What the National Clinical Guideline for stroke means for you?

Alex Hoffman and Robert Norbury

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What is a guideline?

What **should** happen to **90%** of patients **90%** of the time.

**Aim:** To **recommend** what to do so that care is **consistently good for everyone**

**BUT**

They are **not directive** – professionals will still need to use their **judgement**
How are guidelines created?

1. Find research evidence
2. Review the evidence
3. Form a **multi-disciplinary** panel including patients/lay reps/
4. The panel weighs up the evidence
Consensus

If no evidence or weak evidence Recommendations are agreed by consensus (vote) and best clinical practice.
History of RCP stroke guidelines


Updated every 4 years to ensure they are based on best current evidence.

Requires 2 years to gather evidence and finalise the recommendations.
4.5 Continence
Loss of bladder and bowel control is common in the acute phase of stroke and may persist. Incontinence of urine greatly increases the risk of skin breakdown and pressure ulceration. Incontinence of faeces is associated with more severe stroke and is more difficult to manage. Constipation is common, occurring in 55% of people within the first month of stroke, and can compound urinary and faecal incontinence. Incontinence has a detrimental effect on mood, confidence, self-image and participation in rehabilitation. It is associated with carer stress. Incontinence is an area of stroke that has received little research interest, despite its substantial negative impact. It needs to be managed proactively to allow people with stroke to fully participate in their own care and recovery both in the acute phase and beyond, e.g. people with mental capacity (section 4.9) should be involved in decisions around the use of catheters and enemas.

Evidence to recommendations
A 2013 review of bowel management strategies (Lim and Childs, 2013) identified three small studies of varying quality, and concluded that the evidence was limited but a structured nurse-led approach may be effective. In a review of therapeutic education for people with stroke, Day et al (2012) concluded from small non-randomised studies that a nurse-targeted education programme may improve longer term continence. A small RCT by Koop et al (2011) provided no evidence for bladder reconditioning with intermittent clamping. A small study by Gupta et al (2012) examined the use of transcutaneous electrical nerve stimulation for the treatment of urinary incontinence over six months and found an improvement in pad use, urgency and frequency. Thomas et al (2015) demonstrated the feasibility of a cluster RCT of a systematic voiding programme for urinary incontinence and proposed a definitive trial. Recommendations are therefore largely based on NICE guidance and Working Party consensus.

4.5.1 Recommendations
A stroke unit staff should be trained in the use of standardised assessment and management protocols for urinary and faecal incontinence and constipation in people with stroke. 
B People with stroke should not have an indwelling (urethral) catheter inserted unless indicated to relieve urinary retention or when fluid balance is tools. 
C People with stroke who have continued loss of bladder and/or bowel control 3 weeks after stroke should be reassessed to identify the cause of incontinence, and be involved in deriving a treatment plan (with their family/carers if appropriate). The treatment plan should include: 
- treatment of any identified cause of incontinence; 
- teaching to the person with stroke and/or their family/carers in the management of incontinence; 
- referral to specialist treatments and behavioural adaptations if the person is able to receive it; 
- adequate arrangements for the continued supply of continence aids and services. 
D People with stroke with continued loss of urinary continence should be offered behavioural interventions, and adaptations such as: 
- timed toileting; 
- prompted voiding; 
- reduction of caffeine intake; 
- bladder training; 
- pelvic floor exercises; 
- pelvic floor equipment prior to considering pharmaceutical and long-term catheter options. 
E People with stroke with constipation should be offered: 
- advice on diet, fluid intake and exercise; 
- a regulated routine of toileting; 
- 3 prescribed drug reviews to minimise use of constipating drugs; 
- a structured bowel management programme which includes nurse-led bowel care 
- education, and information for the person with stroke and their family/carers; 
- education, and information for the person with stroke and their family/carers. 
F People with continued continence problems on transfer of care from hospital should receive follow up with specialist continence services in the community.

4.5.2 Sources
A Working Party consensus
B Thomas et al 2008, Working Party consensus
D NICE, 2013c, 2015a
e NICE, 2007b, Coggrave et al 2006, Working Party consensus
F Working Party consensus

• The problem

• How much we know about what works at present

• What we recommend

Source of the evidence
The problem

4.5 Continence

Loss of bladder and bowel control is common in the acute phase of stroke and may persist. Incontinence of urine greatly increases the risk of skin breakdown and pressure ulceration. Incontinence of faeces is associated with more severe stroke and is more difficult to manage. Constipation is common, occurring in 55% of people within the first month of stroke, and can compound urinary and faecal incontinence.

Incontinence has a detrimental effect on mood, confidence, self-image and participation in rehabilitation and is associated with carer stress. Incontinence is an area of stroke that has received little research interest, despite its substantial negative impact. It needs to be managed proactively to allow people with stroke to fully participate in their own care and recovery both in the acute phase and beyond e.g. people with mental capacity (Section 4.8) should be involved in decisions around the use of catheters and sheaths.
How much we know about what works at present

Evidence to recommendations
A 2013 review of bowel management strategies (Lim and Childs, 2013) identified three small studies of varying quality, and concluded that the evidence was limited but a structured nurse-led approach may be effective. In a review of therapeutic education for people with stroke, Davijet et al (2012) concluded from small non-randomised studies that a nurse-targeted education programme may improve longer term continence. A small RCT by Moon et al (2012) provided no evidence for bladder reconditioning with intermittent clamping. A small study by Guo et al (2014) examined the use of transcutaneous electrical nerve stimulation for the treatment of urinary incontinence over six months and found an improvement in nocturia, urgency and frequency. Thomas et al (2015) demonstrated the feasibility of a cluster RCT of a systematic voiding programme for urinary incontinence and proposed a definitive trial. Recommendations are therefore largely based on NICE guidance and Working Party consensus.
What should happen?

4.5.1 Recommendations

A. Stroke unit staff should be trained in the use of standardised assessment and management protocols for urinary and faecal incontinence and constipation in people with stroke.

B. People with stroke should not have an indwelling (urethral) catheter inserted unless indicated to relieve urinary retention or when fluid balance is critical.

C. People with stroke who have continued loss of bladder and/or bowel control 2 weeks after onset should be reassessed to identify the cause of incontinence, and be involved in deriving a treatment plan (with their family/carers if appropriate). The treatment plan should include:
   - treatment of any identified cause of incontinence;
   - training for the person with stroke and/or their family/carers in the management of incontinence;
   - referral for specialist treatments and behavioural adaptations if the person is able to participate;
   - adequate arrangements for the continued supply of continence aids and services.

D. People with stroke with continued loss of urinary continence should be offered behavioural interventions and adaptations such as:
   - timed toileting;
   - prompted voiding;
   - review of caffeine intake;
   - bladder retraining;
   - pelvic floor exercises;
   - external equipment prior to considering pharmaceutical and long-term catheter options.

E. People with stroke with constipation should be offered:
   - advice on diet, fluid intake and exercise;
   - a regulated routine of toileting;
Where do we find the evidence?

4.5.2 Sources
A. B Working Party consensus
C. Thomas et al, 2008; Working Party consensus
D. NICE, 2013c, 2015a
E. NICE, 2007b; Coggrave et al, 2006; Working Party consensus
F. Working Party consensus
How do we know the guideline can be trusted?
What’s new in 2016?
In first few hours/days?

• All brain imaging within 1 hour

• Update advice on early mobilisation

• Lower blood pressure for stroke caused by bleeding

• Thrombectomy – new treatment
• recommended
What’s new in 2016?
Whilst in hospital?

- Increase who is in the core staffing:
  clinical psychology
  dietitian
  orthoptics

- Key assessments by multidisciplinary team
What is new in 2016

Reviews after stroke

People with stroke, including those in a care home, should be offered a structured health and social care review at 6 months and 1 year and every year.
What’s not new because so little to guide us?

- general cognition “little research”
- apraxia “absence of new evidence”
- attention & memory “only 1 of sufficient quality”
- executive function & neglect “insufficient”
- perception “uncertainty”
- anxiety, depression & distress “more needed”
- Emotionalism “not changed”
Format of the patient version of the guideline

The problem

State of evidence & action

When it should be done

Why it should be done

Bladder and bowel control

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

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

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

When should this be done?
Bladder and bowel control should be assessed during the person’s stay on the stroke unit.

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

Why should this be done?
Regaining bladder and bowel control is important for independent living and self-esteem.
Patient version process

Lots of discussion about format and content.

Led by 3 lay representatives in collaboration with the Intercollegiate Stroke Working Party.

Stephen Simpson, Marney Williams, Robert Norbury

Reviewed by 3 groups of stroke survivors and carers.
Choosing topics

62 problems in the full guideline:

Patient version: 24
How did we select the topics?

Lay representatives on the working party chose the ones they felt would help others understand what to expect from people giving them care.
45 minutes of therapy

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

Why? To **practice skills and activities** as much as possible.
Fatigue

Very common

Should be assessed before discharge from hospital and again at reviews to identify mental or physical triggers.

Why? It can affect quality of life and rehabilitation.
4.10.2 Emotionalism

Emotionalism is an increase in emotional behaviour (crying or, less commonly, laughing) following minimal provoking stimuli. Around 20% of people with stroke are affected in the first six months and although frequency decreases by 12 months, more than 10% remain affected (Hackett et al, 2010). Emotionalism can be distressing for people with stroke and their families and can interfere with rehabilitation.

Evidence to recommendations

Recommendations have not changed since the previous guideline when they were based on one Cochrane review (Hackett et al, 2010) and the consensus of the Working Party, as there have been no subsequent high-quality research studies. There is no evidence regarding the choice of antidepressant or length of treatment, and well designed longer-term studies are needed.

4.10.2.1 Recommendations

A  People with stroke who persistently cry or laugh in unexpected situations or are upset by their fluctuating emotional state should be assessed by a specialist member of the multidisciplinary team trained in the assessment of emotionalism.

B  People diagnosed with emotionalism after stroke should be appropriately distracted from the provoking stimulus when they show increased emotional behaviour.

C  People with severe or persistent emotionalism after stroke should be given antidepressant medication, monitoring effectiveness by the frequency of crying. They should be monitored for adverse effects and treated for at least four months beyond initial recovery. If the person’s emotionalism has not improved after 2-4 weeks, medication adherence should be checked before considering a dose increase or a change to another antidepressant.

Assessment, distraction, antidepressants under some circumstances, keep checking and alter treatment as required
Goal setting

People with stroke should be actively involved and helped to identify their goals.

Assessments agreed and documented.

Rehabilitation needs should be reviewed at six months.
Longer term management

Review of health and social care

Self management plan

Prevention of further stroke:
Drugs, exercise, diet, blood pressure, statins
How SSNAP compares standards to practice – what happens in real life

SSNAP compares hospitals care against the guidelines

You have the right to ask questions and should feel informed.
Watch the video What’s new


A suite of guideline documents

Full guideline  Easy read  Concise guideline
Family / carer involvement

What should be done?

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

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

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

Carers’ needs should be reviewed and addressed.

When should this be done?

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

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

Why should this be done?

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

Providing this care can affect carers’ health.

Local authorities have a legal duty to assess carers.
Principles of rehabilitation

What should be done?

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

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

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

Assessments should be **agreed and documented**.

**Families and carers** should be included where appropriate.

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

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

When should this be done?

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

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

Why should this be done?

Rehabilitation helps people to **increase their independence** after stroke and to **cope with any long term difficulties**.
Tell everyone you know about it
What to do if you don’t get the care you need

Complaints within either an NHS or private hospital should initially be discussed with the people on the ward to see if the matter can be resolved in person. This would usually be the Ward Manager or the lead clinician in charge of your care.

For NHS Hospitals we recommend initially contacting the Chief Executive of the Hospital or Trust.

For further details, please refer to The Patients Association:
http://www.patients-association.org.uk/publications/how-to-make-a-complaint/
Tel: 020 8423 8999 Email: helpline@patients-association.com

NHS Choices:
http://www.nhs.uk/NHSEngland/complaintsand-feedback/Pages/nhscomplaints.aspx
Bob’s experience as a lay representative on the working party