Care after stroke or transient ischaemic attack

What, when, and why?

Plain language summary for people affected by stroke
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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](http://www.strokeguideline.org)

Go to [www.strokeguideline.org/plainlanguagesummary](http://www.strokeguideline.org/plainlanguagesummary) for an online version of this summary.
2 | Background


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.
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.
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*.
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.
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.
### 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.
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.
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.
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.
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.
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.
**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.*
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.
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**.
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.
What do the terms mean? continued

**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.
What do the terms mean? continued

**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.
What do the terms mean? continued

**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.
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

<table>
<thead>
<tr>
<th>Organisation</th>
<th>For people who live in:</th>
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<tbody>
<tr>
<td>E</td>
<td>S</td>
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<tr>
<td>Age NI <a href="http://www.ageni.org">www.ageni.org</a></td>
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<tr>
<td>Age UK <a href="http://www.ageuk.org.uk">www.ageuk.org.uk</a></td>
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<tr>
<td><a href="http://www.ageuk.org.uk/scotland">www.ageuk.org.uk/scotland</a></td>
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<tr>
<td><a href="http://www.ageuk.org.uk/cymru">www.ageuk.org.uk/cymru</a></td>
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<tr>
<td><a href="http://www.ageuk.org.uk/northern-ireland">www.ageuk.org.uk/northern-ireland</a></td>
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<tr>
<td>Alzheimer Scotland <a href="http://www.alzscot.org">www.alzscot.org</a></td>
<td></td>
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<tr>
<td>Alzheimer’s Society (information and support on all types of dementia) <a href="http://www.alzheimers.org.uk">www.alzheimers.org.uk</a></td>
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<tr>
<td>Brain and Spine Foundation <a href="http://www.brainandspine.org.uk">www.brainandspine.org.uk</a></td>
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<tr>
<td>Brain Injury Matters <a href="http://www.braininjurymatters.org.uk">www.braininjurymatters.org.uk</a></td>
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<tr>
<td>Carers UK <a href="http://www.carersuk.org">www.carersuk.org</a></td>
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## Further help and support continued

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

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<thead>
<tr>
<th>Organisation</th>
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<tr>
<td><strong>Same You</strong></td>
<td>E S W NI</td>
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<tr>
<td><a href="http://www.sameyou.org">www.sameyou.org</a></td>
<td>✓ ✓ ✓ ✓</td>
</tr>
<tr>
<td><strong>Scottish Association of Mental Health</strong> (SAMH)</td>
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<tr>
<td><a href="http://www.samh.org.uk">www.samh.org.uk</a></td>
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<tr>
<td><strong>Speakeasy</strong></td>
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<td><a href="http://www.speakeasy-aphasia.org.uk">www.speakeasy-aphasia.org.uk</a></td>
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<tr>
<td><strong>Stroke Association</strong></td>
<td>✓ ✓ ✓ ✓ ✓</td>
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<tr>
<td><a href="http://www.stroke.org.uk">www.stroke.org.uk</a></td>
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**Ireland**

<table>
<thead>
<tr>
<th>Acquired Brain Injury Ireland</th>
<th>Family Carers Ireland</th>
</tr>
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<tbody>
<tr>
<td><a href="http://www.abiireland.ie">www.abiireland.ie</a></td>
<td><a href="http://www.familycarers.ie">www.familycarers.ie</a></td>
</tr>
<tr>
<td>Alzheimer’s Society of Ireland</td>
<td>Headway Ireland</td>
</tr>
<tr>
<td><a href="http://www.alzheimer.ie">www.alzheimer.ie</a></td>
<td><a href="http://www.headway.ie">www.headway.ie</a></td>
</tr>
<tr>
<td>Aphasia Ireland</td>
<td>Irish Heart Foundation</td>
</tr>
<tr>
<td><a href="http://www.aphasialreland.ie">www.aphasialreland.ie</a></td>
<td><a href="http://www.irishheart.ie">www.irishheart.ie</a></td>
</tr>
<tr>
<td>Cork Stroke Support</td>
<td>National Council for the Blind of Ireland (NCBI)</td>
</tr>
<tr>
<td><a href="http://www.corkstrokesupport.ie">www.corkstrokesupport.ie</a></td>
<td><a href="http://www.ncbi.ie">www.ncbi.ie</a></td>
</tr>
<tr>
<td>Crann Centre</td>
<td>Neurological Alliance of Ireland (NAI)</td>
</tr>
<tr>
<td><a href="http://www.cranncentre.ie">www.cranncentre.ie</a></td>
<td><a href="http://www.nai.ie">www.nai.ie</a></td>
</tr>
<tr>
<td>Croi Heart and Stroke Charity</td>
<td>Thrombosis Ireland</td>
</tr>
<tr>
<td><a href="http://www.croi.ie">www.croi.ie</a></td>
<td><a href="http://www.thrombosis.ie">www.thrombosis.ie</a></td>
</tr>
</tbody>
</table>
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
What can I do if care does not meet the guideline? continued

NHS Choices

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

Scotland:
www.nhsinform.scot and search for ‘complaint’

Wales:

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.
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
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](http://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

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33 | How was the guideline developed? continued
34 | Acknowledgements

This plain language summary is an update of the 2016 version. It was produced by patient voice representatives Elizabeth Thomas, Emily Toplis and Marney Williams, with support from Jan Stanier and Jennifer Butt. We are grateful to the following organisations for their thorough review of the draft: Chest Heart & Stroke Scotland, Different Strokes, Headway, Irish Heart Foundation, SIGN, Speakeasy, Stroke Association. The booklet was designed by SIGN.

Much of the work involved in developing this summary happened in 2016. The Intercollegiate Stroke Working Party would like to thank again all those involved in 2016.