

# Palliative care after stroke: what is it and do we need it?

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# Palliative care after stroke

- What is palliative care?
- Is it needed in stroke?
- What should a 'palliative care intervention' include?
- What outcome should be used to measure the effectiveness of palliative care?
- Future research

# Palliative care is:

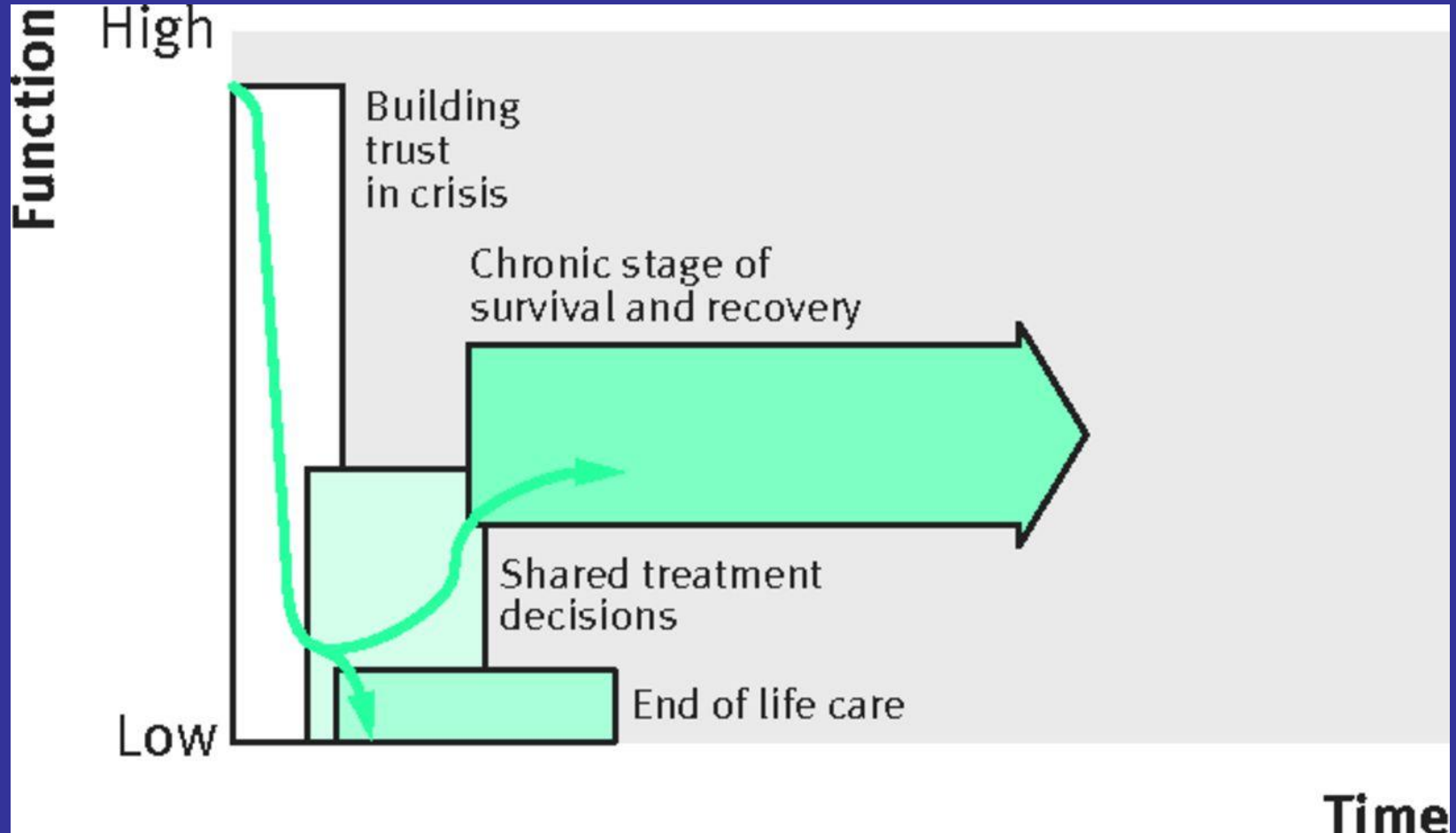
An **approach** that improves the quality of life of patients and their families facing the problems associated with **life-threatening illness**, through the prevention and relief of suffering by means of **early** identification and impeccable assessment and treatment of **pain and other problems, physical, psychosocial and spiritual.**” *WHO (2013)*

- Approach
- Life threatening
- Early
- Four dimensions of need: pain, physical, psychosocial, spiritual



**World Health  
Organization**

# Severe acute brain injury leads to early death or survival with severe disability



# Death OR survival with severe disability often determined by early decisions about treatment



CT brain images: severe stroke

# Do we already provide palliative care after stroke?

<b>WHO definition</b>	<b>Stroke care</b>
Approach (to improve quality of life of patients and families)	Yes (mostly)
Life threatening illness	Yes
Early	Yes
Needs: Pain Physical Psychosocial Spiritual	Yes (mostly)

# So, what are the experiences of palliative care after acute severe stroke?

## RESEARCH

### Outcomes, experiences and palliative care in major stroke: a multicentre, mixed-method, longitudinal study

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See related article at [www.cmaj.ca/lookup/doi/10.1503/cmaj.170956](http://www.cmaj.ca/lookup/doi/10.1503/cmaj.170956)

#### ABSTRACT

**BACKGROUND:** Case fatality after total anterior circulation stroke is high. Our objective was to describe the experiences and needs of patients and caregivers, and to explore whether, and how, palliative care should be integrated into stroke care.

**METHODS:** From 3 stroke services in Scotland, we recruited a purposive sample of

Index questionnaires were completed after interviews. We also conducted a data linkage study of all patients with anterior circulation stroke admitted to the 3 services over 6 months, which included case fatality, place of death and readmissions.

**RESULTS:** Data linkage ( $n = 219$ ) showed that 57% of patients with total anterior

ers faced death or a life not worth living. Those who survived felt grief for a former life. Professionals focused on physical rehabilitation rather than preparation for death or limited recovery. Future planning was challenging. "Palliative care" had connotations of treatment withdrawal and imminent death.

# Longitudinal mixed methods study

- Data linkage (Scottish Stroke Care Audit, National Records data)
  - Glasgow, Lanarkshire and Lothian
  - All patients with Total anterior circulation strokes (TACS), three ASUs, during the same 6/12 recruitment to qualitative study
- Serial qualitative interviews
  - Patients, nominated informal carers and health care professionals
  - Six weeks, six months and one year after index stroke/post-bereavement
- Questionnaire data



# Data linkage: 219 TACS

- 132 (60.3%) died within a year
- Cause of death
  - Cerebrovascular disease 80 (60.6%)
  - Heart disease 33 (25%)
  - Cancer 5 (3.8%)
  - Other 14 (10.6%)
- Place of death
  - NHS Hospital (during admission for stroke) 98 (74.2%)
  - NHS Hospital (readmission) 23 (17.4%)
  - Home for elderly/nursing home 7 (5.3%)
  - Non-institutional 4 (3%)

# Terminology – “palliative”?

*“I sometimes tell the team to scrap the word ‘palliative’... It does give the wrong focus... if they're not dying”*  
(hospital doctor)

HCPs struggled with concept of ‘palliative’ care

Linked with imminent dying

Often associated with stopping tests or treatment rather than adding benefit

Yet HCPs strove for effective communication

# Interviews: purposive sample

Patient participants (n=34)	Number
Median age (range)	75 years (20-98)
Gender	20 female
First or recurrent stroke	29 first; 5 recurrent
Modified Rankin score (0-6)	22=5; 12=4
Feeding: nasogastric or gastrostomy	18 tube feeding; 15 no oral route
Not for CPR	14 DNA CPR form
Adults with incapacity certificate	19 lacked capacity for decisions
Ability to consent to participate	12 able to complete own consent
Aphasia	24 with aphasia

# Qualitative interviews

34 index patients	Baseline interview	6 month interview	12 month interview	<b>Total</b>
Patient alone	6	5	5	16
Joint patient and carer	5	4	2	11
Carer alone	21	5	4	30
Bereavement (family carer)	2	7	0	9
Health and social care professionals	16	12	5	33
<b>Total</b>	50	33	16	99

# Phase 1 – Decisions and uncertainty

Difficult life and death decisions from outset

Uncertainty of prognosis

*“I felt helplessness, I felt as if my mother was dead but yet she wasn’t dead. I felt guilty because I had phoned the ambulance and I thought perhaps I shouldn’t have phoned the ambulance and then she would have died, and perhaps that would have been better” (L03.1 daughter)*

# Phase 1: Rehabilitation focus

Optimism

Focus on active rehab, recovery, motivation, successful discharge

*“We need her to really try hard so we need to keep her thinking it’s going to get better otherwise she won’t commit and then you won’t get the same outcome. You’re very positive even though you think long term it might not happen”*

(physiotherapist)

# Phase 2: “A life worth living”?

Existential and  
psychological distress

Those with better physical  
recovery grieved for  
former life

*“I remember saying to my daughter, I feel so disabled, and that upsets me, because what does the future hold at this moment – nothing worthwhile looking forward to. So then I got told off and she said what about the man who comes in the afternoon and is in a wheelchair? I said I know. I mustn’t be like that, but it is how I feel” (patient)*

# Phase 3: Resources, quality of life

Difficulty in accessing services and equipment

- ramps
- wheelchairs

Social situation & resources

- family carer at home
- type of housing
- finance private therapy

*“Yes you can bring people back from these severe strokes but I don’t feel that the infrastructure is there to give them a reasonable quality of life. It’s like bringing someone back from a major stroke and then putting them in solitary confinement...”* (Bereavement interview daughter)



# Family communication preferences

Families would welcome realistic early information on likely poor outcome

*“If we’d had honesty from the start, rather than the end of the process, we would have done things differently... rather than pushing him, pushing him for something that was never going to happen.”*  
(bereavement interview with daughter)

# Family communication preferences

But some upset by  
direct approaches

*“Doctor X, she was a very nice person, but she really took me unawares when she said “what do you think of your mother-in-law’s quality of life?” And she said “we could stop feeding her” and I thought no, I couldn’t cope with that. It’s not for us to decide how long she’s going to live. I was really, really upset. I said you can’t do that and she left it at that”*  
(bereavement interview daughter-in-law )

# The key challenges of discussing end-of-life stroke care with patients and families: a mixed-methods electronic survey of hospital and community healthcare professionals

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J R Coll Physicians Edinb 2018; 48: 217–224

# Quantitative data

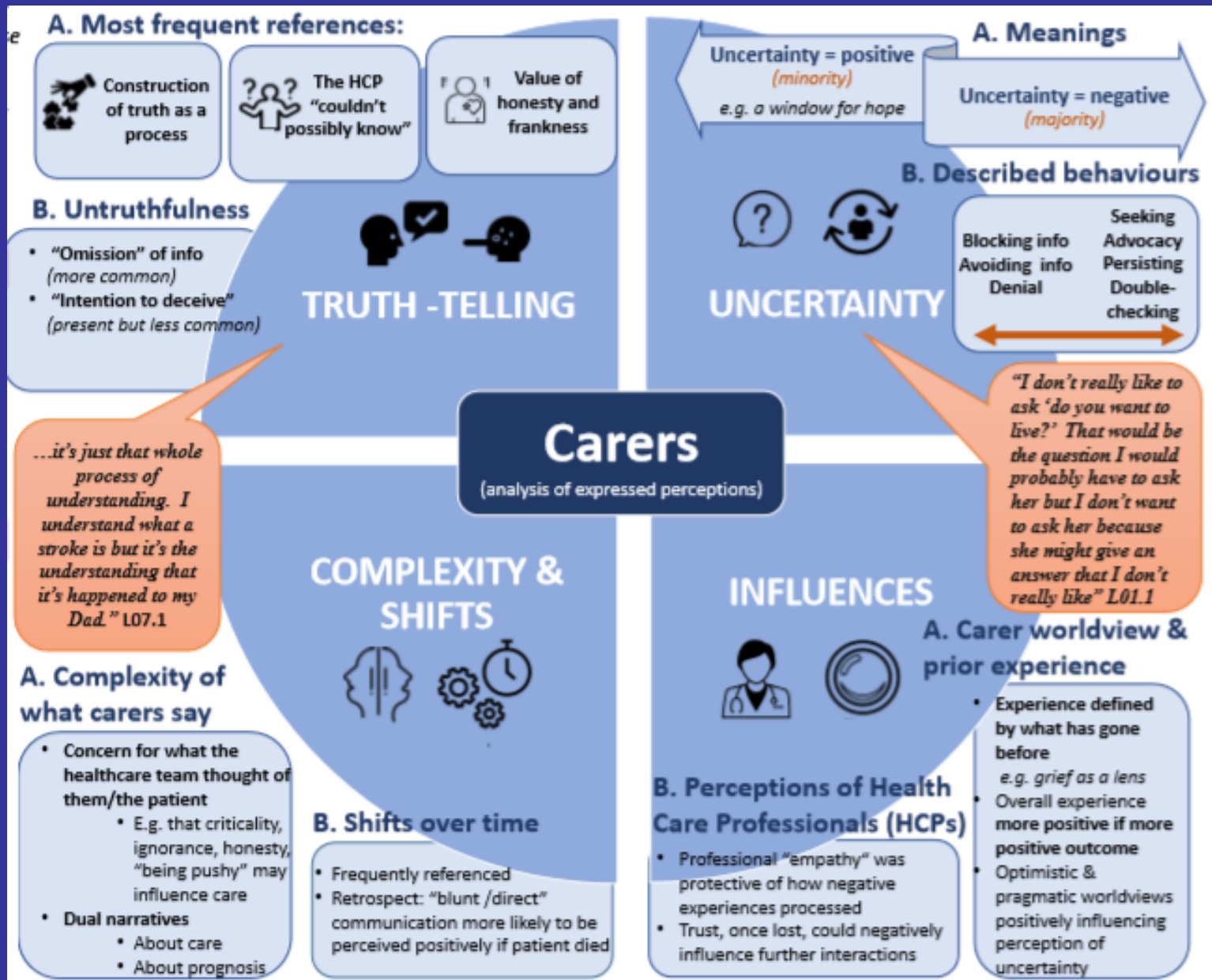
599 healthcare professionals responded.

Educational topics either 'definitely' or 'probably needed'

- Ensuring consistent messages to families and patients (88%)
- Resolving conflicts among family members (83%)
- Handling unrealistic expectations (88%)
- Involving families in discussions without them feeling responsible for decisions (82%)
- Discussion of prognostic uncertainties (79%)
- Likely mode of death (72%)
- Oral feeding for 'comfort' in patients at risk of aspiration (71%)

# How is professional "truth-telling" perceived by carers? Secondary analysis of 20 transcripts from 15 carers of patients with Total Anterior Circulation Stroke?

- Bidirectional process
- Perceptions are complex
- Healthcare professionals (HCPs) view “the truth” through a lens of their own worldview, knowledge & prior experience
- HCP expressions of “the truth” (e.g. prognosis) seen through carers’ “lenses”
- Carers’ understanding can change as “the truth” is constructed over time
- What a carer says can be influenced by concern for what the HCP thinks of them



# What is the 'truth' for people with acute severe stroke?

- Prognosis
  - Not just death or survival
  - Walk again?
  - Oral feeding?
  - Continence?
  - Living in a nursing home or at home?
- How can we do better?
  - Better prognosis models
  - Ability to talk about uncertainty
  - Integrating patient and carers views to reach a shared decision

# How else can care be improved?

- Families would like 'statistics' and viewing of brain scan
- Very early discussions about likely outcome (death and level of disability) could be more direct
- Avoid 'dual narratives' (family expecting poor outcome but health care professionals being 'positive')
- Acknowledge and address grief (anticipatory, loss of 'former self' and bereavement)



# On-line resource for health care professionals

The screenshot shows the top navigation bar of the Chest Heart & Stroke Scotland website. It includes the organization's logo, a freephone advice line number (0808 801 0899), a search bar, and a 'Donate' button. The main content area features a breadcrumb trail: 'Health professionals > Training and education > STARS (Stroke Training & Awareness Resources)'. The title 'STARs (Stroke Training & Awareness Resources)' is prominently displayed. On the left, there is a list of links: 'What is STARs?', 'Who is STARs for?', 'What are the levels of training?', 'Latest update', 'The STARs modules', and 'Contact'. In the center, the STARs logo is shown, which consists of a stylized pink star with three smaller stars above it and the text 'STARs www.StrokeTraining.org'. On the right, a 'Health professionals' section is highlighted with a blue header, containing a list of resources: 'CHSS Stroke National Training & Education', 'Out of Hospital Cardiac Arrest-Strategy for Scotland', 'Professional forums & groups', 'Training and education', and two entries for 'Scottish courses relevant to respiratory health professionals' and 'cardiac health professionals'. A partially visible link for 'Scottish courses relevant to' is at the bottom of the list.

**Chest Heart & Stroke Scotland** Call our freephone Advice line: [0808 801 0899](tel:0808 801 0899)  [Donate](#)

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Health professionals > Training and education > STARS (Stroke Training & Awareness Resources)

## STARs (Stroke Training & Awareness Resources)

- [What is STARs?](#)
- [Who is STARs for?](#)
- [What are the levels of training?](#)
- [Latest update](#)
- [The STARs modules](#)
- [Contact](#)

What is STARs?  
STARs is a free online stroke training resource. All the information is reliable, researched, best practice or evidence based.  
[Back to top](#)

**STARs**  
www.StrokeTraining.org

**Health professionals**

- CHSS Stroke National Training & Education
- Out of Hospital Cardiac Arrest-Strategy for Scotland
- Professional forums & groups
- Training and education
  - Scottish courses relevant to respiratory health professionals
  - Scottish courses relevant to cardiac health professionals
  - Scottish courses relevant to

<https://www.chss.org.uk/health-professionals/training-and-education/stars/>

# Measuring the effectiveness of a palliative care intervention

- Stroke trials usually use 'death or severe disability' as a 'bad' outcome
- For people with severe stroke-these outcomes are unavoidable
- Need other outcomes
  - Delphi consensus study to agree on best 'outcomes'- will be launched in July 2019- experts including stroke survivors and carers are now needed.

# For discussion

- Stroke care already includes aspects of the WHO definition of palliative care but is the term 'palliative' helpful?
- Multiple challenges exist around 'truth telling' and early decision making-'should this be the focus of a 'palliative care' intervention in stroke?
- What should be the primary outcome (and secondary outcomes) in a future trial of 'palliative care' in stroke?

# Thanks to

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