



Royal College
of Physicians

Stroke
association



Care after stroke or transient ischaemic attack

What, when, and why?

Information for patients and their carers

2016

About this book

What is this book?

This is a short “**easy read**” version of the detailed National Clinical Guideline for Stroke.

- It tells you **what care should be provided** after stroke
- It tells you some **key points** but in less detail
- It is written for **people with stroke** and their **carers**
- It is for anyone with **difficulty reading or understanding**

Who wrote it?

A **working party** including people with stroke, NHS staff, university researchers, and charities.

It is **published and distributed by:**

The Royal College of Physicians London, and the Stroke Association.

Where can I read more?

Find more detail in the **full guideline** at www.strokeaudit.org/guideline

NICE has accredited the process used by the Royal College of Physicians London to produce its practice guidelines. Accreditation is valid for five years from September 2016 and is applicable to guidance produced using the processes described in the National Clinical Guideline for Stroke process manual (2016). More information on accreditation can be viewed at www.nice.org.uk/accreditation.

Background

The Royal College of Physicians has produced a **National Clinical Guideline** for Stroke every 4 years since 2000.

This contains **recommendations for the treatment** of people who have had a stroke or transient ischaemic attack.

Recommendations are based on the **best current research evidence**.

It covers **the whole stroke pathway** from emergency hospital treatment through to long term rehabilitation and how to prevent further strokes.

The **recommendations set standards** for what should be provided by professionals and managers for patients and their carers.

This 'easy read' version produced by people with stroke includes:

- **information on stroke** and transient ischaemic attack (TIA)
- a glossary **explaining more technical words**

It will tell you:

- **what** care should be provided after stroke
- **when** this care should be provided
- **why** this care is important

What is stroke?

A stroke occurs when **the blood supply to part of the brain is cut off**.

This could be due to a **blockage** in one of the blood vessels, known as an ischaemic stroke (infarction), or a **bleed** in the brain (haemorrhage).

Most stroke patients have a blockage (infarction).

Around 1 out of 9 people have a bleed (haemorrhage).

Stroke **affects people differently**. This depends on the part of the brain affected, the size of the stroke and how healthy the person was before.

Some of the effects include movement, speech, vision, thought processes and feelings.

A suspected stroke is an emergency.

People **should NOT wait** to see if the symptoms get better.

An ambulance should be called immediately.

What is a transient ischaemic attack (TIA)?

A TIA is a transient ischaemic attack, meaning that stroke **symptoms get better quickly** (usually in minutes or hours).

A suspected TIA is an emergency.

People **should NOT wait** to see if the symptoms get better.

An ambulance should be called immediately.

Urgent specialist assessment is needed to **prevent a full stroke**.

Diagnosis and admission



What should be done?

All patients with stroke symptoms should have a **brain scan**.

Patients with **suspected stroke** should be admitted to a **specialist stroke unit** and assessed **without delay**.

Stroke units should include a **team** of skilled nurses, doctors, therapists and others who:

- diagnose and treat stroke
- advise on prevention of further strokes
- provide stroke rehabilitation and support for families

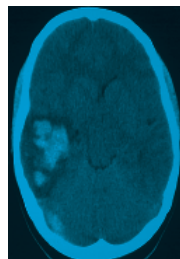
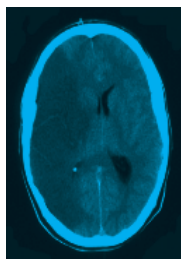


When should this be done?

All patients should have a brain scan **within 1 hour** of arriving in hospital.

Patients should go to a stroke unit **within 4 hours** of arrival at hospital.

The left scan shows an infarct or blockage (black areas). The right scan shows a haemorrhage or bleeding (white areas).



Why should this be done?

Fast treatment can **reduce** the **damage** caused by stroke.

More people will **survive** and with **less disability**.

Clot busting treatments: thrombolysis and thrombectomy

What should be done?



Thrombolysis is a special clot-busting treatment using a drug called **alteplase**.

Thrombectomy is a very new operation to remove a blood clot.

Clot-busting and clot-removal are **only suitable** for some patients.

When should this be done?



Thrombolysis should be done as soon as possible (at most within **4.5 hours of stroke**).

Thrombectomy should be done quickly, usually within 5 hours of stroke.



Why should this be done?

Thrombolysis and thrombectomy treatments can **reduce disability**.

Family / carer involvement



What should be done?

Patients should be **asked** whether they want their **family / carer** to be **involved in their stroke care**.

If the patient agrees, the carer should be **given information** about stroke, training and be **involved in decision-making**.

Carers should be offered an **assessment of their own needs** and offered support for these.

Carers' needs **should be reviewed** and addressed.



When should this be done?

The patient should be asked about the involvement of a carer **during the hospital stay**.

The carer's needs should be assessed **on transfer from hospital** and reviewed **when things change**.



Why should this be done?

Carers often support people with stroke **long after services have ended**.

Providing this care can **affect carers' health**.

Local authorities have a **legal duty** to assess carers.

Swallowing problems (dysphagia)



What should be done?

Patients with stroke should have their **swallowing tested** before drinking, eating or swallowing medicine.

Patients with an **unsafe swallow** (dysphagia) should **receive alternatives** such as **nasogastric tube feeding** (through the nose).

Patients with dysphagia should receive specialist **swallowing rehabilitation**.

Patients with dysphagia should have their **teeth brushed** three times a day.



When should this be done?

Swallowing should be **tested within 4 hours** of arriving at hospital.

Patients with swallowing difficulties should be considered for **nasogastric tube feeding within 24 hours**.

During **end-of-life care** (palliative) people should not have food and drink restricted **if that causes suffering**.



Why should this be done?

Stroke often causes **swallowing difficulties** (dysphagia) which can lead to **choking** or **pneumonia**.

Hydration and nutrition

What should be done?



Stroke patients should have an **assessment** of how **well hydrated** they are and whether they are **adequately nourished**.

If there are concerns about nourishment patients **should be referred to a dietitian** for advice and support.

Patients with **difficulty feeding themselves** should be assessed and provided with equipment to help.



When should this be done?

Hydration should be assessed **within 4 hours of arrival at hospital**.

Risk of malnutrition should be assessed **on admission**.



Why should this be done?

Malnutrition and dehydration cause **major health problems** and **reduce the chance of recovering rapidly**.

Principles of rehabilitation



What should be done?

People with stroke should be helped to **identify their goals** for rehabilitation.

They should be **actively involved** in rehabilitation and **their wishes should be considered**.

All members of the team should be involved.

Assessments should be **agreed and documented**.

Families and carers should be included where appropriate.

People should receive each therapy that they need for **45 minutes a day** for as long as they show a benefit.

People should have the chance to **practice skills and activities** as much as possible.



When should this be done?

Rehabilitation should **begin in hospital** and continue as necessary after transfer.

Therapy for mobility should begin **24-48** hours after stroke. Rehabilitation needs should be **reviewed at six months**.



Why should this be done?

Rehabilitation helps people to **increase their independence** after stroke and to **cope with any long term difficulties**.

Moving and walking



What should be done?

Patients with **difficulty moving** should be **assessed**.

Therapists should choose from a range of exercises, for example for **balance, strength or to practise walking**.

If needed, people should be **trained to use equipment** such as a wheelchair for safe independent mobility.

Repeated practice should be offered, including **treadmill training** if suitable.



When should this be done?

Patients with **difficulty moving** should be assessed by a physiotherapist **within 24 hours of stroke**.

Activities such as sitting out of bed, standing and walking should begin **24-48 hours** after stroke.

In the first two weeks short therapy sessions should be **repeated several times** a day with plenty of rests.

Therapy should continue **for as long as it is needed**.



Why should this be done?

Therapy is an important part of **recovering the ability** to move and walk.

Independence in daily life

What should be done?



People with stroke should be assessed for their **safety** and **independence** in activities of daily living.

They should be offered occupational therapy, for difficulties such as **dressing, bathing and eating**.

Carers should be included and trained in how to help.



When should this be done?

Patients with **difficulties** caring for themselves should be seen by an **occupational therapist** within **3 days** of referral.



Why should this be done?

Occupational therapy can **increase the chances of independence** in daily activities.

Bladder and bowel control

What should be done?



Stroke unit staff should **assess for constipation and incontinence** (loss of bowel or bladder control).

People with a continued loss of bowel or bladder control should be **re-assessed** and **involved in treatment plans**.

People with a continued loss of continence should be **offered information, exercises and equipment**.



When should this be done?

Bladder and bowel control should be assessed during the person's stay **on the stroke unit**.

If difficulties persist **after two weeks** they should be re-assessed.



Why should this be done?

Regaining bladder and bowel control is important for **independent living** and **self-esteem**.

Communication difficulties



What should be done?

People with difficulty communicating **should be assessed** by a speech and language therapist to diagnose dysarthria (speech difficulties), aphasia (language difficulties) or other difficulties.

Therapists should **explain the problem** to the person with stroke and **train family, carers, and communication partners**.

Early after stroke people should be given **opportunities to practice everyday communication**.

Difficulties should be **reviewed** to provide **additional therapy, communication aids or technology** if needed.



When should this be done?

Early after stroke the focus should be on **explanation and practising communication**.

People with continuing difficulties should be **reviewed for further therapy**.



Why should this be done?

Communication is important for independence, confidence and well-being. **Speech and language therapists** can help people with communication difficulties.

Psychological effects of stroke



What should be done?

Psychological care should be provided by **the stroke team**.

People with stroke should be assessed for **mood and cognitive problems**, and the findings should be **explained**.

Some people will need a **specialist psychologist** who should work with other professionals.

Information, advice and brief psychological treatments should be considered before antidepressants.



When should this be done?

Assessment of mood and cognition should be done **within six weeks** of stroke, **on transfer** from hospital and at **reviews**.



Why should this be done?

Many people with stroke **do not get the psychological support** that they need.

Good psychological care could help people to participate in rehabilitation, improve their independence in daily living and their ability to cope.

Reducing the risk of further stroke: Lifestyle



What should be done?

People should be advised to be **physically active** every day, **avoid smoking** and **limit alcohol intake** to 2 units per day.

People should be advised to **eat a healthy diet** and **reduce saturated fat and salt**.

People should be **offered advice and support** to eat healthily, reduce alcohol, stop smoking and increase activity.



When should this be done?

Advice to prevent stroke should be offered **before transfer from hospital** and **at regular reviews**.



Why should this be done?

Being overweight, smoking, high alcohol intake, and not being active can **increase the risk of a further stroke**.

The **risk of a further stroke can be reduced** by improving diet, lifestyle and taking medicines as prescribed.

Reducing the risk of further stroke: Blood pressure control



What should be done?

Patients with **high blood pressure (hypertension)** should be given **blood pressure lowering treatment**.

Treatment varies depending on the type of stroke, time after stroke, and other factors.

In the long term, systolic blood pressure should usually be kept below 130 mmHg to prevent a further stroke.



When should this be done?

Blood pressure lowering treatment should start **before leaving hospital** or **at 2 weeks**, whichever is sooner.

After hospital GPs should **check blood pressure frequently**.



Why should this be done?

Controlling blood pressure **prevents or reduces the risk of a further stroke**.

Reducing the risk of further stroke: High cholesterol



What should be done?

Patients with acute ischaemic stroke or TIA who were taking a drug called a **statin** prior to stroke should continue.

All patients who have had a stroke or TIA should be **offered statin treatment**, unless there are medical reasons not to.



When should this be done?

This should be done **before discharge from hospital** and again at **reviews**.



Why should this be done?

Statins **lower blood-cholesterol** level, which can help to **prevent a further stroke**.

Reducing the risk of further stroke: Abnormal heart rhythm



What should be done?

People with stroke need to have their **pulse checked** to ensure they do not have an **irregular heart rhythm (atrial fibrillation or AF)**.

People in AF should be offered **anticoagulant treatment**.



When should this be done?

This should be done **before discharge from hospital** and again **at reviews**.



Why should this be done?

Treatment of AF with an anticoagulant is very important because it **reduces the risk of a further stroke** by thinning the blood to prevent clots from forming.

Medication: antiplatelets



What should be done?

People with acute ischaemic stroke or TIA should receive an **antiplatelet treatment** such as **aspirin** or **clopidogrel**.



When should this be done?

This should be done **as soon as possible within 24 hours**.

People who have had **thrombolysis** (see page 10) should receive an **antiplatelet after 24 hours**.



Why should this be done?

Antiplatelet treatment is very important because it **reduces the risk of a further stroke**.



Leaving hospital



What should be done?

People with stroke and carers should be **involved** in decisions about transfers of care from hospital, and offered **copies of transfer documents**.

Home environments should be assessed before transfer.

Early Supported Discharge (ESD) should be provided if appropriate to enable people to leave hospital early.

People with stroke should **continue to receive specialist care and rehabilitation** after they leave hospital.



When should this be done?

Transfer should occur when appropriate **without delay**.

Early Supported Discharge should provide treatment at home **within 24 hours of transfer**.



Why should this be done?

Many patients **want to leave hospital as early as possible** but the process can be stressful.

Early Supported Discharge **can benefit patients and their rehabilitation**.

Driving and working



What should be done?

People with stroke should be **asked if they wish to drive**.

They should be **advised about any difficulties** that might make driving unsafe and illegal.

They should be alerted to the **exclusion period** within the latest DVLA guidelines and informed about **when to notify the DVLA**.

People with stroke should be asked if they wish to **return to work**.

They should be **assessed** to determine their **ability to return to work**.

They should be **provided with support and information** about **vocational rehabilitation** programmes.



When should this be done?

Patients should be asked about driving and working **before they leave hospital**.



Why should this be done?

Stroke can make it **unsafe to drive** and difficult to **return to work**.

Specialist support is available and can help.

Sex after stroke



What should be done?

People with stroke **should be asked** if they have any **concerns or questions** about **sex** after stroke.

Partners should also be invited to raise the subject.

People **should be reassured** that having sex **will not** lead to further strokes.

They should be **referred to a specialist** if they are experiencing problems with sexual functioning.



When should this be done?

People should be asked if they have any **concerns or questions** soon after their transfer from hospital, and **at six months and annual reviews**.



Why should this be done?

Stroke can affect sexual functioning and sexual relationships.

Staff are often reluctant to raise the subject but could provide reassurance.

Life after stroke



What should be done?

People with stroke should be **offered a review** of their health and social care.

Information, support and advice should be provided.

Further rehabilitation should be offered if required.

People should be helped to develop a **self-management plan**.

People should be helped to plan their **social and leisure** activities.

People living in **care homes** should not be excluded.



When should this be done?

The **review** should be at **six months, one year** and **annually** after stroke.



Why should this be done?

Many people have **lifelong** disability that would **benefit** from **rehabilitation and support**.

Fatigue

What should be done?



It is **very common** for people to experience fatigue and a **loss of energy** after stroke.

People with stroke who feel fatigued **should be assessed** to identify mental or physical triggers that could be adding to their fatigue.

Information, support and advice should be provided.



When should this be done?

This should be done **before discharge** from hospital and again at **reviews**.



Why should this be done?

Fatigue can affect a person's **quality of life**, which **may include work**. It can also affect a person's **ability to participate in rehabilitation** and **other activities** after stroke.

Vision



What should be done?

People with stroke often have **visual problems** including **hemianopia** (loss of part of their field of vision), blurred or double vision.

They should be assessed by a specialist and **receive information, support and advice**.

Stroke rehabilitation units should have easy access to orthoptists (vision specialists).



When should this be done?

This should be done **before discharge from hospital** and again at **reviews**.



Why should this be done?

Many people with stroke **do not receive the information and support** that they need for their **visual problems**.

This could be provided by **orthoptists** (vision specialists).

Pain and sensation



What should be done?

People with stroke sometimes experience **problems with pain**, including **shoulder pain**.

People also experience **changes or loss of sensations** such as **touch or temperature**.

They should be **checked for sensory problems and advised on how to avoid injury** to the parts of the body that are affected.

Measures should be taken to **prevent pain**, such as **arm positioning or the use of supports**.

Simple pain relief can help, and people with pain and abnormal sensation in the limbs can often benefit from **medication**.

If the pain **persists**, further treatment with a specialist may be necessary.



When should this be done?

This should be done **before discharge from hospital** and again at **reviews**.



Why should this be done?

Experiencing pain and/or abnormal sensations **can cause distress** and may also be detrimental to rehabilitation.

Palliative care

Unfortunately some individuals will not recover from stroke, either because the stroke is very severe or it is combined with other health problems.

If this is the case and death is inevitable, patients should have access to specialist care to relieve any symptoms that are causing distress.

What should be done?



People with stroke with limited life expectancy should be offered advanced care planning.

Patients dying of stroke should have access to specialist end-of-life (palliative) care. They should be offered a timely transfer to home or a hospice or care home.

All end-of-life decisions, including the withholding or withdrawal of life-prolonging treatments, should be in the dying person's best interests.

What do the terms mean?

Alteplase

The drug used to dissolve blood clots during thrombolysis

Anticoagulant

A type of drug that reduces blood clotting; examples include warfarin

Antiplatelet drug

A type of drug that helps prevent the formation of blood clots by affecting the function of blood cells called platelets; examples include aspirin and clopidogrel.

Clopidogrel

An antiplatelet drug used for stroke prevention

Dysphagia

Difficulty swallowing

Early Supported Discharge (ESD)

A system in which rehabilitation is provided to stroke patients at home instead of at hospital at the same intensity as inpatient care

Haemorrhagic stroke

A type of stroke caused when a blood vessel bursts, resulting in bleeding into the brain.

Ischaemic stroke

A type of stroke that happens when a clot blocks an artery that carries blood to the brain.

Nasogastric tube

A fine plastic tube inserted through a nostril and passed into the stomach. This allows a person with dysphagia to receive fluids, food and medication directly into the stomach.

Pneumonia

Pneumonia is an infection in the lungs partly caused by stomach contents inhaled into the lungs, usually because of dysphagia.

Statin

A type of drug used to lower cholesterol levels.

Systolic blood pressure

The upper figure on the blood pressure reading. If a blood pressure is recorded as 130/80, 130 is the systolic reading and 80 the diastolic.

Thrombectomy

The surgical removal of a blood clot

Thrombolysis

Treatment with a drug that breaks down blood clots

Transient Ischaemic Attack (TIA)

A TIA happens when the brain's blood supply is interrupted for a very short time.

Further help and support

Stroke Association

Helpline: 0303 3033 100

Textphone: 18001 0303 3033 100

stroke.org.uk

info@stroke.org.uk

Chest Heart & Stroke Scotland

Advice Line: 0808 801 0899

www.chss.org.uk

advice@chss.org.uk

Northern Ireland Chest Heart & Stroke

Helpline: 028 9032 0184

www.nichs.org.uk

mail@nichs.org.uk

Different Strokes (run by and for younger stroke survivors)

Helpline: 0845 130 7172

www.differentstrokes.co.uk

info@differentstrokes.co.uk

NHS Choices (Medical advice and information on health services)

NHS non-emergency number: 111

www.nhs.uk

Headway (Charity for people who have had a brain injury)

Helpline: 0808 800 2244 (Mon–Fri, 9am–5pm)

www.headway.org.uk

helpline@headway.org.uk

Brain and Spine Foundation

Helpline: 0808 808 1000

www.brainandspine.org.uk

helpline@brainandspine.org.uk

Age UK

England: 0800 169 2081

Northern Ireland: 0808 808 7575

Scotland: 0800 4 70 80 90

Wales: 08000 223 444

www.ageuk.org.uk

Disabled Living Foundation

Helpline: 0300 999 0004 (Mon-Fri, 10am-4pm)

helpline@dlf.org.uk

www.dlf.org.uk

Mind / Mind Cymru (England and Wales)

Infoline: 0300 123 3393

info@mind.org.uk

www.mind.org.uk

Niamh Mental Wellbeing (Northern Ireland Association for Mental Health)

Enquiries: 028 9032 8474

info@niamhwellbeing.org

www.niamhwellbeing.org

Royal National Institute of Blind People (RNIB)

Helpline: 0303 123 9999

helpline@rnib.org.uk

www.rnib.org.uk

Scottish Association of Mental Health (SAMH)

0141 530 1000

enquire@samh.org.uk

www.samh.org.uk

Alzheimer's Society (Information and support on all types of dementia)

Helpline: 0300 222 1122

enquiries@alzheimers.org.uk

www.alzheimers.org.uk

What can I do if care does not meet the guideline?

Complaints within either an **NHS** or **private hospital** should initially be **discussed with the people on the ward** to see if the matter can be resolved by **speaking with them face to face**.

This would usually be either the **Ward Manager** or the **lead clinician** in charge of your care.

For **NHS Hospitals** we recommend initially contacting the **Chief Executive of the Hospital or Trust** under which it is managed.

For further details, please refer to:

The Patients Association:

Helpline Tel: 020 8423 8999

Helpline email: helpline@patients-association.com

URL: <http://www.patients-association.org.uk/publications/how-to-make-a-complaint/>

NHS Choices:

URL: <http://www.nhs.uk/NHSEngland/complaints-and-feedback/Pages/nhs-complaints.aspx>

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