NATIONAL CLINICAL GUIDELINE FOR STROKE for the United Kingdom and Ireland

Plain language summary

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Patient voice representatives on guideline development group
What, when, and why?

This presentation:
• Why a plain language summary?
• What is in it?
• When should it be used?
• Who produced it?
• How was it produced?
• Where can you find it?
• What can you do now?
• When should you do it?
• Why a plain language summary?
Why a plain language summary?

• Inform
  • Person with stroke
  • Family, carers, friends

• Empower
  • Person with stroke
  • Family, carers, friends

{ • What is happening now and why
  • Where journey is going and why

Being informed => can participate in process more effectively
What is in the plain language summary?

- Key points from full guideline of interest to people affected by stroke
  - What should be done
  - When should it be done
  - Why should it be done
6 | Treatments to remove a blood clot: thrombolysis and thrombectomy

**What should be done?**

- *Thrombolysis* is a treatment to break up a blood clot blocking an artery. It is given within 4½ hours of stroke onset.
- *Thrombectomy* is an operation to remove a large blood clot from an artery in the brain. It is given within 6 hours of stroke onset.

**Why should this be done?**

- Thrombolysis and thrombectomy can reverse the physical effects of stroke and reduce disability.
- These treatments can also improve a person's ability to live independently.

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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.

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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.
What is in the plain language summary?

- Additional information of interest
- How guideline was developed
- Sources of help and support
- How to complain
- List of unfamiliar terms
- Link to full guideline for more detail
When should it be used?

- **Whenever** people affected by stroke have questions about their stroke care
- **Whenever** a doctor, nurse, therapist, care staff wants to talk to a person affected by stroke about treatment or next steps on care pathway
- **When** someone has first had a stroke or TIA and their families/carers want to understand what has happened and what will happen
Who produced it?

Guideline development group (GDG) patient voice representatives:

Emily Toplis
Stroke survivor thriver; member of return to work, fatigue & extended rehab topic groups

Marney Williams
Stroke survivor; member of thrombectomy, cognitive & consensus imaging topic groups

Liz Thomas
Carer of stroke survivor; member of rehabilitation & recovery topic groups

Jan Stanier
Scottish Intercollegiate Guidelines Network (SIGN) representative on GDG; speech & language therapist

Jennifer Butt
Stroke guideline programme manager
Who produced it?

SIGN designed pdf

Itineris produced online version
How was it produced?

What?
• ‘What, when, why?’ format
• ‘If it ain’t broke, don’t fix it’
• 2016 text reviewed for:
  • Up to date
  • Relevant to all 5 nations
  • Clarity of language

Who?
➢ 2016 patient version group
➢ Small focus group early 2022
➢ Reviewed by:
  • Martin James, GDG chair
  • Roberta James, SIGN
  • 7 UK & Irish patient organisations
    (enthusiastic engagement, hundreds of comments)
How was it produced?

• Pdf, print & online versions
  • How reader feels most comfortable
  • Screen readers & browser options increase accessibility

• Bold face, lots of white space
  • Aphasia-friendly

• Plain language
  • Maximum accessibility, not just for person with stroke

• ‘Plain language summary’ of guideline, not ‘patient version’ (2016)
Where can you find it?

- Online version
- Pdf to download
- A4 poster to download
  - Summary
  - A4 poster
  - A5 leaflet
- Small no. print copies available

www.strokeguideline.org/plainlanguagesummary
What can you do now?

- Include it in newsletter
- Use it in clinical practice
- Put up A4 poster
- Distribute A5 leaflet
- Tweet about it (or other social media)
When should you do it?

Tomorrow

(or tonight on the way home)
Why a plain language summary?

For people like us...

...who’ve been affected by stroke