

# 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.

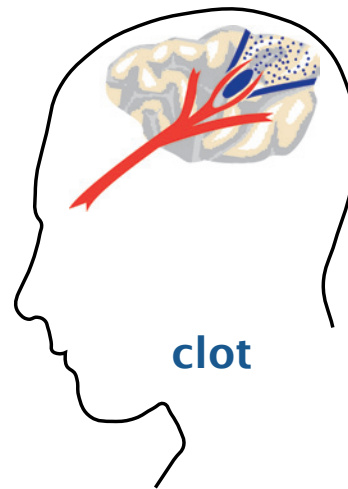
A stroke on one  
side of the brain  
can make the  
**opposite side** of  
the body weaker.



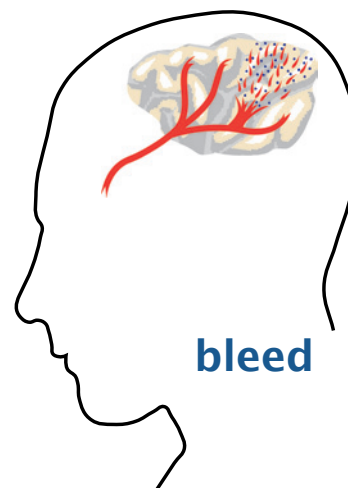


## A stroke happens when there is

- 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**

The Scottish Government produced a **Better Health, Better Care Action Plan.**



# 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

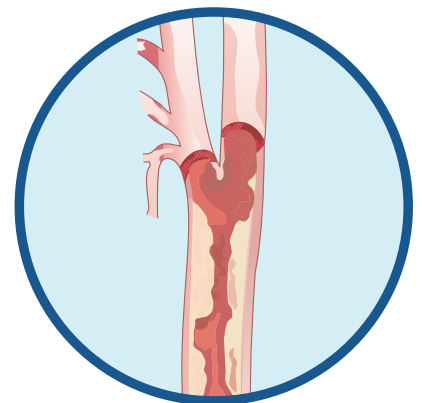
People with high blood pressure should have

- 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



There are 14 Health Boards in Scotland



Each health board has a Managed Clinical Network (MCN)



Staff and people with stroke work together  
to improve local stroke services

Stroke services need to

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

recognise stroke  
↓  
treatment

## Action



Health Boards should make sure that stroke services offer a full service.

# Raising awareness of stroke

A stroke can happen at any time. Think FAST & save a life. Call 999.

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

**F**ace

**A**rm

**S**peech


**T**ime 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

# Stroke journey – the beginning



## 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

### Mini strokes

= small strokes

They are sometimes call 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



treatment

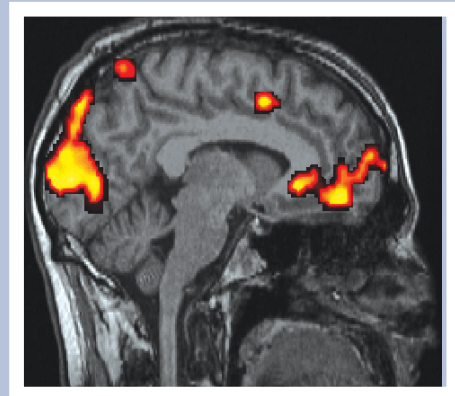
# Thrombolysis

## Thrombolysis

A drug to reduce clots in blood vessels.

It works best up to 4<sup>1</sup>/<sub>2</sub> 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.

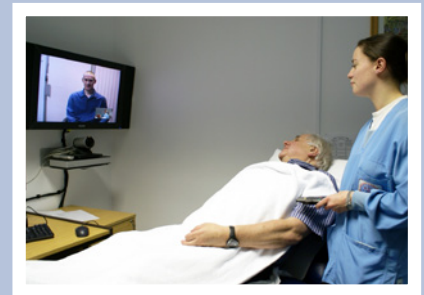
In Aberdeen stroke specialists have links with doctors in Orkney and other areas so that people can have **early treatment**.

### Telemedicine

Stroke specialists use computers and telephone links.

They discuss results with local doctors.

People with stroke can have treatment as soon as possible.

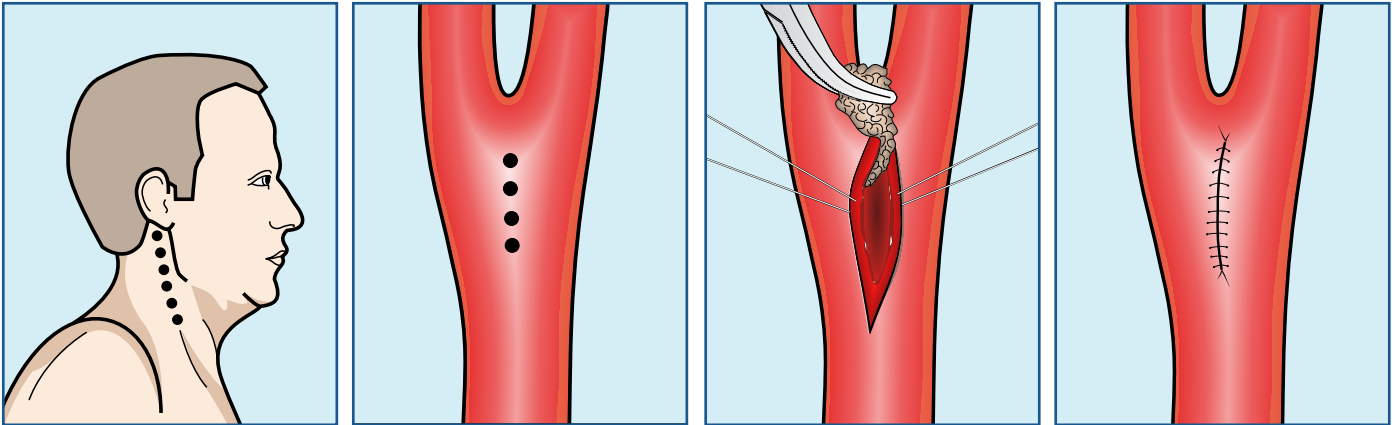


### Action



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

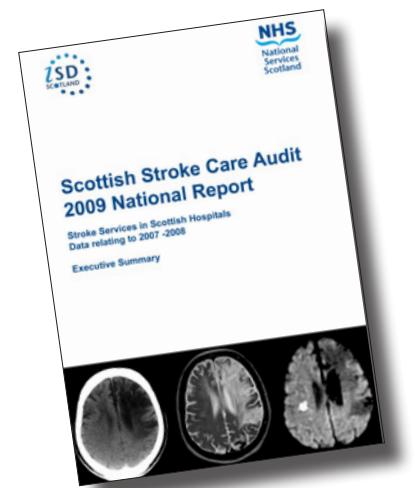


## Stroke unit

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

Stroke units in Scotland		
year	number of stroke units	number of stroke beds
2002	31	583
2007	38	768

Standards about going to a stroke unit – within 24 hrs	
old standard	70 % of people should go to a stroke unit
new standard	90 % of people should go to a stroke unit

### 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.

# Stroke journey – after hospital



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 – under 65



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



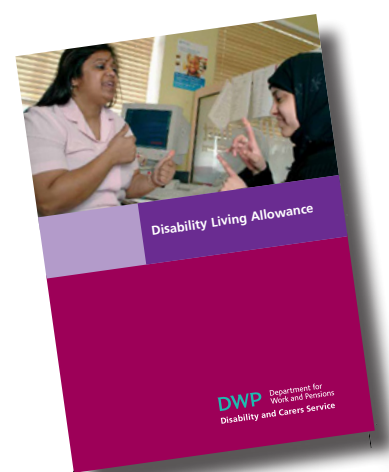
GPs should be aware that **younger people can have a stroke**

## 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



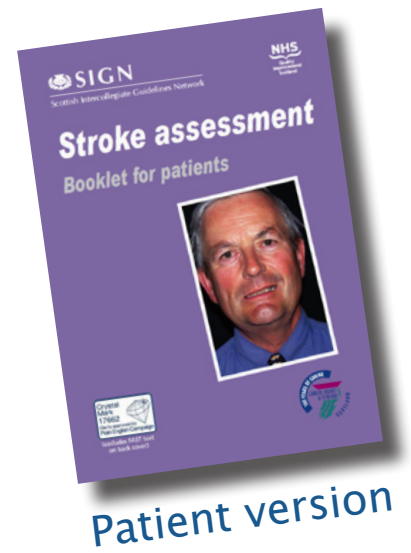
## Guidelines for stroke care in hospital

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

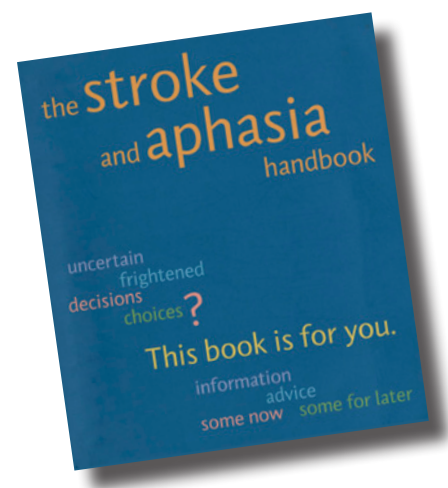


## Stroke and aphasia handbook

– 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: \_\_\_\_\_

Registered Charity No. 211015 and in Scotland No. SC037789

**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.

More information, resources  
and additional cards available from  
**Connect – the communication disability network.**

phone: 020 7367 0840  
email: publications@ukconnect.org  
[www.ukconnect.org](http://www.ukconnect.org)



**I have  
aphasia**

**I have had a stroke.**

As a result, I have **aphasia**.  
This means I have difficulty talking,  
reading and writing, particularly  
when under pressure.

**You can help**  
by taking things slowly  
and giving me time.

**Thank you**




**Aphasia  
Friendly**

**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



Advice Line: 0845 077 6000  
[www.chss.org.uk](http://www.chss.org.uk)



1 Royal Street  
London SE1 7LL  
Tel. **080 8808 9572** (UK48hrs)  
Advice for Dysphasic Adults  
Registered Charity number: 101010

Name \_\_\_\_\_  
Tel \_\_\_\_\_  
Address \_\_\_\_\_

**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.**

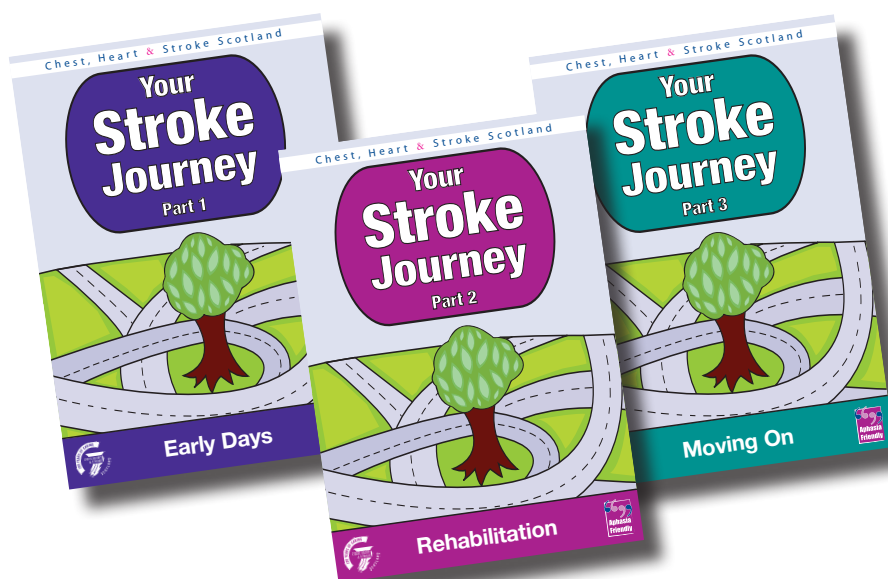
Thank you

**Chest, Heart & Stroke Scotland has published conversation support book**



stroke journey

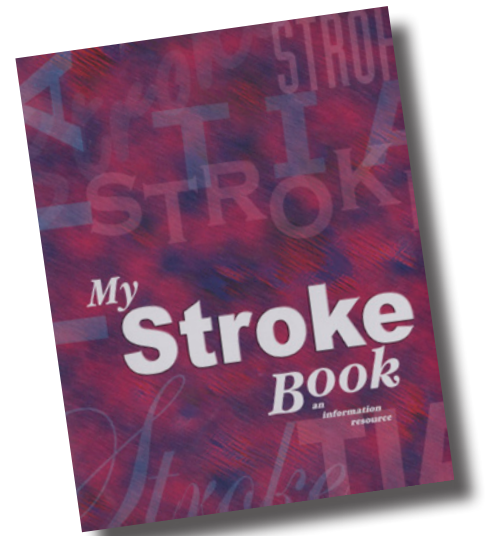
- early days
- rehabilitation
- moving on



## 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](http://www.nhs24.com/content/default.asp?page=s5_4&articleId=351)

## **NHS Education for Scotland**

<http://www.strokeinfoplus.scot.nhs.uk/cmspi/strokepi/index.aspx>

## **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/>



# Useful words

## Aphasia

People with aphasia have difficulty

- talking
- understanding
- reading
- writing

When people with aphasia are under stress it makes communication harder or impossible.

## Carotid endarterectomy

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

These blockages can **cause a stroke**.

## Cholesterol

Fat that can build up in the blood vessels and cause blockages



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Staff and people with stroke work together to improve stroke services in the area.

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= small strokes

They are sometimes call transient ischaemic attacks (TIAs)

## National Advisory Committe 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.

**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.

## **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.

## **Services**

- health care
- social care and charities

## **Stroke unit**

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

## Telemedicine

Stroke specialists use computers and telephone links.  
They discuss results with local doctors.

People with stroke can have treatment as soon as possible.

## Thrombolysis

A drug to reduce clots in blood vessels.

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

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

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