NATIONAL CLINICAL GUIDELINE FOR STROKE
for the United Kingdom and Ireland

2023 edition

Care after stroke or transient ischaemic attack

What, when, and why?

Plain language summary for people affected by stroke

Healthcare Improvement Scotland | SIGN
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Contents

Contents continued

1 | What is this summary about?

This is a short **plain language summary** of the **2023 National Clinical Guideline** for **Stroke** for the UK and Ireland.

It gives you **information about stroke** and transient ischaemic attack (TIA or mini stroke).

It tells you:

- **What care** should be provided after a stroke.
- **When** this **care** should be **provided**.
- **Why this** care is **important**.

It tells you some **key points** from the guideline but in less detail.

It can help you find out **what to do** if you have **concerns** about **your care**.

A list of **terms explaining** more **technical words** used in this summary starts on page 32. This will help explain words that readers might not see often. Words in the list have an ***asterisk** by them when they appear in the text.

Who is it for?

- It is written for ***people affected by stroke**, that is, **people who have had a stroke** and their **families** and **carers**.
- It can be used by **doctors**, **nurses** and **therapists** to talk with people with stroke and their carers about their care.

Who wrote it?

The *__Intercollegiate Stroke Working Party__ wrote the guideline. The Working Party includes:

- People with stroke
- Doctors, nurses and therapists
- University researchers
- Charities.

There is **more** about how the **guideline** was **developed** on page 43. This plain language summary was **written by** ***people affected by stroke**.

Where can I read more?

Find the full guideline at www.strokeguideline.org

Go to www.strokeguideline.org/plainlanguagesummary for an **online version** of this summary.

2 | Background

The *Intercollegiate Stroke Working Party has produced **six editions** of the **National Clinical Guideline for Stroke** since 2000.

The guideline contains **recommendations** for **treating** people who have had a **stroke** or *transient ischaemic attack (sometimes called a TIA or a *mini stroke).

Recommendations are based on the **best current research** and on the **experience** of *healthcare professionals and of *people affected by stroke.

It **covers** the **whole patient pathway**, from emergency hospital treatment to long term *rehabilitation and prevention of further strokes.

The **recommendations set standards** for the treatment that people with stroke and their carers should receive. These standards should be **met everywhere** in the **UK** (England, Scotland, Wales, and Northern Ireland) and the **Republic of Ireland**.

3 | What is stroke?

A stroke happens 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 (*infarction), known as an *ischaemic stroke, or a **bleed** in the brain (*haemorrhage).

Most strokes are caused by a **blockage** (*infarction).

Around **1 in 9** strokes are caused by a **bleed** (*haemorrhage).

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

The **effects** of stroke are **sudden**.

The **FAST test** can help you recognise the most common signs.

- **Facial weakness:** Can the person smile? Has their mouth or eye drooped?
- **Arm weakness:** Can the person raise both arms?
- **Speech problems:** Can the person speak clearly and understand what you say?
- **Time to call 999 or 112:** if you see any one of these signs.

Some **other effects** include sudden changes to:

- **Movement** – feeling weakness in the arms and legs, feeling wobbly, falling over
- **Swallowing**
- **Vision** – double vision, missing areas of vision.
- **Thought processes** – memory loss or confusion.

A suspected stroke is an **emergency**.

People **should NOT wait** to see if the symptoms get better.
An **ambulance** should be **called immediately**.

4 | What is a transient ischaemic attack (TIA)?

A ***transient ischaemic attack** (TIA) is sometimes called a ***mini stroke**. Transient means that stroke **symptoms** only **last** a **short time**. In fact, they usually **get better** 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 **stroke**.

5 | Diagnosis and admission

What should be done?

Everyone with **stroke symptoms** should have a **brain scan**.

People 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. This team's responsibility is to:

- **Diagnose** and **treat** stroke
- **Advise** on how to **prevent further strokes**
- Provide **stroke** *__rehabilitation__ and **support** for **families**.

When should this be done?

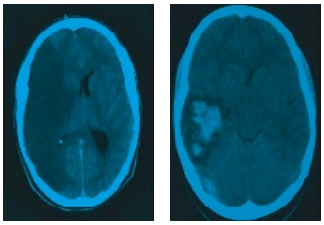
Everyone should have a **brain scan within 1 hour** of **arriving** at the hospital.

Everyone should go to a **stroke unit within 4 hours** of **arriving** at the hospital.

Why should this be done?

Fast treatment:

- Can **reduce** the **damage** caused by stroke
- Means more people will **survive** their stroke
- Means people will have **less disability** caused by their stroke.



The left scan shows an infarct or blockage (black areas).

The right scan shows a haemorrhage or bleeding (white areas).

6 | Treatments to remove a blood clot: thrombolysis and thrombectomy

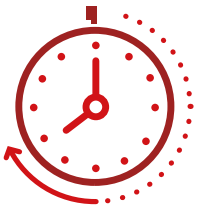
What should be done?

*__Thrombolysis__ is a __treatment__ to __break up__ a __blood clot__ that is blocking an artery (*infarction). It is given by injection.

*__Thrombectomy__ is an operation __to remove a blood clot__ from an artery in the brain.

Breaking up or removing a clot is usually __only suitable__ for people who arrive at hospital __soon after their stroke__.

When should this be done?



*__Thrombolysis__ should be done as soon as possible (mostly __within 4½ hours__ of stroke).

*__Thrombectomy__ should be done as soon as possible (usually __within 6 hours__ of stroke).

Why should this be done?

*Thrombolysis and *thrombectomy treatments can __reduce disability__.

These treatments can also improve a person's chances of __living independently__.

7 | Family and carer involvement

What should be done?

People with stroke should be **asked** if they want their **family or carer** to be **involved** in their **care**.

If the person with stroke agrees, the carer should **receive information** about stroke, and be **involved** in **decision-making**.

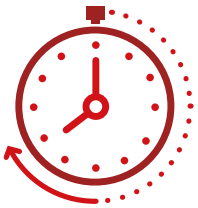
Carers should be offered an **assessment** of **their own needs** and **offered support** for these.

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

When should this be done?

The person with stroke should be **asked** about a **carer's involvement early** in their **hospital stay**.

The **carer's needs** should be **assessed** on transfer of the person with stroke from hospital and **reviewed** as needed.



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' needs.

8 | Swallowing problems (dysphagia)

What should be done?

People with stroke should **not drink**, **eat** or **swallow medicine** until their swallowing has been tested.

People with **difficulty swallowing** (*dysphagia) should receive **advice** and **support**.

People with some types of *dysphagia should receive specialist **swallowing assessment and** ***rehabilitation** from a *speech and language therapist.

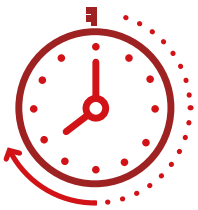
People with *dysphagia should have their **mouth checked** (*mouth care) **three times a day**.

When should this be done?

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

People with serious swallowing difficulties should be considered for ***nasogastric** (through the nose) **tube feeding within 24 hours**.

If people are receiving **end-of-life care** (*palliative care), they should **have food** and **drink** offered how they want it in the safest way possible.



Why should this be done?

Some **swallowing difficulties** (*dysphagia) caused by stroke can lead to **choking** or ***aspiration pneumonia**.

9 | Eating and drinking (hydration and nutrition)

What should be done?

People with stroke may be at risk of *__dehydration__ (not enough water in the body) or *__malnutrition__ (too little food). They should be __assessed__ to see if they have been eating or drinking too little.

If there are concerns about *malnutrition, people should be __referred__ to a *__dietitian__ for __advice__ and __support__.

People who find it __hard__ to __feed themselves__ should be assessed and __receive equipment__ and __support__ to help them eat.

Some people may need to be __fed__ through a __tube__ for a while.

When should this be done?

*__Hydration__ should be __assessed within 4 hours__ of arrival at hospital.

Risk of *__malnutrition__ should be __assessed when__ the person is __admitted__ to a stroke unit.

Why should this be done?

*Malnutrition and *dehydration can cause __major health problems__ for people who have had a stroke and can __delay recovery__.

10 | Principles of rehabilitation

What should be done?

*__Rehabilitation__ is a set of treatments and activities to **promote recovery** and **reduce disability**. *Rehabilitation treatments are **provided by therapists** and therapy assistants.

The *stroke team should help people with stroke to **decide** what **their** ***rehabilitation goals** are.

The *stroke team should **actively involve** people with stroke in their *rehabilitation and consider **their wishes**.

All members of the ***stroke team** should be **involved**.

Assessments should be **agreed by all** those involved and **documented** by staff.

Families and **carers** should be **included** in ***rehabilitation activities** when appropriate.

People with physical disabilities after a stroke should receive at least **3 hours** of **therapy** a **day**.

People should be supported to **remain active** for **6 hours** a **day**, including the hours of therapy. They should have the chance to **practise** normal **daily skills** and **activities**.

When should this be done?

*Rehabilitation should **begin in hospital** and **continue** for as long as it is needed after leaving hospital.

Treatment to help mobility should begin **24–48 hours** after the stroke if possible. *Rehabilitation needs should be **reviewed six months after** the **stroke**.

Why should this be done?

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

11 | Moving and walking

What should be done?

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

Therapists should choose from a **range** of **exercises**. This could include exercises to improve **balance**, regain **strength** or **practise walking**.

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

Lots of **repeated practice** should be offered, including **training using equipment** such as a treadmill if suitable.

When should this be done?

People with **difficulty moving** should be **assessed** by a *__physiotherapist within 24 hours__ of having a stroke.

Activities such as sitting in a chair, standing and walking should **begin 24–48 hours** after stroke.

In the **first 2 weeks**, people should have **short treatment sessions several times** a day, with plenty of rest breaks.

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

Why should this be done?

Therapy is important in helping people **move** and **walk again**.

12 | Independence in daily life

What should be done?

People with stroke should be **assessed** on how **safely** and **independently** they can go about their daily activities.

They should be offered ***occupational therapy** for difficulties they may have with activities like **dressing, bathing** and **eating**.

Carers should be **included** and **supported** with how to help with these activities.

When should this be done?

People with difficulties caring for themselves should be **seen** by an ***occupational therapist within one day** of **referral** for occupational therapy.

Why should this be done?

***Occupational therapy** can help a person **become more independent** in their daily activities.

13 | Bladder and bowel control

What should be done?

The *stroke team should **assess** the person with stroke for ***constipation** (difficulty passing stool) and ***incontinence** (loss of bladder or bowel control).

The *stroke team should **re-assess** people with **continued** ***constipation** or ***incontinence** and **involve them** in their **treatment plans**.

People with a continued loss of continence should **receive information**, exercises and **equipment** to help.

When should this be done?

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

If there are still difficulties **after two weeks**, staff should **re-assess** the person.

Why should this be done?

Regaining bladder and bowel control is important for a person's **self-esteem** and their ability to **manage independently**.

14 | Speech and communication difficulties

What should be done?

People with **difficulty communicating** should be **assessed** by a ***speech and language therapist** to diagnose:

- *Dysarthria (unclear speech)
- *Aphasia or *dysphasia (language difficulties)
- Other communication problems.

The therapist should **explain** the **problem** to the person with stroke, and **support family members**, **carers** and **people** they might have conversations with.

People should have **opportunities** to **practise everyday communication**.

Staff should **review** any difficulties and provide **additional treatment**, **communication aids** or **technology** if needed.

When should this be done?

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

People with **continuing difficulties** should be **offered further treatment** and **support**.

Why should this be done?

Communication is important for **independence**, **confidence** and **wellbeing**.

15 | Psychological, thinking and memory difficulties

What should be done?

Psychological care such as **emotional support** and **wellbeing** should be provided by the ***stroke team**.

People with stroke should be **assessed** for **changes in mood** and **problems** with **thinking** and **memory**, and the **findings** should be **explained** to them.

A **range** of **support** should be available, including:

- **Information** and **advice** about mood and emotions after stroke
- **Psychological treatment** without medication
- **Medication** when appropriate.

Some people will need **a specialist psychologist**, for instance to help with thinking and memory. The ***psychologist** will **work with** other professionals on the ***stroke team**.

When should this be done?

A person's mood, thinking and memory should be **assessed within 6 weeks** of stroke, **when** they **leave hospital**, and at **regular reviews**.

Why should this be done?

Anxiety and **depression** are **common** after a stroke.

Problems with **thinking**, **memory**, **multi-tasking**, and **attention** are common after a stroke.

Psychological **support can help**.

16 | Reducing the risk of another stroke: lifestyle

What should be done?

People should be encouraged to:

- Be **physically active** every day
- **Avoid smoking**
- **Limit alcohol intake** to no more than 2 units per day
- **Eat a healthy diet** and reduce saturated fat and salt.

People should be **offered advice**, **support** and be directed to services and groups that can help with **changes** in **lifestyle**.

When should this be done?

People should receive **advice** to **prevent another stroke before leaving hospital** and at **regular reviews**.

Why should this be done?

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

A person can **reduce** the **risk** of **another stroke** by **improving** their diet and **lifestyle**, and taking medicines as prescribed.

17 | Reducing the risk of another stroke: blood pressure control

What should be done?

There are two important **numbers** when measuring blood pressure. They **measure different things**.

Healthy blood pressure is around **120/80**. This **first figure** should usually be **kept below 130** to help prevent another stroke.

People with **high blood pressure** (*hypertension) should have **treatment** to lower it.

Treatment varies depending on many factors.

People should **tell** their **doctor** if their blood pressure is **not staying low** and **stable** with treatment.

When should this be done?

Treatment to lower blood pressure should start **before leaving hospital** or at **2 weeks after a stroke**, whichever is sooner.

After leaving hospital, a person's blood pressure should be **checked frequently** at their **local GP surgery** until it is under control.

Why should this be done?

Controlling blood pressure can **reduce** the **risk** of **another stroke**.

18 | Reducing the risk of another stroke: high cholesterol

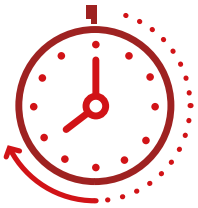
What should be done?

People who were taking *__statin medication before__ their __stroke__ or TIA (*mini stroke) should __continue__ to take them.

__Everyone__ who has had a __stroke__ or TIA (*mini stroke) should __start statin treatment__, unless there are medical reasons not to.

People who have __difficulty__ with their *__statin treatment__ should __tell__ their __doctor__.

When should this be done?



People should __start__ taking *__statins before leaving hospital__ and continue taking them as directed by their doctor.

Why should this be done?

*__Statins lower blood cholesterol__ level, which can help to __prevent another stroke__.

19 | Reducing the risk of another stroke: abnormal heart rhythm

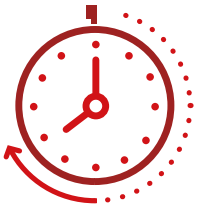
What should be done?

People with stroke need to have their **pulse checked** to make sure that they do not have an **irregular heartbeat** (this is called ***atrial fibrillation** or AF).

People with *atrial fibrillation should **receive** ***anticoagulant treatment**.

People who have **difficulty** with their *anticoagulant **treatment** should **tell** their **doctor**.

When should this be done?



Pulse checks should happen **before discharge** from hospital and again at **reviews**.

Some people should have their **pulse checked** whenever they have their **blood pressure measured**.

Why should this be done?

Identifying *atrial fibrillation (AF) and treating it with an *anticoagulant can **prevent blood clots** from **forming** and **reduces** the **risk** of **another stroke**.

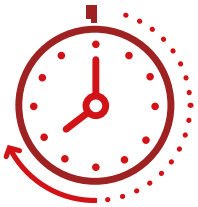
20 | Medication: antiplatelets

What should be done?

People with an ***ischaemic stroke** or TIA (*mini stroke) should receive ***antiplatelet treatment** to stop their blood cells sticking together.

People who have **difficulty** with their *antiplatelet **treatment** should **tell** their **doctor**.

When should this be done?



People should start this **treatment as soon as possible within** the first **24 hours** after a stroke or TIA.

People who have had ***thrombolysis** (see page 7) should start their *antiplatelet tablets **after 24 hours**.

Why should this be done?

If blood cells stick together they can form a clot. *Antiplatelet treatment **helps prevent blood clots** and **reduces** the **risk** of **another stroke**.

21 | Leaving hospital

What should be done?

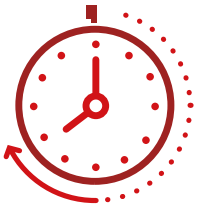
The *stroke team should **involve people with stroke** and their **carers in decisions**. This includes decisions about when they leave hospital, what care they will need, and who will provide that care. They should be offered **copies** of their **transfer documents**.

The **home environment** should be **checked before** the person **leaves hospital** to make sure it can meet the their needs.

People with stroke should have the option of ***early supported discharge** (ESD), if appropriate, so they can **leave hospital** as **early** as possible.

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

When should this be done?



People should **leave hospital** as soon as they are **ready**. Any **necessary help** at home should be in place.

*Early supported discharge services should provide **treatment** at home **within 24 hours** of **leaving hospital**.

Why should this be done?

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

*Early supported discharge services can **benefit people with stroke** and their ***rehabilitation**.

22 | Driving

What should be done?

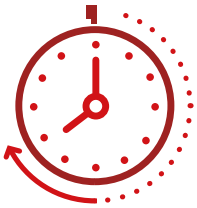
The *stroke team should **ask** people with stroke if they wish to drive.

The *stroke team should explain to people with stroke and their carers **any difficulties** that might make **driving unsafe** or **illegal**.

People **must not drive** for a **certain period** after their stroke (the exclusion period). They **must tell** the **DVLA** (England, Scotland, Wales), **DVA** (Northern Ireland) or **NDLS** (Ireland) about their stroke **if symptoms continue** after the exclusion period.

When should this be done?

It is important for people with stroke and their carers to have a **conversation** about driving **before** they **leave hospital**.



Why should this be done?

People are **legally responsible** for **following** the **rules** about driving after stroke.

There are **many reasons** why **driving** may **not** be **safe** after a stroke. For instance, people may not be able to **see properly**, their **balance** and **coordination** may be affected, or they may have **difficulty concentrating**.

Driving assessment centres can give **individual advice** about driving after stroke. For some people it may be possible to **adapt** the **car** so they can drive.

23 | Working

What should be done?

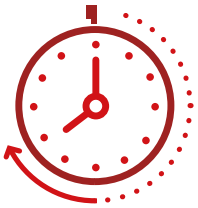
The *stroke team should ask people with stroke if they want to **return to work**.

If they want to return to work, the *stroke team should **check** their **ability** to do so.

The *stroke team should give **support** and **information** about ***vocational rehabilitation** programmes. These are programmes that **help people** to **return** to **paid** or **voluntary work**. Some organisations are listed on page 37.

When should this be done?

People should be asked about **returning to work before** they **leave hospital**.



Why should this be done?

A stroke can make it **difficult** to **work**. It may take a **long time** to return to work.

Specialist support can **help**. See the list of **organisations** on page 37.

24 | Sex and physical intimacy after stroke

What should be done?

The *stroke team should **ask people** if they have any **concerns** or questions about **sex** and **physical intimacy** after stroke.

The *stroke team should also **invite partners** to **raise** the **subject**.

Couples should be **reassured** that having sex is **very unlikely** to cause **another stroke**.

If necessary these **conversations** should include **specialists** who can help with difficulties in sexual functioning.

When should this be done?

The *stroke team should **discuss sex** after a stroke soon after the person **leaves hospital**. This conversation should be **repeated 6 months** after the stroke and then at **annual reviews**.

Why should this be done?

Stroke can affect sexual functioning. It can also have a **psychological impact** that affects desire and relationships.

It is important to have the opportunity for a **conversation** about **sex after stroke**. **Staff** may be **reluctant** to raise the subject but can provide **reassurance**.

25 | Life after stroke

What should be done?

People with stroke should:

- Have a **review** of their **health** and **social care**
- Receive **information**, **support**, and **advice**
- Have **further *rehabilitation** if needed
- Get help to create a **self-management plan**
- Have help to plan their social and **leisure activities**.

This **support** should be available to people living in **care homes** too.

Charities can provide many **support services** on top of what the health service or local councils provide. There is a list of charities on page 37.

When should this be done?

The **review** should happen **six months** and **one year** after stroke, and then **every year** after that.

Why should this be done?

Stroke affects many aspects of life. For some people these effects can be **lifelong**. However, many people **benefit** from ***rehabilitation** and **support** at **different stages** of their **recovery journey**.

26 | Fatigue

What should be done?

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

The *stroke team should check for any **mental** or **physical triggers** that could be adding to a person's *fatigue.

Everyone should get **information**, **support** and **advice** to help with their *fatigue.

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 **ability** to **take part** in ***rehabilitation** and to **work** or do other **activities** after stroke. **Managing** ***fatigue** can help with a person's overall **quality of life** after a stroke.

27 | Vision

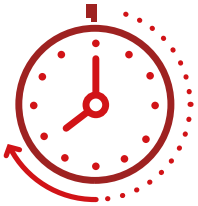
What should be done?

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

They should be **assessed** by a **vision specialist** (***orthoptist** or ***optometrist**) and **receive information**, **support** and **advice**.

When should this be done?

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



Why should this be done?

A stroke can **affect** a person's eyes and vision in many **different ways**. Overcoming vision problems can **help** people to be **independent** again after a stroke.

28 | Pain and sensation

What should be done?

People with stroke sometimes experience:

- **Problems with pain**, including **shoulder pain**
- **Changes** or **loss** of **sensations**, such as **touch** or **temperature**
- **Heightened sensations**, such as pins and needles or muscle spasms.

The *stroke team should **check** for **sensory problems** and **offer advice** on how to avoid injuring the affected parts of the body.

The *stroke team should advise on how to **prevent pain**, for instance by **changing arm position**, **using supports**, or taking pain relief **medication**.

Sometimes it can be necessary to see a **specialist** who **manages pain**.

When should this be done?

Pain and sensation should be assessed **before discharge** from **hospital** and again at **reviews**.

Why should this be done?

Pain or **abnormal sensations** after a stroke can be **distressing** and may make it difficult to do any *rehabilitation.

Loss of touch or reduced sensitivity may **increase** the **risk** of **harm** or **accidents**.

29 | Palliative (end-of-life) care

What should be done?

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

If this is the case, people with stroke should have **access** to **specialist** ***palliative (end-of-life) care** to relieve any distressing symptoms.

When should this be done?

People whose life expectancy is limited should be **offered advance care planning** to say what should happen at the end of their life.

People dying of stroke and their family should have **support** from **specialist end-of-life** (*palliative) **care staff**. They should be offered a **timely transfer** to their **home**, a **hospice** or a **care home**.

All end-of-life decisions, including decisions around food and drink, should be in the **dying person's best interests**.

Why should this be done?

Not every stroke can be treated, and some people will **unfortunately die** as a **result** of their **stroke**. However, they still need **access** to **specialist care** to relieve any distressing symptoms, and to make things **as comfortable as possible** for them and their families.

30 | What do the terms mean?

Anticoagulant medicine
A blood thinning medicine that reduces blood clotting in the case of atrial fibrillation.

Antiplatelet medicine
A blood thinning medicine that helps prevent blood clots.

Aphasia
Communication difficulties after a stroke which can affect a person's speech, processing, reading and writing.

Aspiration pneumonia
An infection in the lungs that can affect people with swallowing difficulties (dysphagia) if food or drink enters the airways.

Atrial fibrillation (AF)
An irregular heartbeat.

Constipation
Infrequent or difficult evacuation of the bowels.

Dehydration
Insufficient water in the body.

Dietitian
A professional who specialises in nutrition.

Dysarthria
Difficulty producing clear speech, caused by muscle weakness.

Dysphagia
Difficulty swallowing.

Dysphasia
Another term for aphasia.

Early supported discharge (ESD)

A service that lets people leave hospital as early as possible, if they are able, by offering rehabilitation at home at the same intensity as the care they received when in hospital.

Fatigue

Physical or mental exhaustion that does not get better through normal periods of rest.

Haemorrhage

A burst blood vessel, leading to bleeding into nearby tissue.

Haemorrhagic stroke

A stroke that happens when a blood vessel bursts, leading to bleeding in the brain (also called a 'brain haemorrhage').

Healthcare professional

A professional involved in stroke care, such as a doctor, nurse, therapist, or care staff.

Hemianopia

Loss of half of the field of vision.

Hydration

Drinking liquids or eating watery food to make sure there is enough fluid in the body.

Hypertension

High blood pressure.

Incontinence

Difficulty with controlling bladder or bowels.

Infarction

Obstruction or blockage of blood supply causing death of nearby tissue.

Intercollegiate Stroke Working Party

A group of stroke healthcare professionals, university researchers, charities and people affected by stroke looking at ways to improve stroke care in England, Wales and Northern Ireland. A list of members can be downloaded here.

Ischaemic stroke

A stroke that happens when a blood clot blocks an artery that is carrying blood to the brain.

Malnutrition

Not enough food to provide nourishment.

Mini stroke

Another term for a transient ischaemic attack, also known as TIA.

Mouth care

Keeping the mouth clean and moist by removing bits of food, brushing teeth or cleaning dentures.

Nasogastric tube

A fine plastic tube that passes from the nose into the stomach. This allows a person with swallowing difficulties (dysphagia) or other difficulties to receive fluids, food and medication.

Nutrition

Food or other forms of nourishment.

Occupational therapy

Therapy that helps a person do everyday tasks like washing, dressing or eating.

Optometrist

A professional who specialises in eyesight, mainly concerned with examining the eye itself.

Orthoptist

A professional who specialises in eyesight, mainly concerned with how the eyes and the brain work together.

Palliative care

Care to make someone comfortable at the end of their life.

People affected by stroke

People who have had a stroke or a TIA, their carers, and their families.

Physiotherapist

A specialist in using physical methods such as massage, heat treatment and exercise to help restore movement and function.

Psychologist

A specialist who assesses and treats people with thinking, memory and emotional difficulties.

Rehabilitation

Rehabilitation is a set of treatments and activities to promote recovery and reduce disability. Rehabilitation treatments are provided by therapists and therapy assistants.

Speech and language therapist

A specialist providing support and care for people who have difficulties with communication, eating, drinking and swallowing.

Statin

A type of medicine used to lower cholesterol levels.

Stroke team

A group of skilled nurses, doctors, therapists and other staff based in hospital or the community. Their responsibility is to diagnose and treat stroke; to advise on how to prevent further strokes; to provide stroke rehabilitation and support for families.

Thrombectomy

Surgery to remove a blood clot from an artery in the brain.

Thrombolysis

Treatment with a medicine that breaks down blood clots.

Transient ischaemic attack (TIA)

A stroke with symptoms that last no more than 24 hours.

Vocational rehabilitation

Support that helps a person take part in paid or voluntary work to the best of their ability.

31 | Further help and support

Support and **help** from **organisations outside** the **NHS** in the UK or the **HSE** in **Ireland** is important. The following **charitable organisations** may be able to help. This list does not include every organisation that provides support to people with stroke, and **information** can go **out of date** quickly.

England, Scotland, Wales and Northern Ireland

In this table,

E = England W = Wales
S = Scotland NI = Northern Ireland

Organisation	For people who live in:			
	E	S	W	NI
Age NI www.ageni.org				✓
Age UK www.ageuk.org.uk www.ageuk.org.uk/scotland www.ageuk.org.uk/cymru www.ageuk.org.uk/northern-ireland	✓	✓	✓	✓
Alzheimer Scotland www.alzscot.org		✓		
Alzheimer's Society (information and support on all types of dementia) www.alzheimers.org.uk	✓		✓	✓
Brain and Spine Foundation www.brainandspine.org.uk	✓		✓	
Brain Injury Matters www.braininjurymatters.org.uk				✓
Carers UK www.carersuk.org	✓	✓	✓	✓

Organisation	For people who live in:			
	E	S	W	NI
Cedar Foundation www.cedar-foundation.org				✓
Chest Heart & Stroke Scotland www.chss.org.uk		✓		
Dewis Cymru (signposting to local services, groups and support) www.dewis.wales			✓	
Different Strokes (run by and for working age or younger stroke survivors) www.differentstrokes.co.uk	✓	✓	✓	✓
Disabled Living Foundation www.dlf.org.uk	✓	✓	✓	
EPP Cymru (Public Health Wales education programmes for patients) www.phw.nhs.wales			✓	
Headway (charity for people who have had a brain injury) www.headway.org.uk	✓	✓	✓	✓
Mind / Mind Cymru www.mind.org.uk	✓		✓	
Niamh Mental Wellbeing (Northern Ireland Association for Mental Health) www.niamhwellbeing.org				✓
Northern Ireland Chest Heart & Stroke www.nichs.org.uk				✓
Royal National Institute of Blind People (RNIB) www.rnib.org.uk	✓	✓	✓	✓

Organisation	For people who live in:			
	E	S	W	NI
Same You www.sameyou.org	✓		✓	
Scottish Association of Mental Health (SAMH) www.samh.org.uk		✓		
Speakeasy www.speakeasy-aphasia.org.uk	✓			
Stroke Association www.stroke.org.uk	✓	✓	✓	✓

Ireland

Acquired Brain Injury Ireland www.abiireland.ie	**Family Carers Ireland** www.familycarers.ie
Alzheimer's Society of Ireland www.alzheimer.ie	**Headway Ireland** www.headway.ie
Aphasia Ireland www.aphasiaireland.ie	**Irish Heart Foundation** www.irishheart.ie
Cork Stroke Support www.corkstrokesupport.ie	**National Council for the Blind of Ireland** (NCBI) www.ncbi.ie
Crann Centre www.cranncentre.ie	**Neurological Alliance of Ireland** (NAI) www.nai.ie
Croí Heart and Stroke Charity www.croi.ie	**Thrombosis Ireland** www.thrombosis.ie

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

England, Scotland, Wales and Northern Ireland

Organisations in **England**, **Wales** and **Northern Ireland** that provide stroke care are **regularly measured** on how well they meet the **standards** in the guideline. These organisations are hospitals, trusts, local health boards, and community services. This **measurement** is carried out by the **Sentinel Stroke National Audit Programme** (SSNAP). Results are published on **www.strokeaudit.org**. Results are published quarterly, 6-monthly and annually.

But even with these reviews, **care might not always meet** the **expected standard**.

If you have a **complaint** about an NHS or private hospital, you should first discuss it with the **people on the ward** to see if it can be **resolved face to face**.

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

If you still have concerns, the **patient liaison service** in your **hospital** (such as PALS in England) can usually help. They can let you know about the **hospital's complaints procedure** and what your **next steps** are.

If you are **not satisfied** with the outcome of these steps, you could contact the **chief executive** of the **trust** or **local health board** that manages the hospital.

For further details, please refer to:

England:

The Patients Association

www.patients-association.org.uk/making-a-complaint

NHS Choices

www.nhs.uk/using-the-nhs/about-the-nhs/how-to-complain-to-the-nhs

Healthwatch

www.healthwatch.co.uk/help-make-complaint

Scotland:

www.nhsinform.scot and search for 'complaint'

Wales:

www.gov.wales/nhs-wales-complaints-and-concerns-putting-things-right

Northern Ireland:

To find out how to make a complaint in Northern Ireland
www.nidirect.gov.uk

Ireland:

The Irish National Audit of Stroke (INAS) is a **clinically-led quality audit**. It **measures** the **quality** of **stroke care** in all **Irish hospitals** that admit acute stroke patients. It also measures the structure of stroke services. Activity in the participating hospitals is **measured against evidence based standards**. This **helps improve** the standard of **acute stroke care** in hospital groups across the country. INAS is governed by the National Office of Clinical Audit (NOCA). There is more information here:
www.noca.ie/audits/irish-national-audit-of-stroke-inas

But even with these reviews, **care might not always meet** the **expected standard**.

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

If you have a **complaint** about stroke care, you should first **discuss** it with the **people on the ward** to see if it can be **resolved face to face**.

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

If you still have concerns, the **patient advocacy service** in your **hospital** can usually help. They can let you know about the hospital's **complaints procedure** and what your **next steps** are.

If you are **not satisfied** with the outcome of these steps, you could contact the **chief executive** of the hospital.

For further details, please refer to:

Health Information and Quality Authority (HIQA)

www.hiqa.ie

Irish Patients Association

www.irishpatients.ie

Office of the Ombudsman

About public hospitals in the Health Service Executive (HSE)

www.ombudsman.ie

33 | How was the guideline developed?

Previous editions of the guideline were **developed** by the ***Intercollegiate Stroke Working Party**. The Working Party reviewed the previous edition in 2021, looking for **areas** where the **evidence** had **changed significantly** since it was published in 2016.

The Working Party set up a **guideline development group** which included ***people affected by stroke**, **health** and **social care staff**, **university researchers** and **charities**. The group included people from **Scotland** and **Ireland** because the updated guideline would apply to these countries for the first time, as well as to **England**, **Wales** and **Northern Ireland**.

Medical literature from all over the world was searched for articles containing **new evidence**. This **evidence** was **reviewed** by professionals in stroke care and *people affected by stroke. If the evidence was **high quality** and it meant the **existing guideline** should be **updated**, they **recommended** these **changes** to the guideline development group. The **group discussed** and agreed or amended the changes.

The draft updated guideline was **peer reviewed** before being published. 'Peer review' is when **experts** in a subject area **evaluate** a piece of work in their field. 33 medical and therapy societies and Royal Colleges across the UK and Ireland peer reviewed the draft. The guideline development group **discussed** and **agreed changes** to the draft to answer the peer review comments.

The final step was when the Royal College of Physicians, the Scottish Intercollegiate Guidelines Network and the Royal College of Physicians of Ireland agreed to **endorse** the **updated guideline**. Overall more than **half** of the **recommendations** were **updated** in 2023.

There is **more information** about the guideline development process on www.strokeguideline.org

Accreditation by NICE

The National Institute for Health and Care Excellence (NICE) has **accredited** the **process** used by the *Intercollegiate Stroke Working Party to produce this guideline. Accreditation is valid until December 2023 and applies to guidance produced using the processes described in the National Clinical Guideline for Stroke methodology overview (2016, updated in 2023). **More information** on accreditation can be found at www.nice.org.uk/about/what-we-do/accreditation

34 | Acknowledgements

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To read this summary online, or to download a pdf, go to
www.strokeguideline.org/plainlanguagesummary