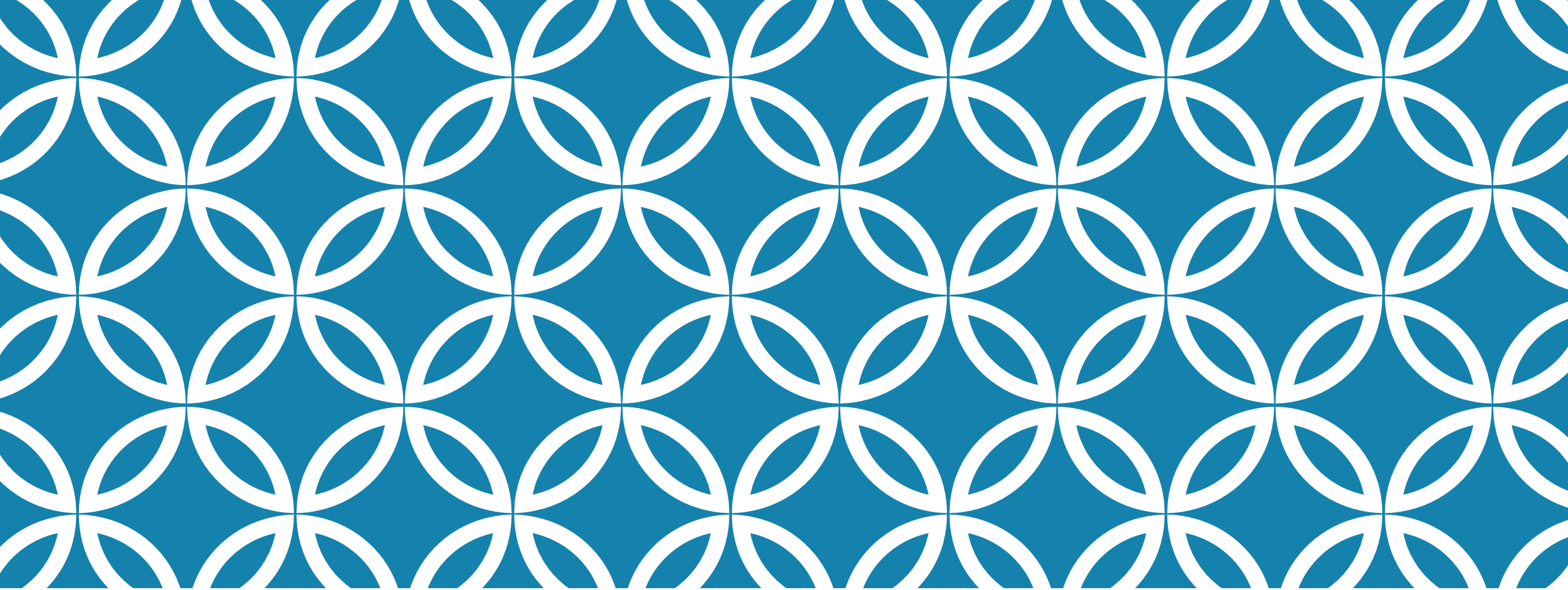
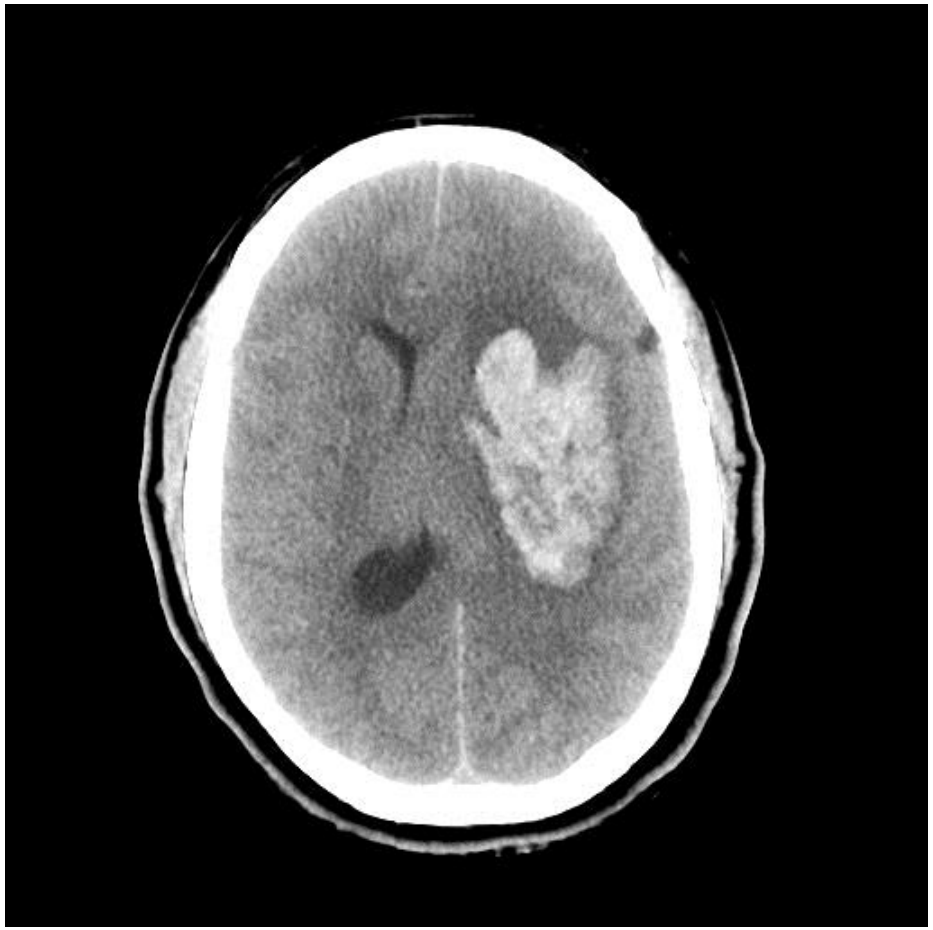


PALLIATIVE CARE

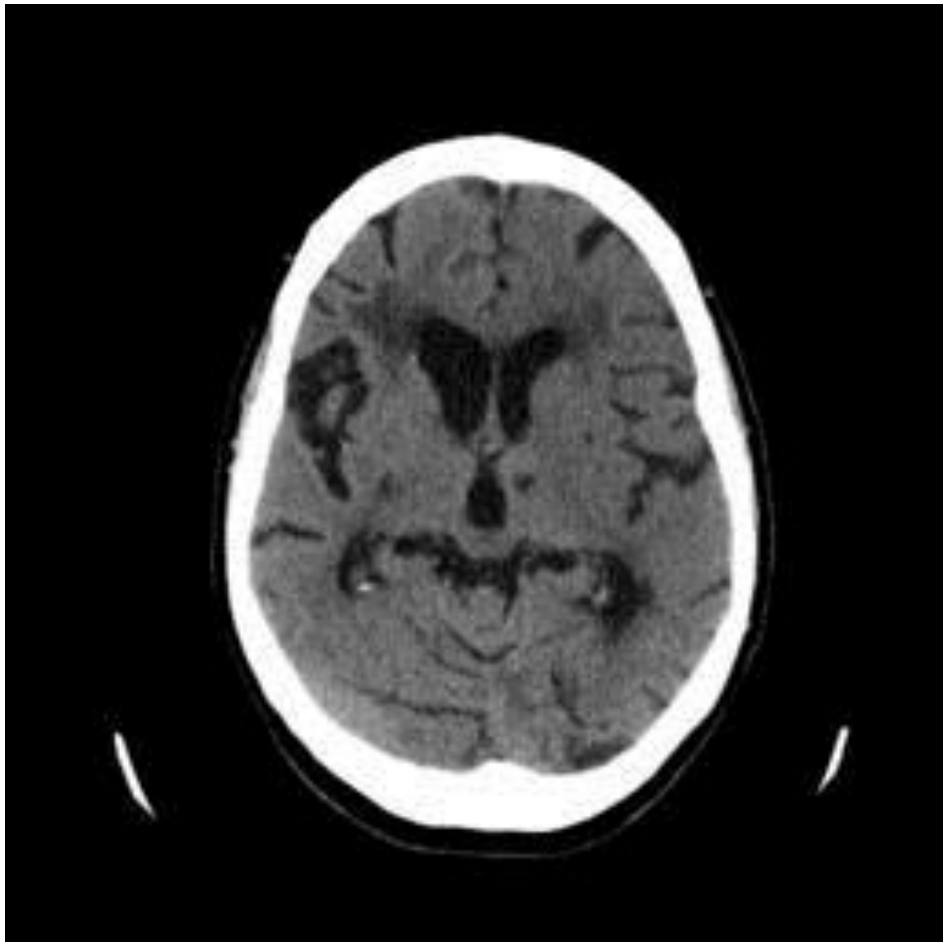
BENSON CHEN

PATIENT 1



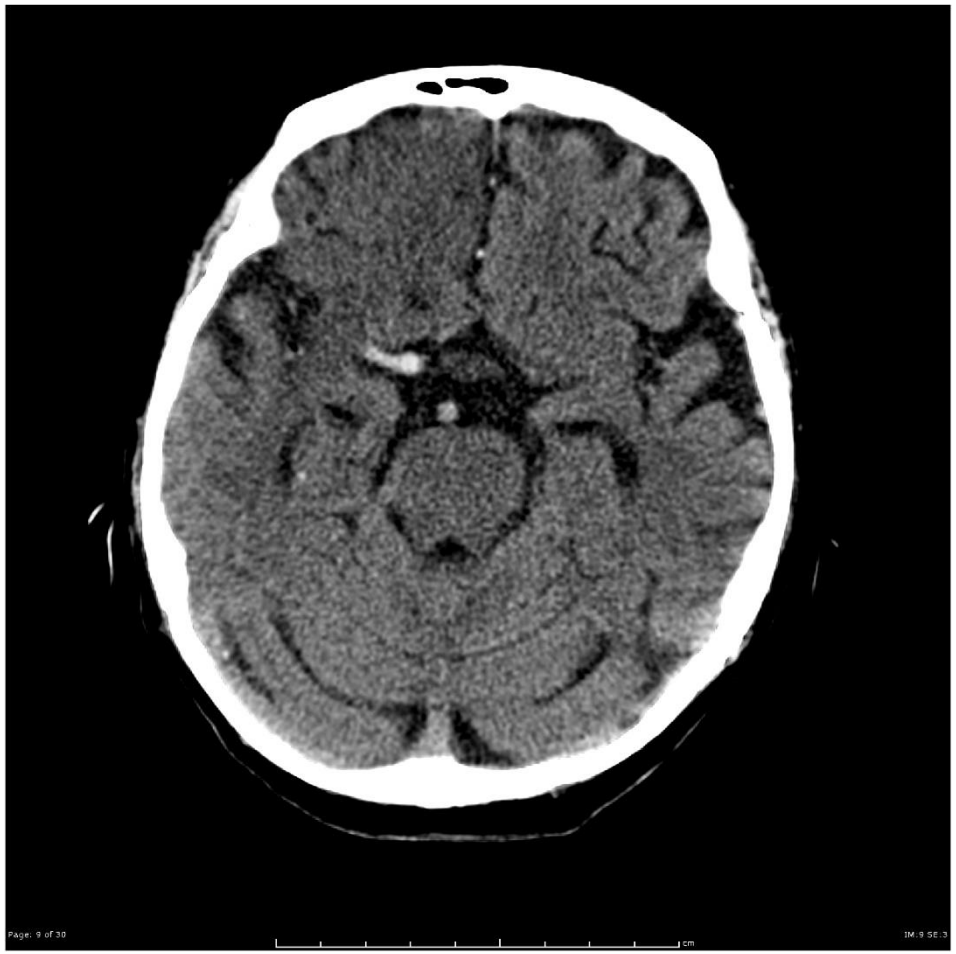
- 66 year old business analyst
- Headache and then collapsed
- SBP >230 mmHg at the scene
- GCS 8/15
- Fixed left gaze preference

PATIENT 2



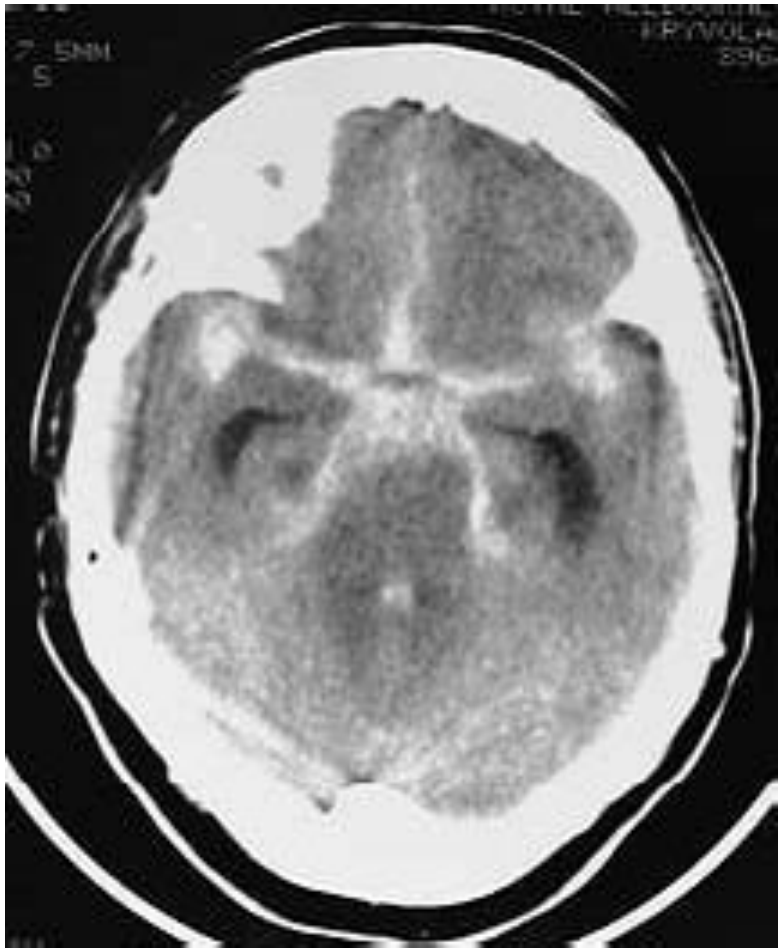
- 94 year old pensioner
- Found face down in bed
- Dense right hemiplegia
- Severe dysarthria and dysphagia

PATIENT 3



- 68 year old retired civil engineer
- Witnessed collapse while in the garden
- Moderate left sided weakness
- Severe dysarthria
- Agitated

PATIENT 4



- 63 year old Samoan female with ESRF
- Didn't wake up her usual time for PD
- Unconscious GCS 3/15
- SBP >240 mmHg at admission

PALLIATIVE CARE

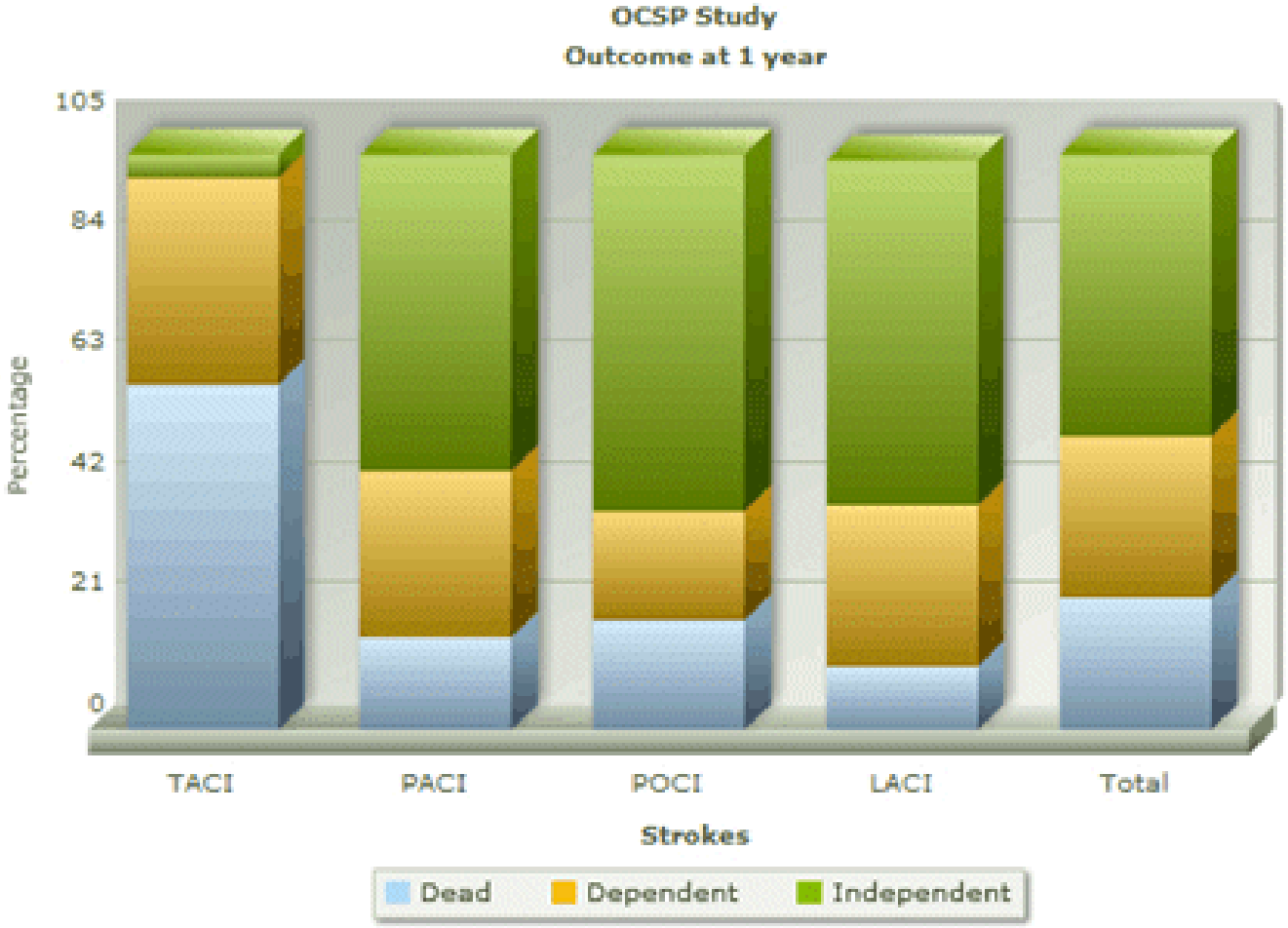
" An approach that **improves the quality of life of patients and their families** facing the problems associated with **life-threatening illness,** through the **prevention and relief of suffering** by means of **early identification** and **impeccable assessment** and **treatment of pain and other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

World Health Organisation, 2002

ILLNESS TRAJECTORIES AND END OF LIFE

adapted from Murray et al. *BMJ* 2005; 330 :1007

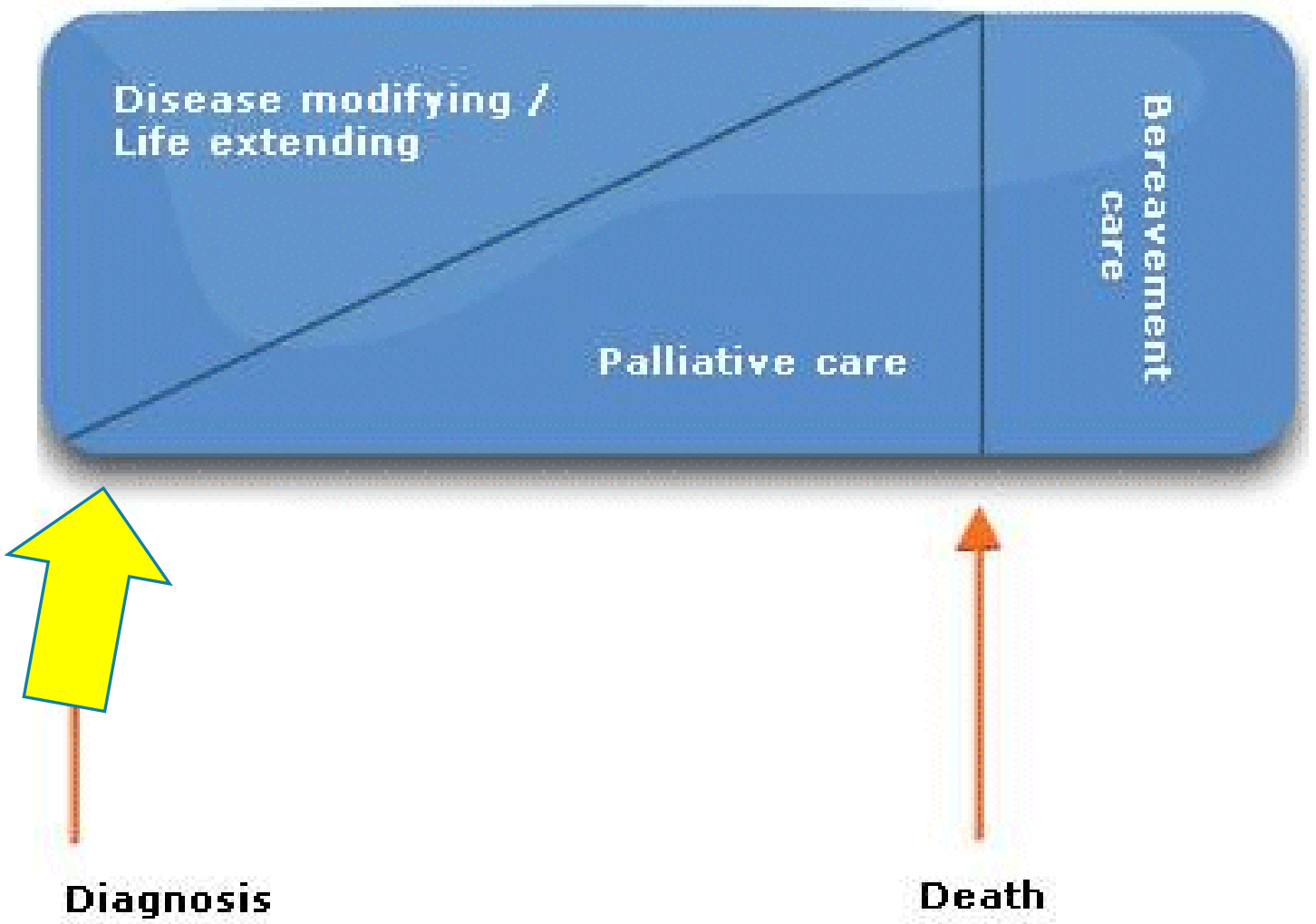
WHY DOES IT MATTER?



adapted from Bamford et al. *Lancet* 1991; 337(8756): 1521-1527

WHY DOES IT MATTER?

- Palliative care needs after stroke are common and substantial
- Scarce literature on exact nature and best methods of identifying and managing these needs post-stroke
- Literature mainly focuses on EOLC and dying with an emphasis on symptom control for the dying patient
- What about stroke patients with palliative care needs who are not actively dying?


Disease modifying /
Life extending
Palliative care
Bereavement
care
Diagnosis
Death

CHALLENGES

- A time of ‘crisis’
- Surrogate decision makers
- Prognostic uncertainty
- Identifying patient needs

WHAT DECISIONS NEED TO BE MADE?

WHAT DECISIONS NEED TO BE MADE?

- Decisions about thrombolysis, clot retrieval, neurosurgery
- Decisions about nutrition and hydration
- Decisions about swallowing, weighing up safety and patient preference
- Resuscitation status
- How active treatment should be if a complication develops e.g. pneumonia
- Decisions about a patient's capacity to make individual decisions

SURROGATE DECISION MAKING

- Decision making in the acute phase is complex and may involve life and death decisions
- Relatives play an important role by informing physicians about the patient's values and preferences
- Four categories reflecting relatives' experiences *de Boer et al. 2015*
  1. Making decisions under time pressure
  2. The feeling of 'who am I' to decide
  3. Reluctance in saying 'let them die'
  4. Coping with unexpected changes
- The prevailing tendency of relatives in making treatment decisions is to follow the proposal(s) of the physician

PROGNOSIS

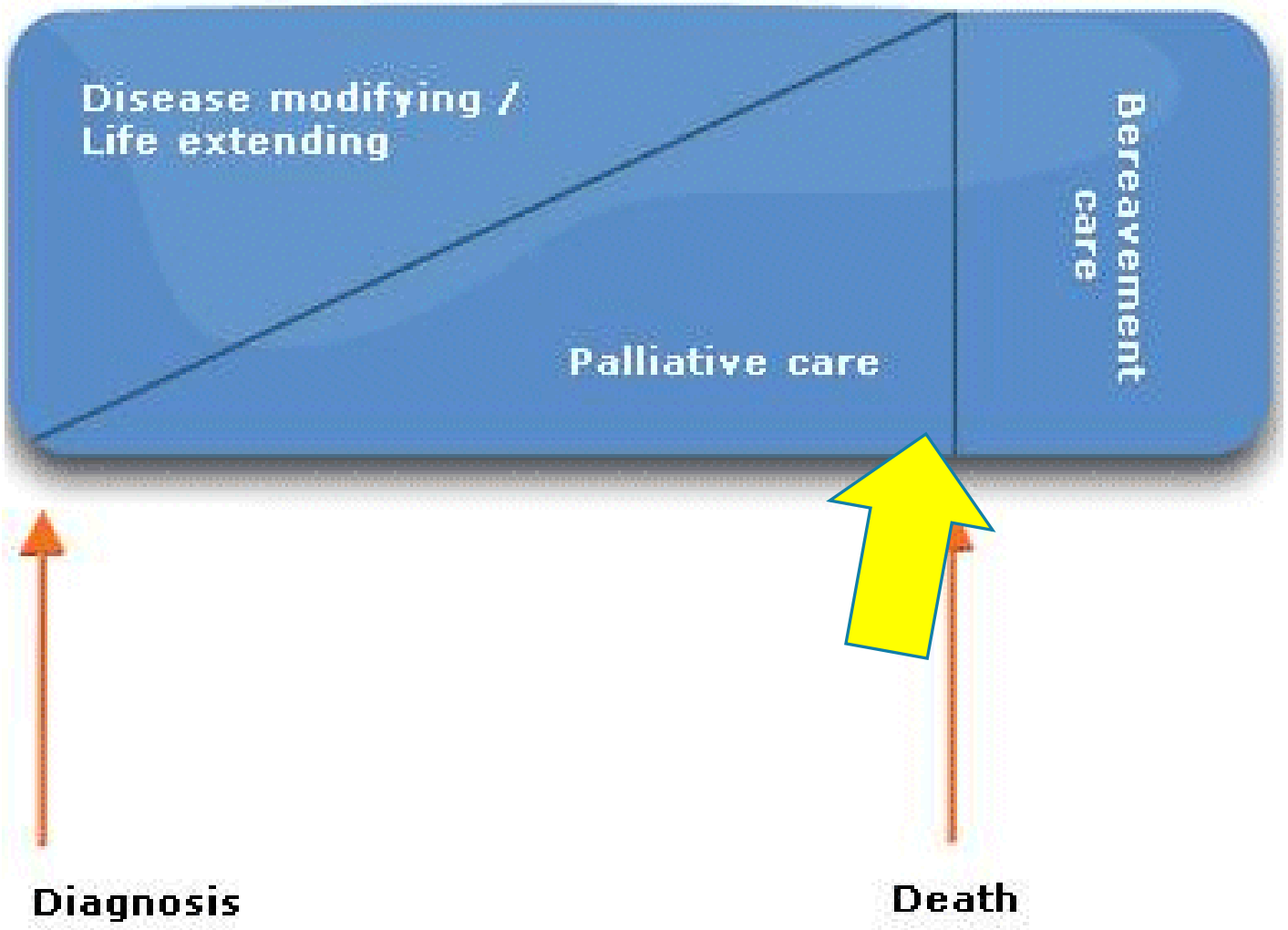
- NIHSS score / OCSP classification
- Age
- Neuroimaging
  - Infarct volume
  - Infarct location
  - Diffusion-perfusion mismatch
  - Poor collateral flow
- Ischaemic stroke mechanism
- Co-morbidities
- Complications of stroke

PROGNOSIS

- In the period from 12 hours to 7 days after ischaemic stroke, many patients without complications experience moderate but steady improvement in neurologic impairments

- Greatest proportion of recovery after stroke occurs in the first 3-6 months, though some patients experience further improvement up to 18 months

- Prognosis differs between ischaemic stroke, haemorrhagic strokes and subarachnoid haemorrhages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END OF LIFE CARE DECISIONS IN ACUTE STROKE PATIENTS

- Possible indicators of decision to withdraw treatment include:
  - Disturbed consciousness at presentation, or
  - Dysphagia on day 1, or
  - Large supratentorial stroke

- Patient death occurred after a mean time of 7.0 days and 2.6 days after therapy restrictions

Alonso et al. *BMC Palliative Care* 2016; 15(38)

END OF LIFE CARE

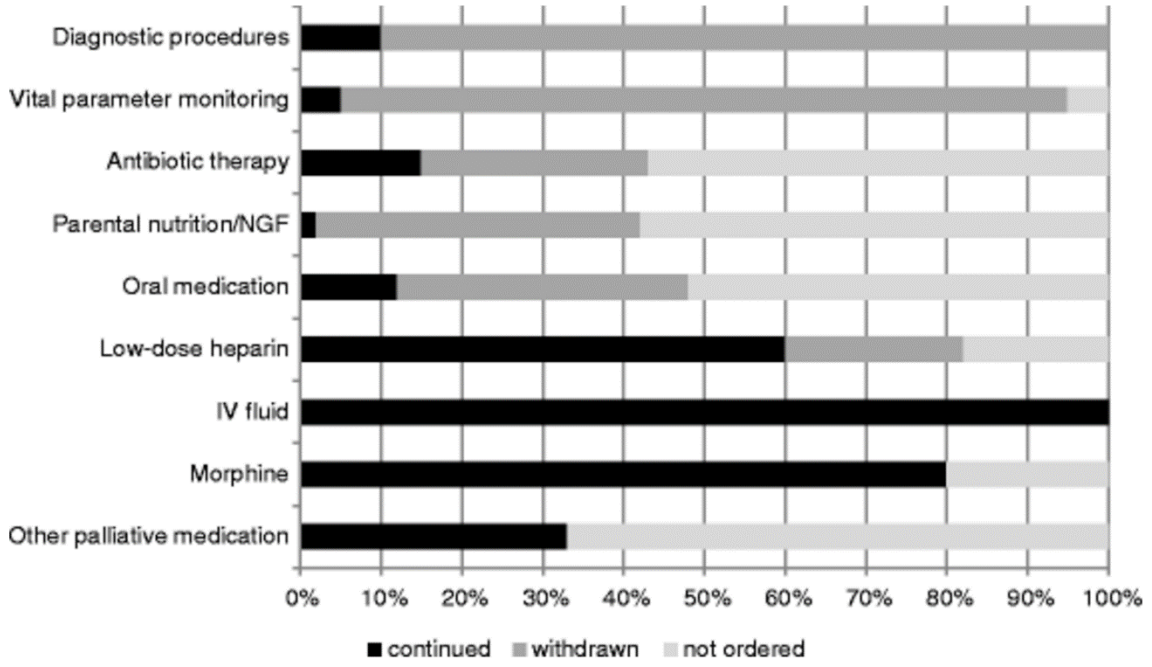


Fig. 2
Relative frequencies in percentage of different proceedings after decision to withdraw or withhold therapy ($n = 40$).
NGF: Nasogastric feeding; IV: intravenous

Alonso et al. *BMC Palliative Care* 2016; 15(38)

END OF LIFE CARE

- Significantly higher prevalence of death rattles
- Lower prevalence of nausea, confusion, dyspnoea, anxiety and pain
- Higher prevalence of healthcare staff not knowing whether symptoms were present or not
- Patients were less likely to have been told about the transition to end of life care

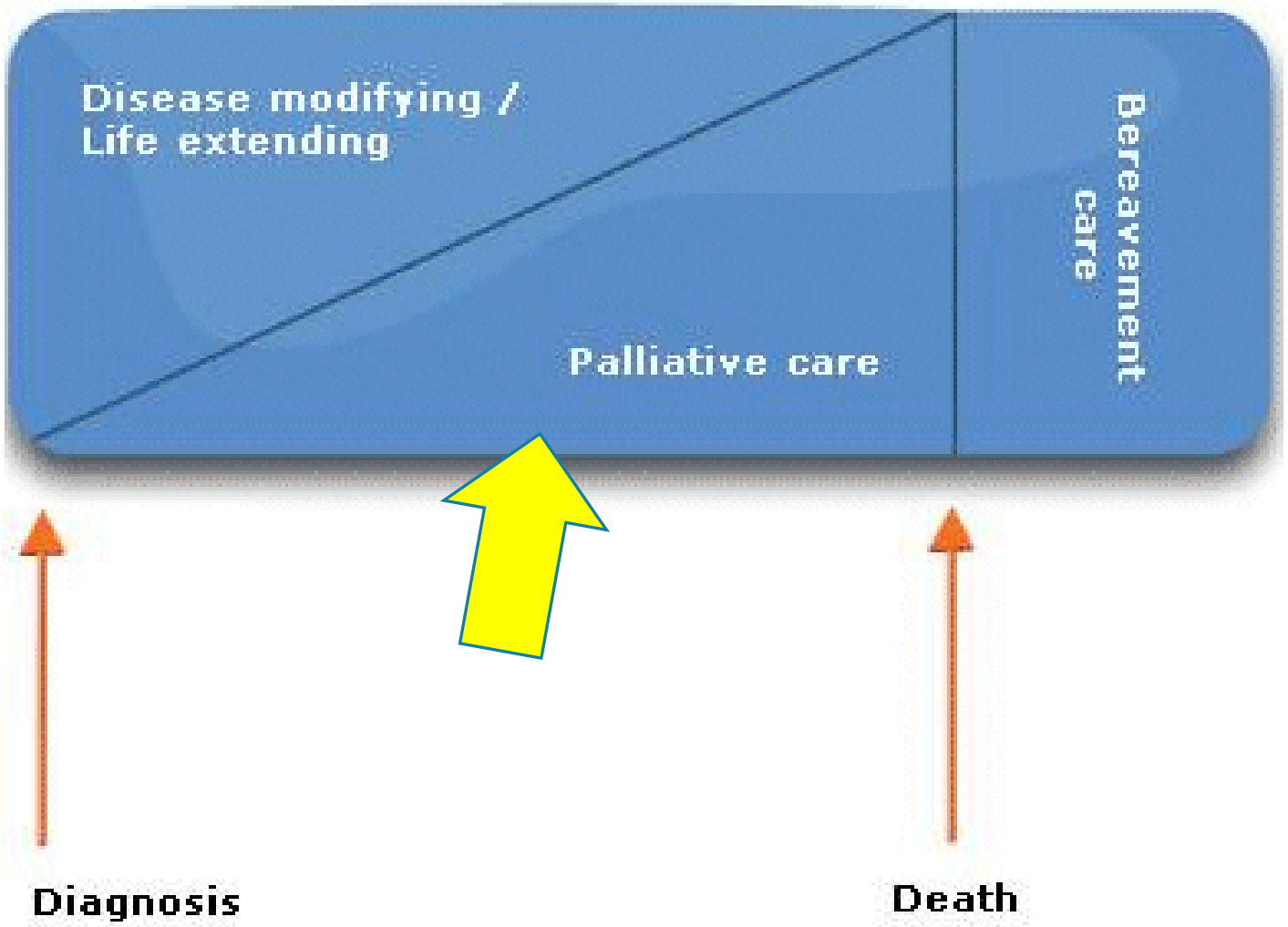
Eriksson et al. *PLoS ONE* 2016, 11(2): e147694

END OF LIFE CARE

- Clarify and establish treatment goals early on; plan ahead
- Hierarchy of decision making is important:
  - Is there an Advanced Directive? Advanced Care Plan? Activated Enduring Power of Attorney? Court appointed welfare guardian?
- Family are important
- Care plans / pathways can be helpful
- Utilise the abilities of the Palliative Care team
- Images and analogies can be helpful to explain the situation

QUESTIONS WE WILL OFTEN GET ASKED

- He is touching his head and groaning. Does he have a headache?
- She is unconscious. Can she hear what we are saying?
- Can you give him something to stop the gurgling?
- Why aren't you feeding her? She is starving to death.
- How long has he got? How can you tell when he is dying?


Disease modifying /
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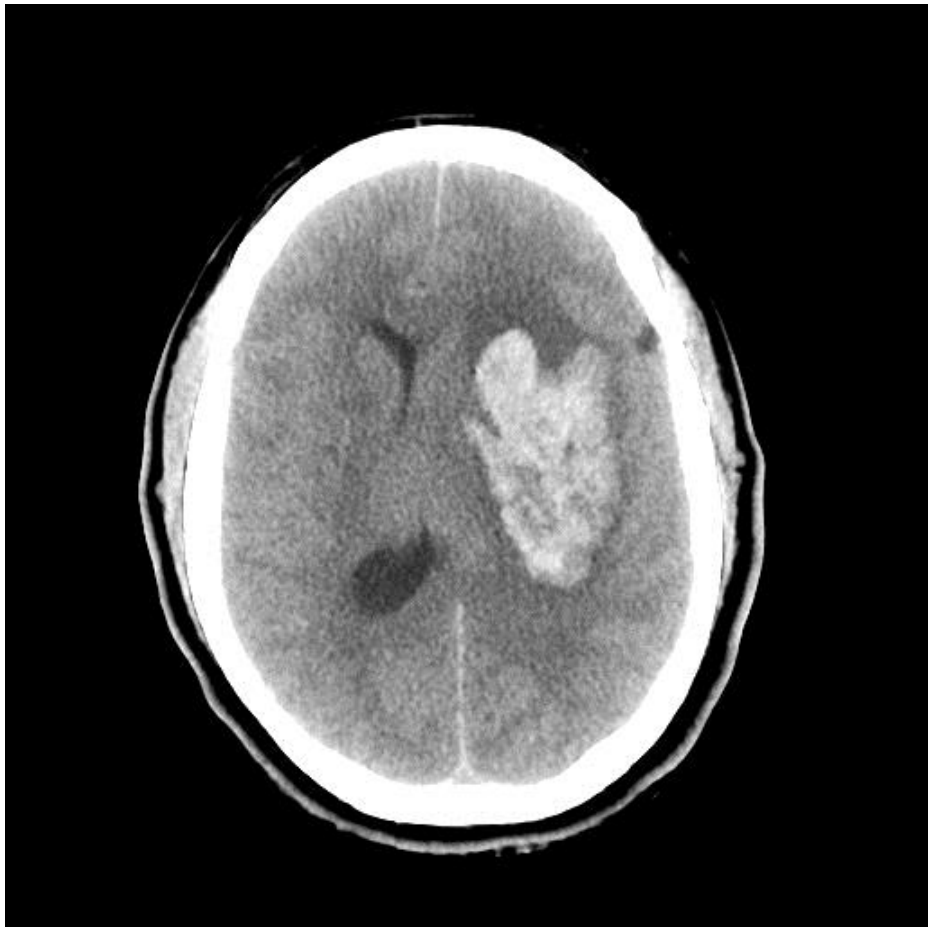
THE GREY ZONE

- Not a lot of literature on patients with stroke who are not actively dying
- Do they have unmet needs?
- Palliative Care or Chronic Care management?

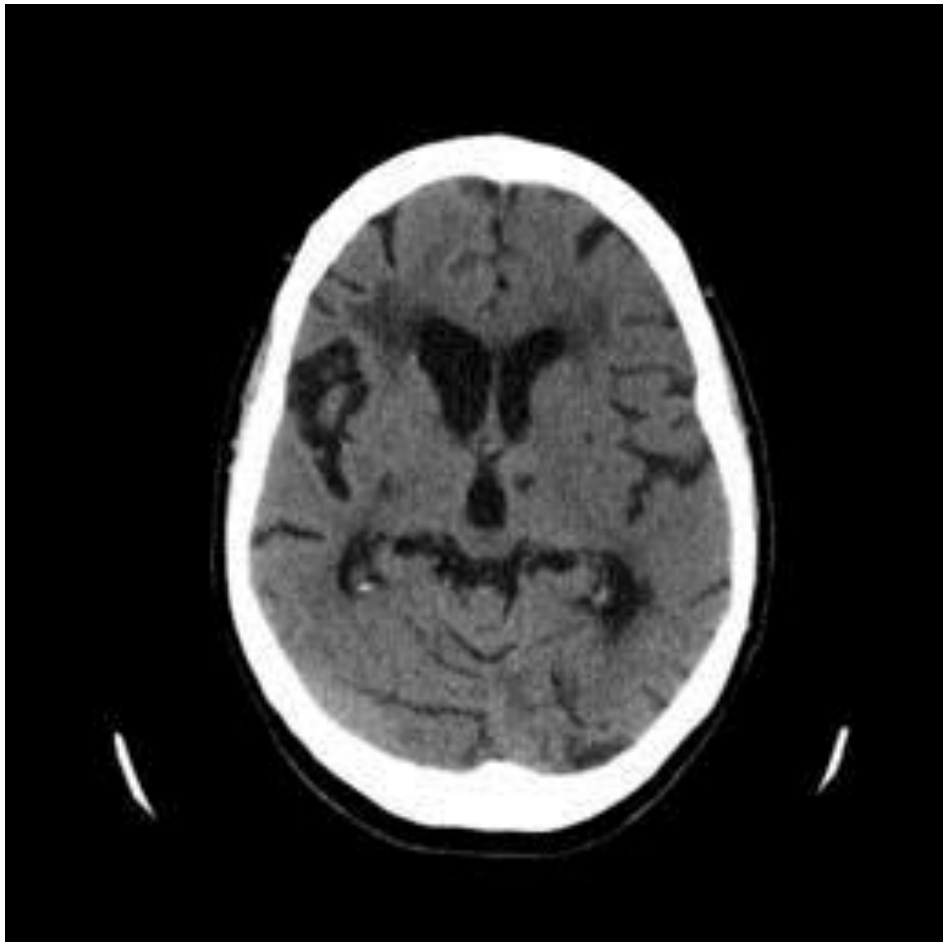
Advanced Care Planning is essential to help guide future healthcare decisions

PATIENT 1



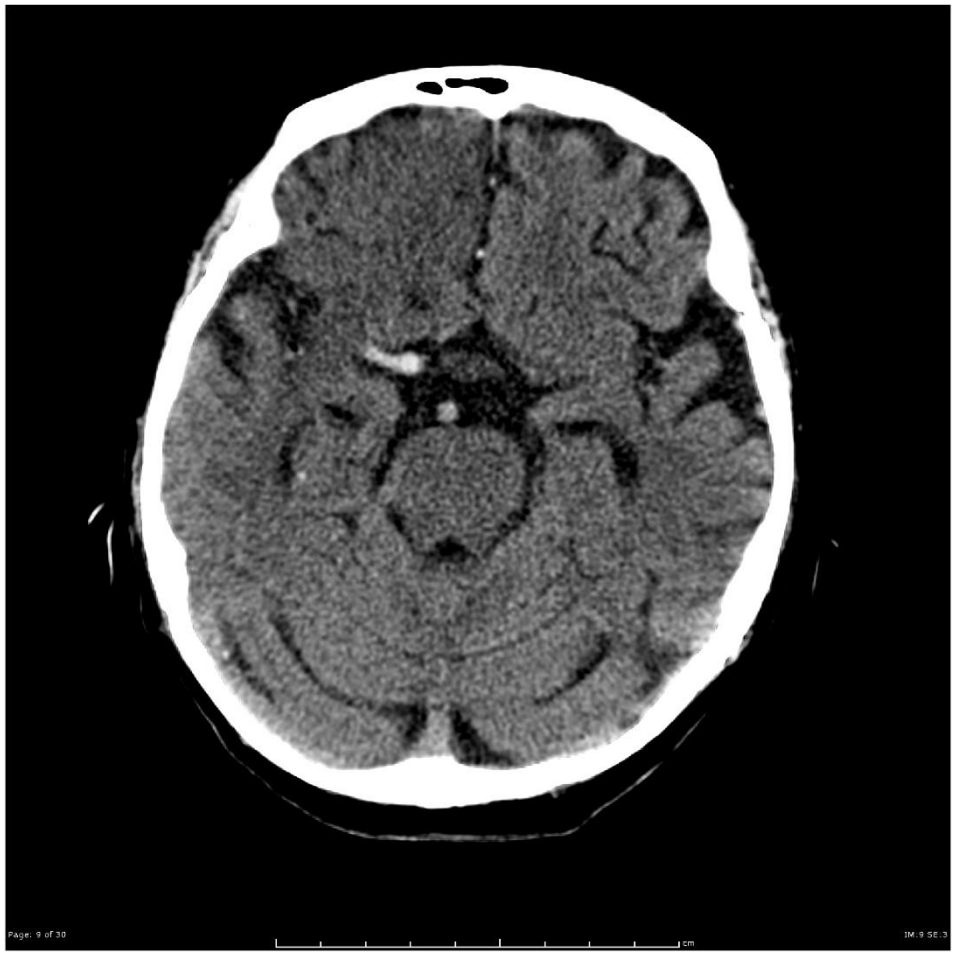
- Family were told she would die within a week
- She was discharged to private hospital after 10 days and survived another 2 months
- Not for PEG or NG feeding; able to comfort feed with understanding not for treatment of any infections
- A court appointed guardian for welfare and property were sought by way of PPPR Act

PATIENT 2



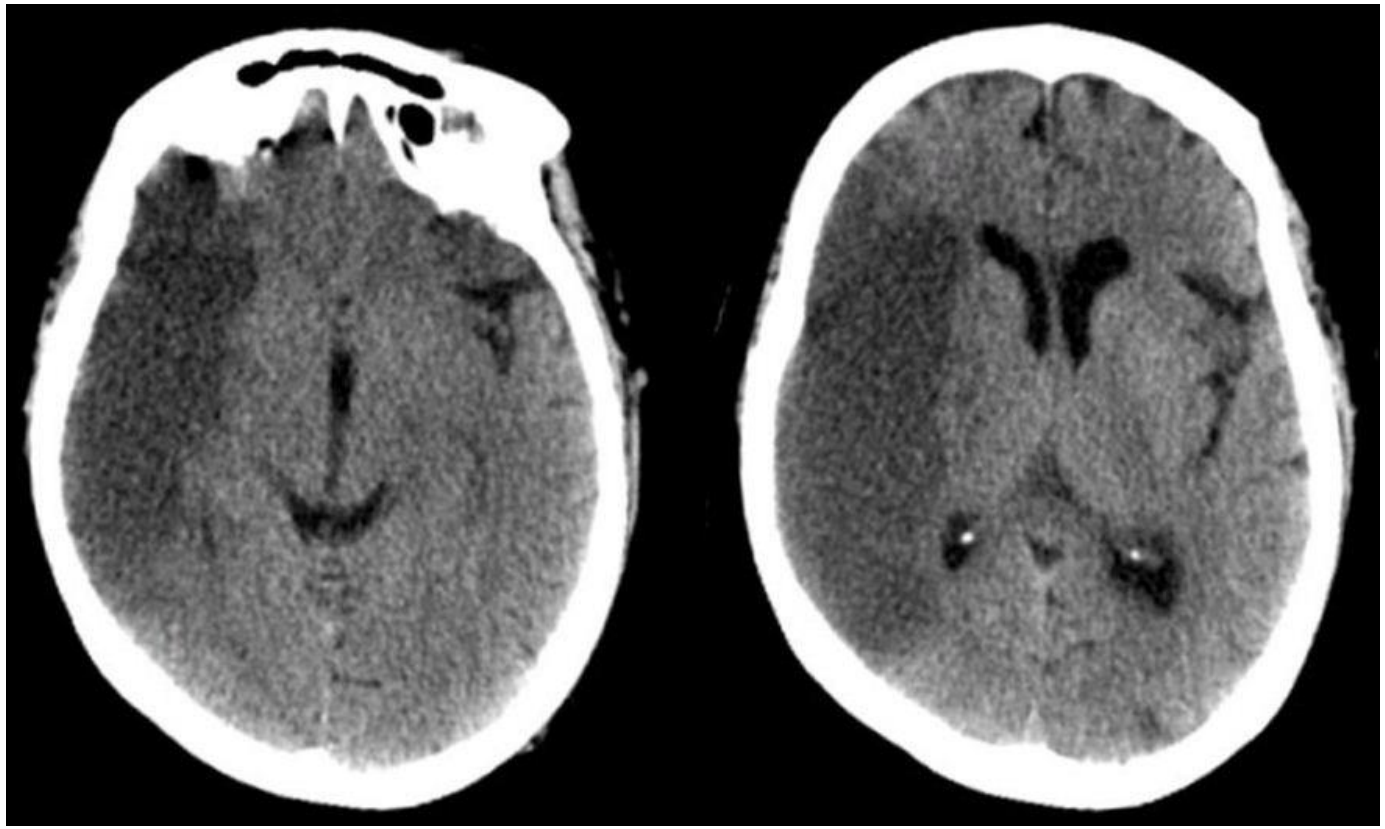
- No EPOA but ACP very clear for comfort cares only; daughter insistent on IV fluids
- After 3 days, dysarthria improved and some return in strength; swallowing improved
- Reviewed by MDT; good rehab candidate
- Family meeting held; patient not keen for rehab. Discharged to PH near daughter's residence

PATIENT 3



- Wife consented for thrombolysis and clot retrieval
- Post procedure mild improvement in strength and speech but remained very agitated and combative
- Went into fast AF; NG tube inserted to enable administration of rate controlling meds
- NG feeds commenced

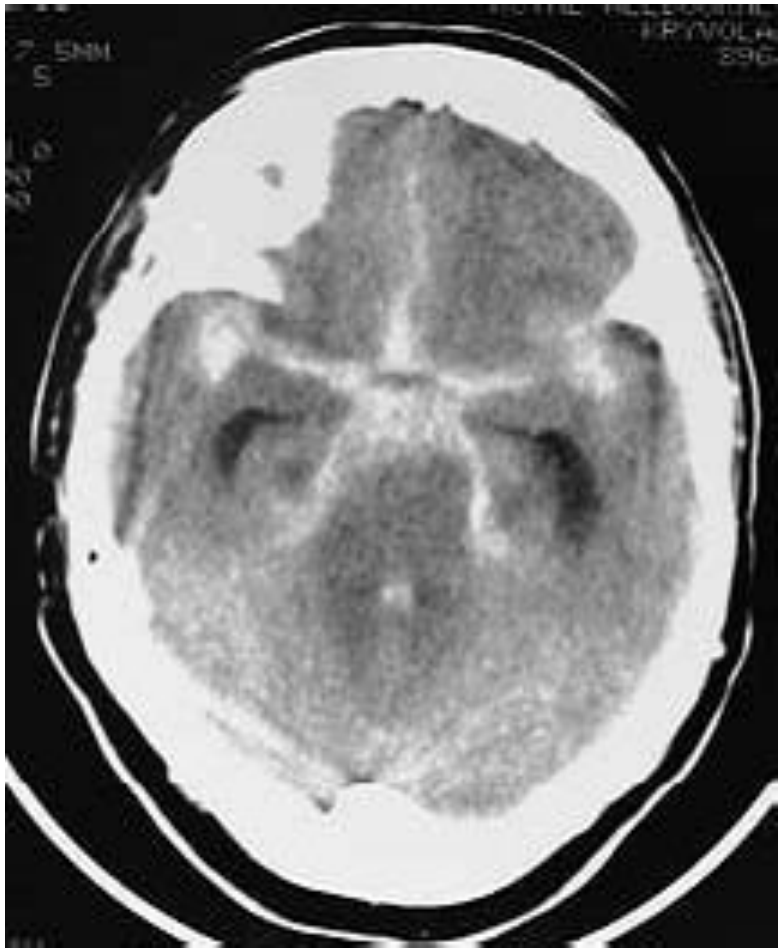
PATIENT 3



PATIENT 3

- Continued with NG feeds and boluses of fluids via NG
- Deterioration in neurology on D3-5; no new infarct or haemorrhagic transformation on CT. Deterioration presumed to be related to pneumonia
- Appeared to be in distress with chest pain on D6; elevated troponin on bloods
- D12 – stable enough to be transferred to rehab ward but remained densely hemiplegic requiring hoist transfers, swallow remained unsafe and still NG fed
- D28 died on rehab ward as a result of bowel obstruction and subsequent perforation

PATIENT 4



- Family not accepting of diagnosis
- Complex family meeting held in ED
- Commenced fentanyl driver, midazolam and haloperidol via syringe driver
- Died 10 hours after admission

SUMMARY

- Palliative Care in Stroke remains a challenge
- Uncertainty in prognosis is the rule, not the exception
- Balancing hope for the best outcome while preparing for the worst
- Recognising the symptoms of end of life can be challenging

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