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.
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?

*Treatment* 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.
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.
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.
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.
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.
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.
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.
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.
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 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.
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.
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**.
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 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.
The terms mean:

**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></td>
<td>E</td>
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<tr>
<td><strong>Age NI</strong></td>
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<tr>
<td><a href="www.ageni.org">www.ageni.org</a></td>
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<tr>
<td><strong>Age UK</strong></td>
<td>✓</td>
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<tr>
<td><a href="www.ageuk.org.uk">www.ageuk.org.uk</a></td>
<td>✓</td>
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<tr>
<td><a href="www.ageuk.org.uk/scotland">www.ageuk.org.uk/scotland</a></td>
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<tr>
<td><a href="www.ageuk.org.uk/cymru">www.ageuk.org.uk/cymru</a></td>
<td>✓</td>
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<tr>
<td><a href="www.ageuk.org.uk/northern-ireland">www.ageuk.org.uk/northern-ireland</a></td>
<td>✓</td>
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<tr>
<td><strong>Alzheimer Scotland</strong></td>
<td>✓</td>
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<tr>
<td><a href="www.alzscot.org">www.alzscot.org</a></td>
<td>✓</td>
</tr>
<tr>
<td><strong>Alzheimer’s Society</strong> (information and support on all types of dementia)</td>
<td>✓</td>
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<tr>
<td><a href="www.alzheimers.org.uk">www.alzheimers.org.uk</a></td>
<td>✓</td>
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<tr>
<td><strong>Brain and Spine Foundation</strong></td>
<td>✓</td>
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<tr>
<td><a href="www.brainandspine.org.uk">www.brainandspine.org.uk</a></td>
<td>✓</td>
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<tr>
<td><strong>Brain Injury Matters</strong></td>
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<tr>
<td><a href="www.braininjurymatters.org.uk">www.braininjurymatters.org.uk</a></td>
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<tr>
<td><strong>Carers UK</strong></td>
<td>✓</td>
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<td><a href="www.carersuk.org">www.carersuk.org</a></td>
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### Further help and support continued

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

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<thead>
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<th>Organisation</th>
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<tr>
<td>Same You</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>
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<tr>
<td>Scottish Association of Mental Health (SAMH)</td>
<td>✓</td>
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<tr>
<td><a href="http://www.samh.org.uk">www.samh.org.uk</a></td>
<td></td>
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<tr>
<td>Speakeasy</td>
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<tr>
<td><a href="http://www.speakeasy-aphasia.org.uk">www.speakeasy-aphasia.org.uk</a></td>
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<tr>
<td>Stroke Association</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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</table>

Ireland

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

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.