

The stroke patient pathway: ideals, influences and the impact on patient experience

Dr Julia Slark

INCIDENCE OF STROKE

- Global health challenge: 5 million
- 9000 new events each year
- 2500 deaths per year in NZ*
- Maori and Pacific Peoples, 2-3 times greater risk of ischaemic and haemorrhagic stroke**

Timing is everything....

- Struck down – Stroke
- Recognising it's a stroke - FAST
- Rapid response to stroke – 111
- Target timing 3-4.5hrs for thrombolysis
- Get to a stroke unit for:
 - Diagnosis
 - Treatment
 - Management
 - Plan for recovery
- Get to a stroke rehabilitation unit
- Get home with more rehabilitation



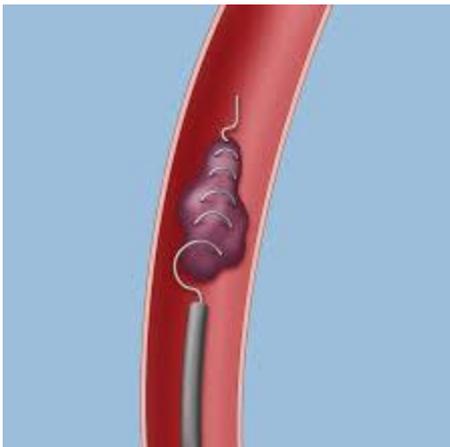
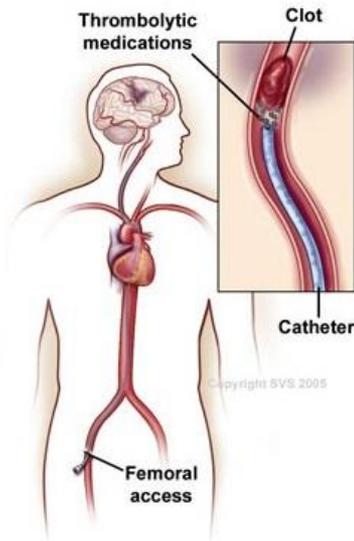
Public Awareness essential New Zealand campaign



<http://www.stroke.org.nz/See-a-Stroke-FAST>

- Every minute that a large vessel ischaemic stroke is untreated, the average patient loses **1.9 million neurons** (Saver, 2006)

Thrombolysis and Thrombectomy



⇒ Clot retrieval ⇒



Barriers to thrombolysis

- Family and patient recognition of stroke signs and symptoms
- Not calling an ambulance
- Paramedics not triaging stroke as emergency
- Delay in neuro imaging
- In-hospital stroke care – assessment
- Difficulties gaining informed consent
- Physician uncertainty

» Kwan et al., 2004



THROMBOLYSIS pathway

- 1 Arrival to ED**
- 2 Stroke team already informed and waiting
- 3 ROSIER & NIHSS ax
- 4 Priority CT Head
- 5 CT scan performed
- 7 CT report obtained
- 8 Patient informed and consent obtained
- 9 Reconstitute & draw up Alteplase
- 10 Thrombolysis is initiated**

DTN

INCLUSION CRITERIA

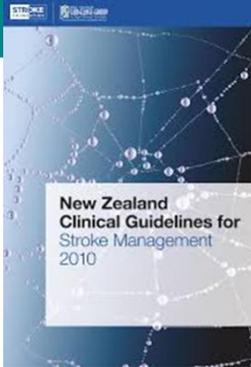
- Clinical signs and symptoms of definite acute stroke
- Clear time of onset
- Presentation within 3 hrs of acute onset
- Haemorrhage excluded by CT scan
- Age 18 +
- NIHSS less than 25
- Consent to treat (every effort must be made to contact next of kin)

EXCLUSION CRITERIA

- Rapidly improving
- Stroke or serious head injury 3 months
- Major surgery, obstetrical delivery, external heart massage last 14 days,
- Seizure at onset of stroke
- Prior stroke and concomitant diabetes
- Severe haemorrhage last 21 days
- Increase bleeding risk
- Blood pressure above 185 mmHg systolic or 110 mmHg diastolic
- Known clotting disorder
- Patient on heparin or warfarin
- Suspected iron deficient anaemia or thrombocytopenia
- Suspected hypoglycaemia or hyper glycaemia <3 mmol/l > 22 mmol/l
- Ulcerative GI disease last 3 months, oesophageal varices, arterial-aneurysm, arterial/venous malformation.
- Severe liver disease including cirrhosis, acute hepatitis

So what is the evidence for a stroke unit anyway?

- ‘...absolute benefits of organised inpatient (stroke unit) care appear to be sufficiently large to justify the reorganisation of services’ (SUTC 2007)
- Organised stroke unit care
- In-hospital care by **nurses, doctors and therapists** who specialise in looking after stroke patients and work as a coordinated team.
- Review of 31 trials, involving 6936 participants, showed that patients who receive this care are more likely to **survive** their stroke, **return home** and become **independent** in looking after themselves.
- A variety of different types of stroke unit have been developed. The best results appear to come from those which are based in a dedicated ward.



*Life after stroke. **New Zealand** guideline for management of stroke* (Baskett and McNaughton, 2003)

- recommended levels of organisation for DHBs according to the population serviced and the number of expected strokes and stroke admissions per year.
- Large, medium and small DHBs, people with stroke should receive care from a **coordinated multidisciplinary team** (MDT) which includes (or consults with) a designated stroke clinician
- **Written protocols**
- regular staff **education programme** about stroke.
- Specialised stroke units (geographically either separate or designated within a general unit) **integrating acute and rehabilitation care** were recommended for large DHBs and a defined area (i.e. separate or designated) within a general unit for acute care in medium DHBs.

What does that mean in **real life**?

- Better hyper acute care:
 - monitoring for deterioration
 - Maintaining safe levels of BP, O² sats, Temp, BSL
 - Positioning – shoulder care, pressure care
 - Continence care
 - Screening for swallow, communication and mood problems
- Access to early assessment and rehabilitation
- Interdisciplinary approach to care and recovery
- Care for all patients regardless of age

Catheter associated UTI

- Urinary incontinence after stroke is related to **mortality, morbidity** and **dependence**
- Should **only** be placed in stroke patients for:
 - strict monitoring of fluid balance
 - acute bladder obstruction
 - » Poisson et al., 2010
- 100% infection rate at 30 days
 - » Maki and Tambyah, 2001

Younger stroke survivors in New Zealand

- Approx a quarter of the 9000 new stroke events each year occur in <65 year olds
- 10% of deaths occur in <65 year olds
- Maori and Pacific islanders 2.5 times more likely to have a stroke < 65years
- Average age of stroke onset for them is 62 years compared to 75 years for European New Zealanders

Impact of stroke on younger adults

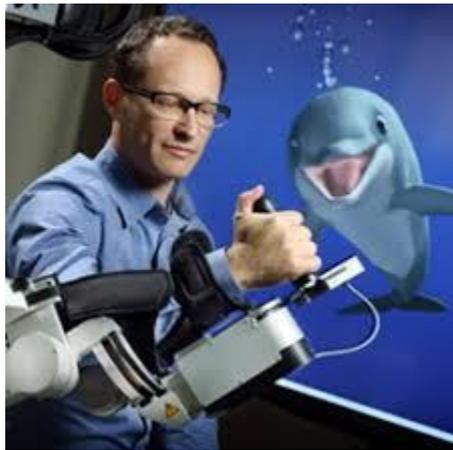
- Reduction in quality of life
- Well documented
 - Low morale
 - Sense of low worth
 - Depression
 - Suicide

(Doswell et al., 2000; Danzl et al., 2013)

- Most stroke research on rehabilitation focussed on quantitative measures of activity rather than patient experience

Question:

- What is the experience of younger, working age stroke survivors of their rehabilitation after discharge from hospital?



Methodology

- Qualitative study design
- Semi-structured interviews
- Stroke survivors who were under 65 years at time of stroke
- Received inpatient rehabilitation
- Contacted by CNS through a database of younger stroke survivors
- Interviews performed at place of convenience either at DHB or in participants home.



Results - Demographics

- 11 participants invited
- 2 refused
- 9 consented and were interviewed
- Interviews lasted between 30-65 mins
- 3 men 6 women
- Average age 56.3 years (range 42-61 years)
- 3/9 received thrombolysis
- 1/9 received neuro-surgical intervention
- Length of stay in rehabilitation approx range 1-3 months



Results

- 3/9 returned to work
- 2/3 returned to previous job but working less hours
- 5/9 unable to return to work or took early retirement
- Highly professional cohort
 - Lawyers
 - Nurse
 - High court judge
 - Medical physician
 - Teachers



Key Themes: Access to rehabilitation, Support and follow-up and Sense of loss

- **Access to rehabilitation**

- No access to ongoing rehabilitation for <65 years;
 - “because I’m under 65 I wasn’t entitled to outpatient physio or occupational therapy which was rather stunning to me”
- Difficult to access ongoing rehabilitation
- Was kept in hospital longer because no ongoing rehabilitation
- Lucky to be able to pay for physiotherapy;
 - “it doesn’t matter for me because I can afford to find services. I know what to look for and I can afford to pay for it when I find it”

Support and Follow-up

- Period following discharge from hospital was a low time;
 - “It was a time when I was low....I wanted to die....I don’t want to die anymore”
- Another participant’s response to leaving hospital;
 - “I feel a bit left out now. Not really down but I was sort of ...had the understanding that we were getting...that they would carry on with the rehab....but they didn't”
- Lack on ongoing therapy and support;
 - “No I didn’t think there was enough support. I was only going to speech therapy and paying for my physio....it wasn’t discussed really”

Support and follow-up

- Specific issues for younger stroke survivors;
 - “ I went to the stroke club 3 times but it was all for old people”
 - “ I didn’t go to the coffee groups because I imagined it was a lot of older people”
- Specific needs of younger survivors;
 - “One of the things is the support – that’s where the gap is. Trying to get support to get that motivation to have that regular exercise and that regular practice”
 - “ All I wanted was to meet other people who have been through the same thing. To meet someone else maybe whose speech was like mine...but that they’d come out the other end”

Sense of loss

- All participants mentioned the sudden loss of self;
 - “my life completely changed....I was very independent, articulate, competent person....the shock. It’s such a sudden transformation”



Intense emotions

- "it's funny, sometimes I just cry for no reason. I'm very emotional.....not for no reason I suppose...I feel as if I've lost something...I've lost the person I was...I'm not that person anymore...I'm a different person...and sometimes I just cry because it's so terrible...I feel...I don't know...I look to the future and I see nothing..."

♥ #3

"Many of the most intense emotions arise during the formation, the maintenance, the disruption, and the renewal of [deep connections]."
~ Dr. John Bowlby

Psychological impact of loss

- Periods of low mood were frequent;
 - “Living with a black dog”
 - “it’s the mood thing I fight the most”
- Impact of loss of contribution to society;
 - “I think with a lot of people who are my age (63), particularly who have lost their careers and who don’t feel like participators in the community and don’t feel they’ve got anything to contribute anymore. Whether it true or not, its how they feel and that low mood stuff is really important”

Loss of career

- Those who have gone back to work feel like they've lost their career;
 - “so I sit there and I write and it's complete rubbish (laughs)....and everybody says don't worry it will come back....but actually I don't think it's going to come back”

Summary

- Younger stroke survivors are more likely to survive now
- Left with physical disability and emotionally traumatised
- Feelings of loss and shock
- Lack of support both physically and emotionally
- How much rehabilitation is enough rehabilitation?



Learning from their experiences

- Are current services for all stroke survivors good enough?
- What small changes could you make in your care?
- What happens to your younger stroke survivors?
- How can we as health professionals support survivors to become the 'new' version of themselves?

Some suggestions...

- Use the stroke guidelines to 'guide' your service delivery
- Look at each step of the patient pathway to make small systematic improvements
- Remember the impact of what you do in the first few days, on the rest of the patient's journey
- The patients may not remember what you said to them but they will remember how you made them feel.....

Thank you!



Any Questions!