 hours of symptoms starting. The effectiveness of the treatment lessens over time.

There are currently 8 hospitals in Northern Ireland that can assess whether a patient can receive clot-busting treatment. Patients who can receive the clot-busting treatment should get it within 1 hour of getting to hospital. The time it takes to give patients clot-busting treatment varies a lot between the different hospitals. Some hospitals only give 5% of patients this treatment within 1 hour, others give 87% of patients treatment within 1 hour.

Research shows that hospitals that admit higher numbers of stroke patients are more likely to deliver this treatment quickly.

What would this idea mean?

- Patients with stroke symptoms may be assessed at fewer, but more stroke specialised, hospitals in Northern Ireland than they are currently.
- Some patients may have to travel further to receive clot-busting drugs in some cases. But overall more patients could receive clot busting drugs.
- More patients could receive thrombolysis.
Idea 3
Make the clot removal procedure Thrombectomy available 24 hours a day and 7 days a week to suitable patients.

A new treatment called Thrombectomy (clot removal) is usually given up to 6 hours after symptoms start. It greatly improves the chances of a good recovery. The new clot removal treatment, Thrombectomy, is currently only available in the Royal Victoria Hospital. This is because clot-removal requires lots of medical experts in one location. Royal Victoria is currently the only place they are all available.

What would this idea mean?

- Clot removal (Thrombectomy) could be available 24 hours a day, 7 days a week and to more patients.
- Eligible patients could travel by ambulance from across Northern Ireland to Belfast to receive this treatment.
- This would prevent many people being disabled as a result of stroke.
Idea 4
Create an appropriate number of hyperacute Stroke Units to deliver special early hospital care to every stroke patient.

The first 3 days after a stroke is called the hyperacute phase. Stroke patients should be brought by an ambulance to a hyperacute Stroke Unit. These special stroke units care for stroke patients in the first 3 days they are in hospital. This type of unit should be available 24 hours a day, 7 days a week.

There is strong evidence that patients who get hyperacute care are more likely to be alive, independent and living at home 1 year after their stroke.

This is because they are likely to receive hyperacute stroke care. Hyperacute stroke care includes swallow tests, early rehabilitation and special assessments.

Health and social care organisations will talk to experts in stroke and stroke survivors to choose which hospitals would be best placed to admit stroke patients in the future.

What would this idea mean?

- We will work with key people to decide how many hyperacute Stroke Units there should be and where they should be located.
- The number of hospitals admitting stroke patients could be reduced.
- All patients will be sent to hyperacute Stroke Units.
- More patients will be able to access hyperacute stroke care in the first 72 hours.
Idea 5
Create an appropriate number of Acute Stroke Units, located alongside hyperacute units where possible.

If a stroke patient needs more care after three days, they are moved to an Acute Stroke Unit. An Acute Stroke Unit is an area in a hospital that is run by a special team of stroke trained professionals. It has equipment for monitoring and rehabilitating patients. Patients treated in an Acute Stroke Unit show more improvement than patients treated in a general ward.

Being treated in a special stroke unit is very important for stroke patients. However, currently around half of patients are admitted to stroke units when they first arrive at hospital. Many existing stroke units don’t meet the required standard.

What would this idea mean?

- We will work with key people to decide how many Acute Stroke Units there should be and where they are located.
- Acute Stroke Units would be located alongside or near hyperacute Stroke Units in most cases.
- Patients will receive all of their hospital care in specialist stroke units.
Idea 6
Provide community stroke services that can give Early Supported Discharge. They will be able to give the recommended amounts of therapy. They will be able to respond over 7 days.

Two thirds of stroke survivors need rehabilitation after leaving hospital. Some will be able to receive Early Supported Discharge. Early Supported Discharge continues therapy currently provided in hospital at home.

Early Supported Discharge improves recovery, long-term survival and shortens stays in hospital.

Every Trust in Northern Ireland has Community Stroke Teams. However, not all Trusts provide Early Supported Discharge or 7 day services.

NICE recommends that patients looked after by Community Stroke Teams should be reviewed every 1 to 3 days after they leave hospital. However patients in Northern Ireland can sometimes wait up to 5 days.

Reports say that it is difficult for patients to get extra therapy. Extra therapy includes physiotherapy, speech therapy and emotional support.

What would this idea mean?

- All patients would be able to get the recommended amount of therapy. This would be 7 days a week in hospital or at home.
- This will enable better recovery.
Idea 7
Make sure that stroke survivors and carers can get services from Health and Social Care organisations and voluntary organisations when they need them. This will help them to make a better recovery.

Services for stroke survivors offered by the Stroke Association and Northern Ireland Chest, Heart and Stroke are very beneficial for patients.

These services allow stroke survivors to continue getting better and adapting to life after stroke. These recovery services help people to improve their general health and wellbeing. The services improve mobility and communication after stroke.

After treatment and rehabilitation, half of stroke survivors have lasting problems which affect their independence. They may also be unable to resume their previous hobbies or employment. It is important to build positive, long-term care services to help stroke survivors and their carers rebuild their lives after stroke. These long-term services should make sure stroke survivors receive the right support at the right time. They should give people the chance to fulfil their potential after stroke.

Health and social care organisations know that this is a time when people have problems accessing services. In particular physiotherapy, speech and language therapy, back to work rehabilitation, counselling and psychological support can be difficult to access.

What would this idea mean?

- Health and social care organisations will work with stroke survivors, carers and stroke organisations to develop long-term support. These will help people get the right support, at the right time and in the right place.

- Health and social care organisations will work with community partners including charities to provide support for stroke survivors and their families.
Have your say

Now you’ve carefully read our 7 ideas for improving stroke services, let us know what you think. Please ‘Have your say’ by filling out the following questionnaire.

Please send your questionnaire by email or post, see details below.

Where to send your questionnaire

Email it to reshapingstroke@hscni.net

Send it to Reshaping Stroke Services, Health and Social Care Board Comissioning Directorate 12-22 Linenhall Street Belfast BT2 8BS

Or you can attend one of the many public meetings organised by Northern Ireland Chest, Heart, Stroke and Have your say.

For more information call Health and Social Care on 028 95363054

Thank you for helping improve stroke services in Northern Ireland.
Idea 1
Give people who are thought to be having a TIA access to treatment at stroke units, 7 days a week.

Please tick the following:

- Agree [ ]
- Neither agree or disagree [ ]
- Disagree [ ]

Your comments
________________________________________________________
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Idea 2
Assess people for the clot-busting treatment thrombolysis at an appropriate number of hospitals.

Please tick the following:

- Agree [ ]
- Neither agree or disagree [ ]
- Disagree [ ]

Your comments
________________________________________________________
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Idea 3
Make the clot removal procedure Thrombectomy available 24 hours a day and 7 days a week to suitable patients.

Please tick the following:

- Agree [ ]
- Neither agree or disagree [ ]
- Disagree [ ]

Your comments
________________________________________________________
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Idea 4
Create an appropriate number of hyperacute Stroke Units to deliver special early hospital care to every stroke patient.

Please tick the following:

- Agree □
- Neither agree or disagree □
- Disagree □

Your comments


Idea 5
Create an appropriate number of Acute Stroke Units, located alongside hyperacute units where possible.

Please tick the following:

- Agree □
- Neither agree or disagree □
- Disagree □

Your comments


Idea 6
Provide community stroke services that can give Early Supported Discharge. They will be able to give the recommended amounts of therapy. They will be able to respond over 7 days.

Please tick the following:

- Agree □
- Neither agree or disagree □
- Disagree □

Your comments


Idea 7
Make sure that stroke survivors and carers can get services from Health and Social Care organisations and voluntary organisations when they need them. This will help them to make a better recovery.

Please tick the following:

- Agree □
- Neither agree or disagree □
- Disagree □

Your comments

________________________________________________________

________________________________________________________

“When my husband had a stroke he received excellent care in the Royal Victoria Hospital and Musgrave. But there isn’t enough practical support to make life better for survivors and carers in the long years after stroke. I want to see more investment in long term support.”

Catherine, from Belfast