Recognition and management of the end of life in stroke patients

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What we shall cover

- overview of stroke and dying
- LCP: advantages and pitfalls
- recognition of the dying patient
- capacity and advance care planning

Why bother?

- 2nd commonest cause of death worldwide

  Ingall *J Insur Med*. 2004;36(2):143-52.

- 10% of all deaths worldwide in 2002

  Clairborne Johnston, S ***Lancet Neurol* *2009; 8: 345–54***

- 5-year mortality up to 50%

  but in good stroke units 20%

- Huge variation in mortality:
  - 26/100,000 in Switzerland (?? Seychelles)
  - 251/100,000 in Russia

Why bother?

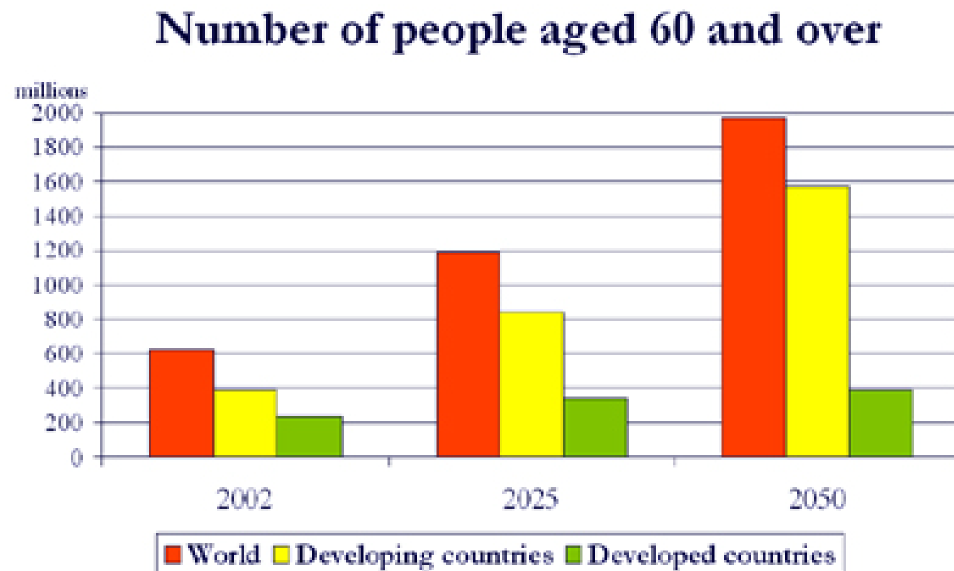
- Commonest cause of disability in the UK
- 3rd commonest cause of death
- Case fatality 20% in 1990

An international problem

"Over the past four decades... there has been a 42% decrease in stroke incidence in high-income countries and

more than 100% increase

in low to middle income countries.



Feigin, *Lancet Neurology* 2009 8, 4, 355-369

What relatives reported after death

- Uncontrolled symptoms
  - Pain
  - Incontinence
  - Confusion
  - Low mood
- Poor communication and information by staff.

Addington Hall et al 1995

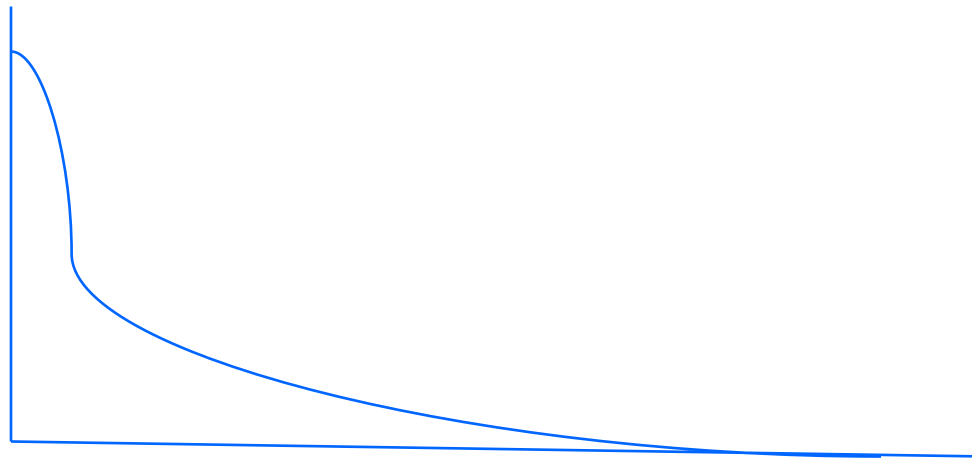
- Carers' needs unmet:
  - domestic: 2/5ths needed help with all ADLs,
    43% needed help with personal care
  - financial
  - emotional

Addington Hall et al 1998

Stroke patients who survive for a few months

- High level of functional and mobility impairment, gradually progressing over the months to death

Teno *J Palliati Med* 2001



- All stroke patients should have access to palliative care expertise when required.
- All staff providing this care should have undergone approriate training.

Intercollegiate Working Party on Stroke *National clinical guidelines for stroke* 2004

Main issues

- Some people with major strokes recover – but which?
- How does one identify dying in someone so severely disabled?
- What care does one need to provide?

Prognosticating

Strokes with a poor prognosis

- strokes resulting in pontine herniation
- pontine hemorrhage with hyperthermia
- basilar artery occlusion with coma and apnoea
- People who need mechanical ventilation: 28% discharged, 8% survived 1 year.

Prognosis in mechanically ventilated stroke patients

- Inpatient mortality 55% (48%-70%).
- 30-day mortality 58% (46%-75%)
- 1 - 2 year mortality 68% (59%-80%).

Holloway, *JAMA.* 2005; 294:725-733.

What do people with stroke die of?

- 1st week: Compression of vital centres in the brain stem due to brain swelling and herniation

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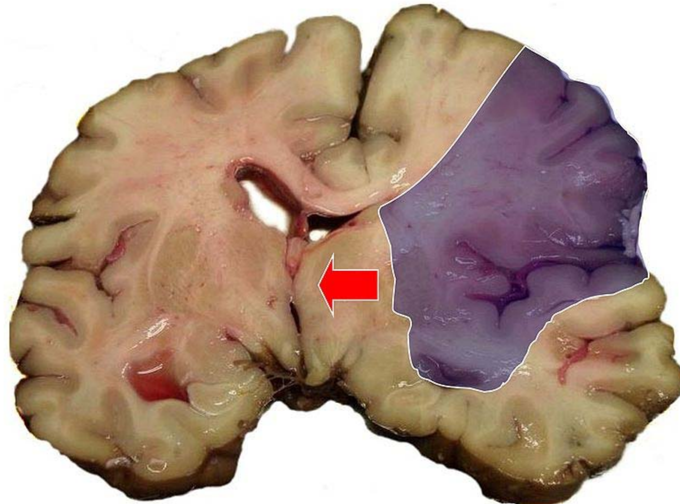

stChristopher's

What do people with stroke die of?

- 1st week: Compression of vital centres in the brain stem due to brain swelling and herniation
- Afterwards: systemic complications e.g. chest infection, aspiration pneumonia, pulmonary embolism

Strokes with a poor prognosis longer term

- Low level of consciousness
- Dense hemiplegia
- Urinary incontinence
- Gaze paresis
- Swallowing impairment

Ebrahim 2001

Not for CPR in the first 2 weeks

1. Severe Stroke

- Persisting (> 24 hours) +/- deteriorating neurological deficit
- Often early impaired consciousness leading to total dependency in ADLs.
  - little or no active movement on at least one side of the body,
  - with impaired consciousness
  - global aphasia,
  - lack of response indicating cognition (GCS <9, Canadian Neurological Scale score <5.0).

2. Life-Threatening Brain Damage

- Brain stem compression by large ICH, usually with intraventricular extension
- large hemispheric infarction with midline shift
- infratentorial strokes involving multiple levels in the brain stem;
- cerebellar lesions.

3. Significant Comorbidities

Important risk factors for death within the first month after stroke: pneumonia, PE, sepsis, recent MI, cardiomyopathy, life-threatening arrhythmias.

Alexandrov, *Stroke* 1996, 27, 232-237

Strokes resulting in severe disability

- large middle cerebral artery infarcts
- pontine strokes resulting in locked-in syndrome (quadriplegia, anarthria, preserved consciousness, vertical eye movements).

These people need long term care put in – with limited resources, we often concentrate on people who can be rehabilitated, at their expense

Why do we need to identify the dying?

- To stop burdensome treatment which will not benefit them
- To give them good and appropriate care (they won't get another chance)
- To communicate with patient and family

The LCP: advantages and pitfalls

Liverpool Care Pathway

The Liverpool Care Pathway (LCP) is an integrated pathway tool which can be used during the last 72 / 48 hours of life.

NHS National End of Life Care Programme, October 2009

The LCP Framework is a continuous quality improvement framework for care of the dying irrespective of diagnosis or place of death.

Why?

To transfer best care of the imminently dying from hospice to other clinical settings

How?

- Ensures staff assess the key areas
- Gives guidance on management
- Highlights variances from expected path and requires explanation
- Allows audit and learning re the management of dying

Key areas

- Symptom assessment
- Stopping burdensome intervention (drugs, feeding, hydration)
- Addressing psychosocial and spiritual concerns
- Communicating with family and staff

So, could it go wrong?

- Diagnosis of dying is the entry point.
- Dying may be very difficult to diagnose, even after long experience.
- Persistence on the LCP in someone who is not dying may deprive them of drugs, food and drink, and may jeopardise their recovery

Therefore....

- Get second opinion if situation is not clear – from an expert (stroke, palliative care...)
- Review, review, review if things are not going as anticipated.

Always ask WHY?

Recognition of the dying patient

Identifying the end-stage in palliative care patients

- Bedridden, profoundly weak
- Drowsy, poor attention span
- Able to take only sips of fluid
- Unable to take tablets
- Semi-comatose

Some of these changes are difficult to identify in stroke patients, or may not mean an irrecoverable situation.

Suggestions

- Functional deterioration as above – change not static disability
- Rate of change best prognostic indicator
- Risk factors: comorbidity (e.g. risk of MI, severe COPD), aspiration.

Symptoms in last 48 hours of life in a hospice

Symptom	%
Noisy & moist breathing	56%
Pain	51%
Restlessness & agitation	42%
Urinary incontinence	32%
Urinary retention	21%
Dyspnoea	22%
Nausea and vomiting	14%
Sweating	14%
Jerking, twitching, plucking	12%
Confusion	9%

Care planning and Advance care planning

- Care planning: preparation for future care needs

- Advance care planning: ascertaining patient's wishes re their care and enabling them to happen as far as possible.
  - E.g. Where to they want to be cared for?
  - Where would they prefer to die?

1. Where would you like to be cared for if you are no longer able to care for yourself?

1st preference

___

2nd preference

___

2. Bearing in mind that your circumstances may change, where would you prefer to be cared for when you are dying? e.g. home, care home, hospital, or hospice.

1st preference

___

2nd preference

___

3. Who knows you well and understands what is important to you?
Please add their full contact details to page 10

___

4. Who do you view as your next of kin?
Please add their full contact details to page 10

___

5. Who or what supports you when things are difficult?

___

6. Do you have a particular faith or belief system that is important to you? Please give details:

___

Would you like to talk to anyone about your faith or beliefs?
(circle as appropriate) YES | NO

If yes who?

___

7. What concerns you most about your health, now and for the future?

___

___

8. Are there discussions with family and /or friends you feel would be helpful?

___

___

___

Would you like anyone to help you with this?
If so who?

___

9. Have you made a will?
(circle as appropriate) YES | NO

If yes, where is it held?

___

If no, would you like to discuss how to make a will?

___

Discharge planning for people with a poor prognosis

- Carers: who, what are their needs? Entitled to individual assessment by law
- OT assessment
- Equipment e.g. hospital bed, commode
- Emergency drugs and anticipatory prescribing: e.g. Injectable opioid, anti-emetic, antimuscarinic, benzodiazepene
- LAS form
- Wishes re CPR

London Ambulance Service NHS
NHS Trust

LA225 - Palliative Care / End of Life Care Handover Form -

Please Complete Electronically and email to ooh.las@nhs.net

or as a secondary option complete form, print and fax to London Ambulance on **020 7921 5287**

FAX TO – OOH GP: FAX:

Also sent to other: FAX:

Are you UPDATING information already held? If YES please tick here ☐ and fill in relevant updated information e.g. Address Change

CONFIDENTIAL MEDICAL INFORMATION: Please update as required.

Patient details	Carer details	GP details
Name:	Name:	Name:
DOB/age: Sex:	Approx age:	Practice/code:
Address:	Address:	Address:
Tel(s):	Tel(s):	Tel (in hours):
NHS No:	Relationship to pt:	Fax:
		Tel (ooh):

Unless it is a medical emergency please contact the nursing service before considering admission.
For specialist end of life care/ palliative advice contact the Named Team.

District Nursing Service	Night Nursing Service	Specialist Palliative Care Advice/Hospice Contact
District Nurse:	Base:	Provider:
Address:	Tel:	Address:
Tel:	Mobile:	Tel:
Fax:	Fax:	Fax:
Working Hours:	Working Hours:	CNS Name:
Mobile(week days):		Community Team Contact Tel:
Mobile(w/e & BHs):		

Hospital Team involved	Further Info
Hosp:	Is the patient on the practice's Gold Standards Framework Register: YES ☐ NO ☐
Consultant:	Is the patient on the Liverpool Care Pathway: YES ☐ NO ☐
Tel:	Is there a Preferred Priorities for Care (PPC) Document in the house: YES ☐ NO ☐
Fax:	Is the patient under direct care/supervision of a Hospice: YES ☐ NO ☐

Medical information

Diagnosis and dates
(Please enclose any other relevant medical summaries)

Patient aware of diagnosis Yes ☐ No ☐ Carer aware of diagnosis Yes ☐ No ☐

Is there an Advanced Directive or Advanced Care Plan? Yes ☐ No ☐ Where?

Consent of patient obtained for transfer of information Yes ☐ No ☐

Medicine Management

Has the patient been prescribed strong opioids? Yes ☐ No ☐

(Please give details)

Emergency drugs left in home (name and dosage)

Syringe Driver. If needed available from:

Plans for OOH period urgent community care (District Nurse / Marie Curie / Hospice Outreach etc)

End of Life Phase

Is death anticipated? Yes ☐ No ☐ How Soon?

Patient Priority Final Place of Care e.g. Home / Hospice etc.

Has Resuscitation been discussed with the patient? Yes ☐ (please give details below) No ☐

Resuscitation discussed with the family / carer? Yes ☐ (please give details below) No ☐

In the event of cardiac arrest, should resuscitation commence? (For Clarity please type YES or NO)

Is there a signed Allow Natural Death / DNAR order in the house? Yes ☐ No ☐ (If YES Please state location below)
Other DNAR notes

Cultural / Religious / Spiritual – Care of the Body after death

Form Complete by: Name: Role: Date:

Email: Phone: Fax:

LAS use only

Mental Capacity assessment and the law

Mental capacity as defined in the MCA

Is the ability to

- understand the information relevant to the decision
- retain that information
- use or weigh that information as part of the process of making the decision
- communicate the decision (whether by talking, using sign language or any other means).

Assessing mental capacity

- Any professional can carry out an assessment – but describe how your assessment addressed each of the above issues in the notes.

- State capacity for what!

Remember…

- Patients may refuse treatment but may not *demand* a particular treatment
- Refusal of treatment can be verbal but refusal of life-sustaining treatment must be signed and witnessed.
- In absence of advance refusal / LPOA / IMCA, consultant has legal duty to act in their best interest.(cf family wishes)

Check

- Can they still express themselves?
- Do they have a living will? Is it specific to the situation?
- If not, do they have a LPOA?
- IMCA: for the person who lacks capacity but has no family or friends

- Many patients with stroke are able to communicate despite their hemiplegia before they lapse into coma.

- Try to ascertain their wishes and impart information needed to make decisions which they can understand.

In summary

- Some people die quickly with stroke – need recognition, protecting from futile, burdensome treatment and care of the dying.
- Others are discharged but die within months – need good care planning, adapting as they change, and their wishes explored and respected.
- In those who recover, strokes often recur – need for ACP even more important.