Better Heart Disease & Stroke Action Plan

easy access version

for people with stroke and aphasia
If you have aphasia you may want to have someone with you to help you to understand the Action Plan.
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Message from Nicola Sturgeon MSP

Heart disease and stroke are priorities for the health service in Scotland.

The Scottish Government asked people in Scotland for their views about stroke.

Many people

- wrote to us
- came to a meeting in Glasgow in December 2008

The Scottish Government has listened to people and included what they said in the Action Plan.

The Scottish Government has worked closely with

- The British Heart Foundation
- Chest, Heart & Stroke Scotland
- The Stroke Association
The Action Plan takes a new approach to health care

• the person is at the centre
• health care is based on what we know from research
• equal care for everyone
• care when it is needed

What are the aims of the Action Plan?

• to prevent heart disease and stroke
• to encourage the health service, charities and others to work together
• to improve care and support
• to provide better services
• to make sure that local services are available

Services

• health care
• social care
• charities
What action is going to happen?

This Action Plan gives a list of actions – to improve care for people with heart disease and stroke.

Who will take action?

The Managed Clinical Networks in each Health Board can take action

**Managed clinical networks (MCNs)**

Each health board has a managed clinical network.

Staff and people with stroke work together to improve stroke services in the area.
The National Advisory Committee for Stroke

- will check that Health Boards are taking action
- will report to the Scottish Government

National Advisory Committee for Stroke

The Committee is a group of people who work in stroke services:
- doctors
- nurses
- therapists
- charities
- Scottish Government
- people who have had a stroke

The meetings are in the Scottish Government health building in Edinburgh.

The future in Scotland

The Scottish Government believes that

- this work will help to change stroke services in Scotland
- Scotland can lead the way in developing good services
**What is a stroke?**

A stroke happens in the brain.

A stroke on one side of the brain can make the **opposite side** of the body weaker.
A stroke happens when there is

- a clot

- or a burst in one of the blood vessels in the brain – this causes a bleed

About 85% of people have a clot and 15% have a bleed.
Why is stroke an emergency?

It is important that people go into hospital as soon as possible after signs of a stroke

- to have a brain scan
- to see a stroke specialist
- to start medical treatment

Reducing Risk

How can we prevent heart disease and stroke?

The health service can help people to find out how to

- live a healthy life
- make lifestyle changes

Not all people in Scotland have the same chance to lead a healthy life.

The Scottish Government wants to change this.

What are the risks for heart disease and stroke?

1. smoking

Smoking increases the risk of heart disease and stroke.

Before a stroke, people should have help to give up smoking to prevent a stroke.

After a stroke, people should have support to stop smoking when they leave hospital.
2. **alcohol**

Alcohol increases blood pressure.

Drinking **alcohol can increase the risk** of heart disease and stroke.

**Action**

Make sure that people have advice and support about alcohol use

3. **high blood pressure**

People with high blood pressure should have

- check ups about their risk of heart disease and stroke
- lifestyle advice

4. **cholesterol**

- fat that can build up in the blood vessels and cause blockages
- people with high cholesterol are at **high risk of stroke**
5. weight

- people who are overweight have 2–3 times the risk of stroke
- Scottish Asians are at greater risk of stroke than others in Scotland

6. diet

- reduce salt – less than 1 teaspoon a day
- reduce fat
- reduce sugar

The Scottish Government is helping

- young children in poor areas
- young mothers in poor areas
- healthier food in schools

7. exercise

- helps to prevent stroke
- helps recovery after a stroke

The Scottish Government wants people to exercise in schools, at home and at work.
8. **counselling and psychological support**

People sometimes feel depressed after a stroke.

They need **support and counselling**.

9. **new approaches are needed about the risks of stroke**

for example chemists could

- check blood pressure
- check heart rate
- do blood tests to check cholesterol levels

**Action**

All GPs and nurses in health centres should have training about healthy living.

They can help people to make lifestyle changes.
Stroke services – how they work

 Stroke services need to

- provide **high quality care**
- make sure that **care is based on evidence**
- provide care **at all stages**

**Action**

⚠️ Health Boards should make sure that stroke services offer a full service.
Raising awareness of stroke

The general public don’t always understand what stroke is. Everyone needs to know that stroke is a medical emergency.

**FAST – campaign to raise public awareness of stroke**

Face
Arm
Speech
Time to call 999

Chest, Heart & Stroke Scotland has supported this campaign.

**Action**

- Health Boards should continue to support the public awareness campaign
- the National Advisory Committee for Stroke will look at the best way to raise awareness of stroke
- Health Boards should develop ways to raise public awareness of stroke locally
Awareness of stroke should be included in First Aid training

- at work
- in schools
- for community groups
- for health service

Action

All staff who see people with signs of stroke should have awareness training

- ambulance staff
- accident and emergency staff
- local GPs and nurses
- NHS 24
Early signs of stroke – warning signs

About 1 in 5 people who have a stroke have warning signs

- headaches
- numbness
- tingling

They can have medication to reduce the risk of stroke

- to stop clots
- to thin the blood
- to lower blood pressure
- to lower cholesterol
Mini strokes

= small strokes

They are sometimes called transient ischaemic attacks (TIAs)

2 services can give people help after mini strokes to reduce the risk of a full stroke

- clinics that are available every day
- phone helpline

recognise mini stroke
\[\rightarrow\]
treatment
Thrombolysis

A drug to reduce clots in blood vessels.

It works best up to $4^{1/2}$ hours after the first signs of stroke.

It can only be used in people who have had a clot, not a bleed.

People need a brain scan first to find out if they have a clot. If so they may have thrombolysis.

It is not a cure, but it can reduce disability in some people.
Thrombolysis can only be used if

- doctors know when the **signs of stroke** started
- the person is assessed by a **specialist doctor**
- the person has a brain scan **immediately**

Thrombolysis is only **appropriate for about 10–15% of people** who have a stroke.

At the moment thrombolysis is not available in all parts of Scotland.

**Training for thrombolysis**

Chest, Heart & Stroke Scotland is **providing training for doctors and nurses** to do thrombolysis

- so that more people with signs of stroke can have this treatment

**Action**

!! Health Boards should look at ways to provide thrombolysis
Examples of early treatment

Lothian is using a phone helpline for **doctors to phone a stroke specialist**. This reduces waiting times.

In Aberdeen stroke specialists have links with doctors in Orkney and other areas so that people can have **early treatment**.

**Telemedicine**

Stroke specialists use computers and telephone links.

They discuss results with local doctors.

People with stroke can have treatment as soon as possible.

**Action**

⚠️ Health Boards should find out whether telemedicine would help in their area.
Operation – Carotid endarterectomy

Carotid endarterectomy

An operation to clear blockages of the blood vessels of the neck.

These blockages can cause a stroke.

- about 500 people a year have this operation
- if people have this operation after a mini stroke it reduces the risk of a full stroke
- the standard is for operation within 14 days
- at the moment the waiting time is longer

Action

Health Boards should look at

- quicker referrals to specialist clinics
- quicker scans
- quicker referral for operations
- more surgeons
Stroke journey – in hospital

Stroke unit

A special ward where stroke patients are looked after by a team of specialists.

People should expect to go to a stroke unit early after a stroke.

In 2008, 57% of people went to a stroke unit (Scottish Stroke Care Audit 2009)

Scans

There is progress with scans for stroke

- brain scans – CT and MRI
- heart scans – ECG and echocardiogram

The health service is looking for ways to improve scans

- immediate access
- available 24 hours a day
Stroke units

More people with stroke can now go to a stroke unit

<table>
<thead>
<tr>
<th>Stroke units in Scotland</th>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>year</td>
<td>number of stroke units</td>
<td>number of stroke beds</td>
</tr>
<tr>
<td>2002</td>
<td>31</td>
<td>583</td>
</tr>
<tr>
<td>2007</td>
<td>38</td>
<td>768</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Standards about going to a stroke unit – within 24 hrs</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>old standard</td>
<td>70 % of people should go to a stroke unit</td>
</tr>
<tr>
<td>new standard</td>
<td>90 % of people should go to a stroke unit</td>
</tr>
</tbody>
</table>

Action

The National Advisory Committee for Stroke should help to make it easier for people to go to a stroke unit.
Stroke unit staff

Stroke units need more nurses to

- check people’s general health – temperature, blood pressure
- check on swallowing
- give early treatment – medication
- check that people have enough to eat and drink, especially if they have swallowing problems

Action

The health education service should find out if all nurses in stroke units have specialist knowledge and skills.

Stroke units need staff with the right skills and training

There are not enough

- nurses and therapists in stroke units
- doctors who specialise in stroke
Specialist training about stroke for doctors, nurses and therapists

Chest, Heart & Stroke Scotland training is available to 70% of staff

- computer training
- thrombolysis training – see page 22

Computer training

All health care staff can use this to learn about stroke.

Staff can learn about all aspects of stroke care.

Action

Health Boards should make sure that staff can access computer training.

Training for

- social care staff
- local GPs and nurses

This was supported by The Stroke Association.
Standards of stroke care

Other standards of care have improved between 2005–2007.

Stroke services need to keep on improving.

Action

The Scottish Government should continue to check

• if Health Boards are meeting the standards
• if they don’t, they should have plans for action

Health Boards collect information about

• how long it takes to get to hospital
• how long it takes for assessment
  - by stroke specialist
  - brain scan

Action

The Government health information department will put this information together and check whether standards are met.
People with stroke have complex needs

Including

- physical health
- thinking and planning
- mental health

At the moment only 1 in 3 stroke units have psychologists.

Psychologists help people who have problems with

- memory
- thinking and planning
- anxiety, depression and stress
- relationships

Psychologists assess people and offer therapy, counselling and advice.
Hospitals and community support need to **work together**

- to help people with stroke to become as **independent as possible**

52% of people in Scotland can have therapy when they leave hospital from

- early support teams
- community therapy

The Scottish Government wants therapy and support to be available **across Scotland**.

Rehabilitation Co-ordinators in each Health Board will look at ways to provide **more support**.

**Rehabilitation Co-ordinators**

Help to make sure that people with stroke and their families have the support they need

- in hospital
- after hospital

There is a rehabilitation co-ordinator in each health board in Scotland.
Support

Action

There need to be standards for rehabilitation and support

Health Boards could look at better ways to support people

• when they leave hospital
• later on

Chest, Heart & Stroke Scotland nurses

In more than $\frac{1}{2}$ of Scotland there are stroke nurses who give

• advice
• information
• support

for up to 12 months after going home

Action

Health Boards must make sure that people with stroke have support after hospital

- to become as independent as possible
Many people have ongoing difficulties after a stroke

Stroke can cause

- aphasia 30–40%
- difficulty with thinking and planning 30–40%
- dementia
- depression 20–50%
- visual problems 60–70% – see page 40

Many people need **support from their family**

**Aphasia**

People with aphasia have difficulty

- talking
- understanding
- reading
- writing

When people with aphasia are under stress it makes communication harder or impossible.
People with stroke should have **ongoing support** to live as independently as possible

- information about health services and support
- information that people can understand
- rehabilitation
- psychological support
- how to reduce the risk of another stroke
- check-ups at GP/nurse every year
- social care
  - home care support
  - personal care
  - equipment
  - sheltered housing
  - nursing homes
- ways that people can help themselves
- exercise and leisure
- support for families
Therapy and support

Support should be available from

- physiotherapist
- occupational therapist
- speech and language therapist & communication support
- psychologist
- optician or eye specialist
- dietitian
- support groups and volunteers

Information about therapy

People with stroke should have

- information and advice about therapy
- at the time they need it
- information they can understand
- information about all services
Access to therapy varies across Scotland

- people with stroke could ask directly for more therapy (self-referral)
- they should have therapy when they need it
- people with stroke want to have more control

**Action**

Health Boards should look at ways that people could refer themselves for therapy

**Exercise**

In some areas of Scotland there is fitness training and exercise classes for people with stroke.

**Action**

Health Boards should work with leisure centres so that people with stroke can exercise safely.
Physiotherapy

Access to physiotherapy is patchy.

Physiotherapy at home after stroke

• helps recovery
• increases independence

Specialist physiotherapy should be available at all stages of the person’s recovery.

Occupational therapy

Research shows that occupational therapy

• helps people to do everyday activities and cope at home
• helps recovery

Action

Health Boards should make sure that people with stroke have occupational therapy

Ankle-foot supports

Ankle-foot supports can help some people with stroke.

People should have these supports if they need them.
Speech and language therapy & communication support

Health Boards need to make sure there is

- enough speech and language therapy
- enough voluntary support

Campaign about communication

In December 2008 there was a campaign by

- The Royal College of Speech & Language Therapists
- Chest Heart & Stroke Scotland
- Speakability
- The Stroke Association
The campaign asked people with aphasia about

- speech and language therapy
- voluntary communication support
- therapy & communication support in hospital
- getting back to life at home

280 people with aphasia replied about

- the challenges that people with aphasia face
- what therapy and support people with aphasia need

Results – there were 4 main messages

1. therapy & support in hospital and later on

People need

- more speech and language therapy
- more voluntary support
- services that work together to help people to live independently
2. **awareness of aphasia in health care**
   - raise awareness of aphasia for health care staff
   - how to communicate with people with aphasia
   - provide easy access information about health services

3. **public awareness** of aphasia
   - raise public awareness of aphasia
   - how to communicate with people with aphasia
   - provide easy access information, for example about benefits and care

4. **more information** – how many people have stroke and aphasia?
   - this would help to plan the therapy and support they need
Chest, Heart & Stroke Scotland support (Volunteer Stroke Service)

Chest, Heart & Stroke Scotland support is available across 90% of Scotland

- group support
- support for people in hospital
- one to one support at home

**Action**

Health Boards should make sure that speech and language therapy & communication support are available

Money is available for self help groups

- long term conditions self-management fund [www.ltcas.org.uk](http://www.ltcas.org.uk)

Visual problems after stroke

- 60–70% of people with stroke have visual problems
- everyone who has a stroke should have a sight test as soon as possible after they leave hospital
Support from Dietitians

People with stroke should have

• an assessment of what they eat
• advice and support about what to eat

Psychological support

People with stroke often need emotional support

People in poorer areas need more support for longer

Return to work

Rehabilitation may help some people with stroke to return to

• work
• education
• doing voluntary work
Younger people with stroke have **specific needs**

They need

- help to return to work
- education and training
- choice of support for themselves
- support for their families
- financial support

GPs should be aware that **younger people can have a stroke**

**Benefits for younger people**

People with stroke under 65 can’t usually claim for free personal care.

They can **only claim for personal care** if they

- live in a nursing home
- have dementia
Care homes

People in care homes should have the **therapy and support** they need.

Staff in care homes should have specialist training in stroke.

Support to die with dignity

People who are very ill need support – for example with pain

**Action**

🛠️ Health boards should help people with stroke to live well and die with dignity
Research & projects – improving care

Research has found that people with heart disease and stroke *don’t have enough information*

Lack of information makes people

- anxious
- confused
- they have less control

**People with stroke need**

- one to one support from a health worker
- to understand what has happened to them
- information immediately after the stroke

**People need to know**

- **why** they have had a stroke
- **what they can do** – for example, change lifestyle
- **how to take responsibility** for their own health
People with stroke and their families want better links

- between hospital and GPs
- care that is **centred on the person** and their needs

**Action**

⚠️ Health Boards need to listen to people’s concerns and take action

**Stroke Voices project**

This project aims to make **sure that** the health service

- **listens to the views of people with stroke** and their families

The project helps people with stroke and their families to

- have skills and confidence to work together with the health service
- have information, training and support
- build links with other people with stroke and their families
- build links with the health service and voluntary support
Guidelines for stroke care in hospital

The guideline for stroke care in hospital was published in December 2008.

It gives up to date evidence for best treatment of stroke

- to prevent a further stroke
- to reduce disability
- to help recovery

Chest, Heart & Stroke Scotland helped to develop a patient version of this guideline.

Guideline for rehabilitation after stroke

This guideline is being updated at the moment.
Quality Improvement Scotland

Quality Improvement Scotland is part of the health service. It has helped to improve stroke care.

- stroke master class for health care staff in 2007 to share best care and knowledge
- response to the Aphasia in Scotland report – the Road to Recovery
- easy access version of the Aphasia in Scotland report
- report on swallowing
- report on ankle-foot support
Collecting information about stroke on computer

Health Boards and GPs are looking at ways to collect information to improve stroke care, for example

- quicker letters from hospital to GPs
- individual information packs for people with stroke
- quicker reports from scans and x-rays
Information

People with stroke need to know about all the information and support that is available from

• health care
• local authority
• voluntary support

A health information service will be available in Spring 2010 – NHS inform.

Advice Lines

Chest Heart and Stroke Scotland 0845 077 6000

Different Strokes 0845 130 7172

Headway 0808 800 2244

Speakability 0808 808 2244

The Stroke Association 0845 3033 100
Stroke and aphasia handbook
- Connect, the communication disability network

This book

- answers questions about stroke and aphasia
- helps people to join in discussions
- gives choices
- helps people to make decisions

It gives information about all aspects of stroke

- early on
- coping with life

People with stroke and aphasia helped to design this book.
Stroke and aphasia identity cards

Stroke Helpline
0845 3033 100
www.stroke.org.uk

Name:
Tel:
Emergency contact:

I have had a stroke and find it difficult to speak, read or write
Please give me time to communicate. Speak clearly, taking your time and write down key words. Your help and patience would be appreciated.

I have had a stroke. I find it difficult to
SPEAK
READ
WRITE
UNDERSTAND

Could you please speak slowly and clearly and give me time.
Thank you

Aphasia Friendly

I have had a stroke/head injury.
As a result I have aphasia.
This means I find it difficult to speak, read or write, especially under pressure.
Please speak clearly, and give me time.
Thank you

I have aphasia

You can help by taking things slowly and giving me time.
Thank you
Chest, Heart & Stroke Scotland has published

conversation support book

stroke journey

• early days
• rehabilitation
• moving on
My Stroke Book –
Glasgow Health Board

This book gives

- information and support for people with stroke and their families
- everyone who goes to the stroke unit in Glasgow gets a copy
- nurses also give the book to people after they go home

Stroke Workbook

This workbook

- helps with recovery for people with stroke and their families
- gives information and support
- uses a diary and relaxation tape

Action

⚠️ Health boards should encourage use of the stroke workbook
Information about stroke is available from

Aphasia help – explains about stroke and aphasia
http://www.aphasiahelp.org/

AphasiaNow – for people with aphasia
http://www.aphasianow.org/

Chest, Heart and Stroke Scotland
65 North Castle Street
Edinburgh
EH2 3LT
Advice Line: 0845 077 6000
http://www.chss.org.uk/

Connect – the communication disability network
16–18 Marshalsea Road
London SE1 1HL
Telephone. 020 7367 0840
http://www.ukconnect.org

Different Strokes
Different Strokes Central Services
9 Canon Harnett Court
Wolverton Mill
Milton Keynes MK12 5NF
Telephone: 0845 130 7172
http://www.differentstrokes.co.uk

Headway – the brain injury association
4 King Edward Court
King Edward Street
Nottingham
NG1 1EW
United Kingdom
Helpline: 0808 800 2244
http://www.headway.org.uk

There are local contacts for areas in Scotland.
NHS 24
http://www.nhs24.com/content/default.asp?page=s5_4&articleId=351

NHS Education for Scotland

Speakability
1 Royal Street
London SE1 7LL
Helpline: 0808 808 9572
http://www.speakability.org.uk

The Stroke Association
Links House
15 Links Place
Edinburgh
EH6 7EZ
Stroke helpline: 0845 3033 100
http://www.stroke.org.uk/
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This easy access version was produced by

**Annette Cameron, Speech and Language Therapist**

A group of people with aphasia across Scotland

Design and layout by Medical Illustration, University of Aberdeen