Crisis management

Managing bleeding and seizures towards the end of life: A multi-disciplinary approach

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Why focus on these?

- Highly distressing for all involved
- Importance of preparatory MDT work:
  - Individualized risk communication
  - Preparatory/pre-emptive decision making
  - Place of care
  - Emergency management plan
- Impact of a calm professional – what we say and how we say it shapes the lasting memories for that family

Case A

- 39yo Male with fronto-parietal glioblastoma
- 18 months post diagnosis self presents to palliative care
- Focal seizures since diagnosis: Managed on lamotrigine, lacosamide and clobazam 10mg BD (rash with levetiracetam). Only 2 generalized seizures ever (peri-operative).
- Difficult to control headaches and vomiting, some erratic behaviours described by wife

- Presents to ED with a seizure failing to respond to 10mg clobazam x 1, buccal midazolam x 1, midazolam SC x1
- Unresponsive, felt to be dying
- CSCI Midazolam 40mg commenced
- CSCI Dexamethasone prescribed to replace oral
- Oral medications stopped

- Referred to hospice day 4 post seizure for EOLC
- Admitted to hospice day 7 post seizure

Challenges

Brother not happy with 50mg midazolam via CSCI “You are sedating him while you wait for him to die”

Sedating side effects

PCF “In last days of life, generally midazolam is used. When patient not imminently dying, a less sedative alternative to midazolam is more appropriate”

SC options

- Levetiracetam CSCI. PO:SC 1:1
- Valproate CSCI. PO:SC 1:1
- Lacosamide?

Oral options

Time to clinical onset (oral)	
Levetiracetam	30-60mins
Lacosamide	1-2 hours
Lamotrigine	Days to weeks
Carbamazepine	6-12 hours
Valproate	1-2 hours
Clobazam	1-4 hours

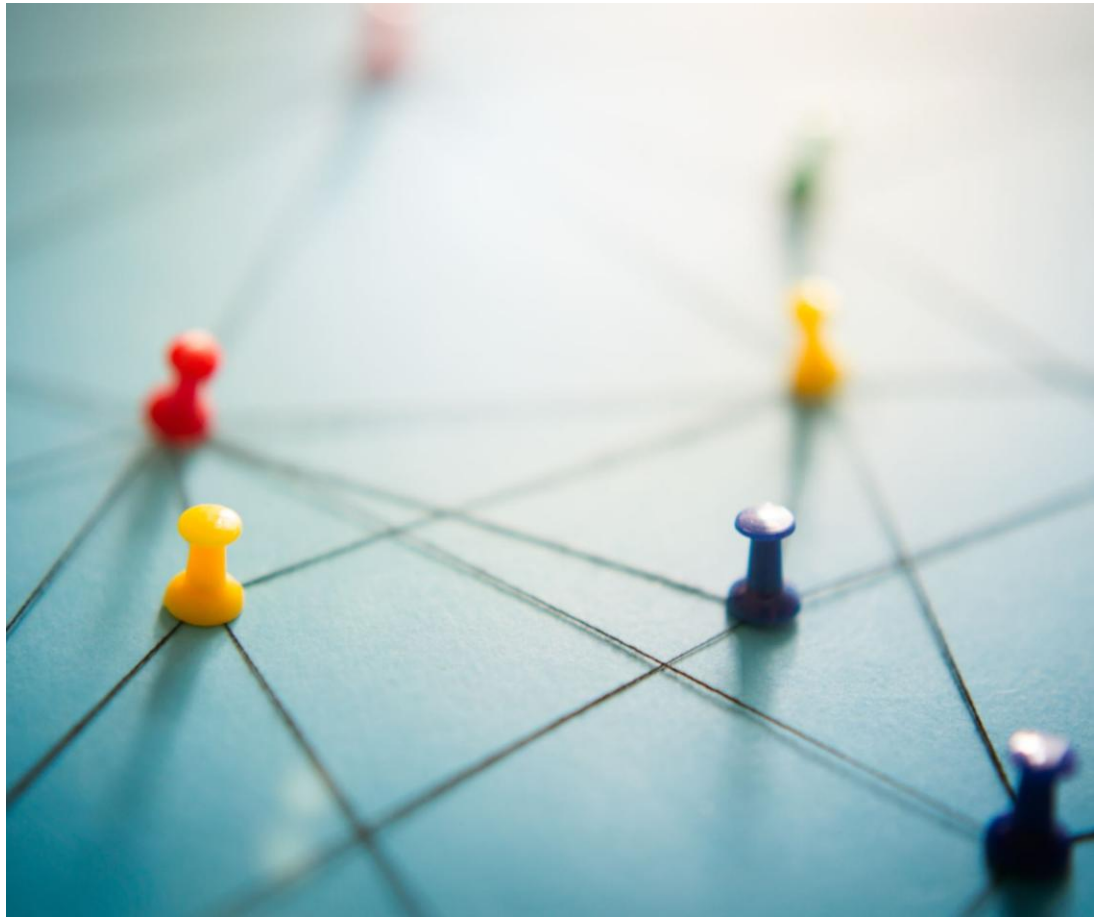
PO options

- Swallow
- Concordance
- Time to onset
- Time for up-titration

Individualised plan

- Neurology advice gained
- Restart of lacosamide immediately
- Restart of lamotrigine at 1 week

MDT discussion with LPA decided to wean midazolam cautiously during oral ‘re-loading’ and stop if concordance troublesome



Challenges

Episodes of erratic and aggressive behaviour not responding to benzodiazepines.

Is it disease?

Is it steroid related?

Is it non convulsive seizures?

Is it benzodiazepine tolerance?

Will antipsychotics lower seizure threshold?

Erratic behaviour and distress

- Listen to the story and unpick the timescale
- Look for what is modifiable
- Acknowledge the uncertainty

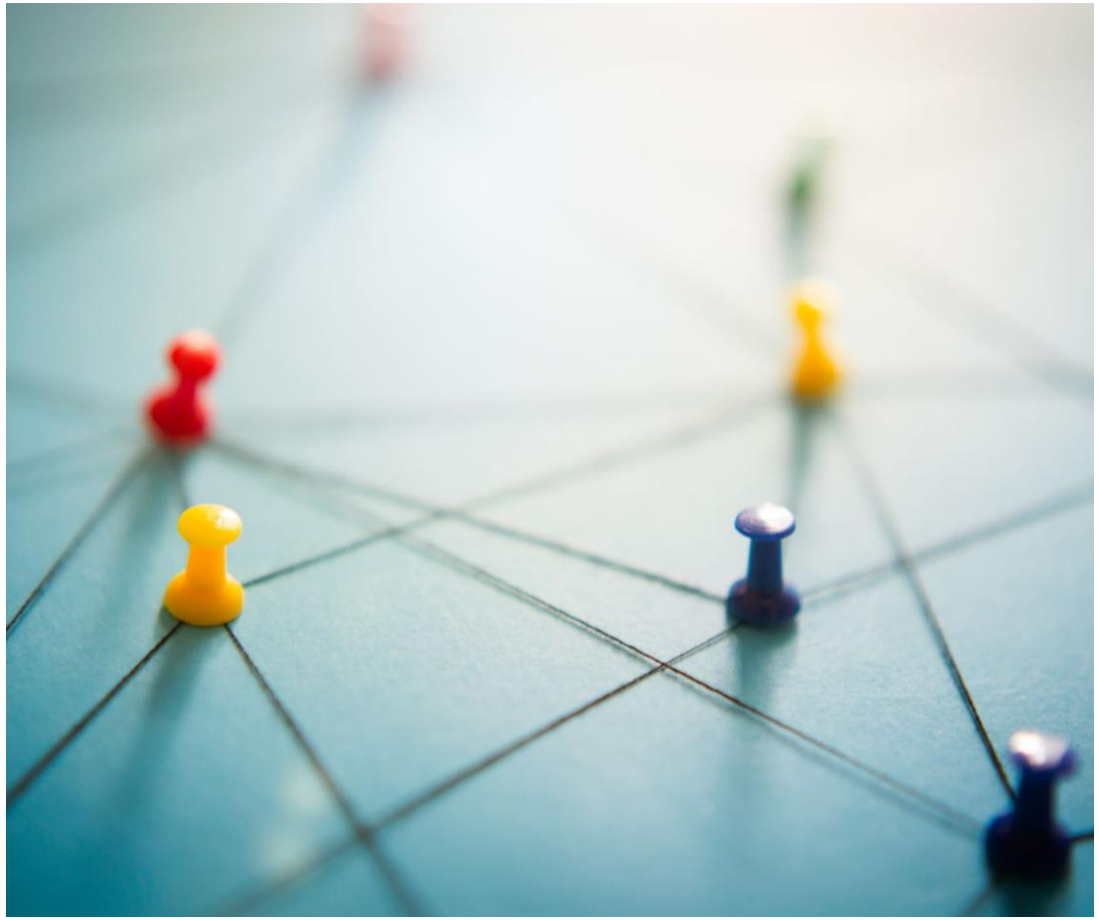
Evidence of seizure threshold reduction with anti-psychotics:

- Anti-psychotic medications, particularly clozapine, can lower the seizure threshold. Phenothiazines carry a ‘modest but definite risk’
- For clozapine, this is a dose dependent effect.
- Newer atypical antipsychotics tend to have lower seizure threshold reduction risk, but none are entirely free from it

Individualised plan

- Avoid triggers
- Toileting
- Low level – lorazepam 1mg
- Agitated / aggressive – levomepromazine 12.5mg ON

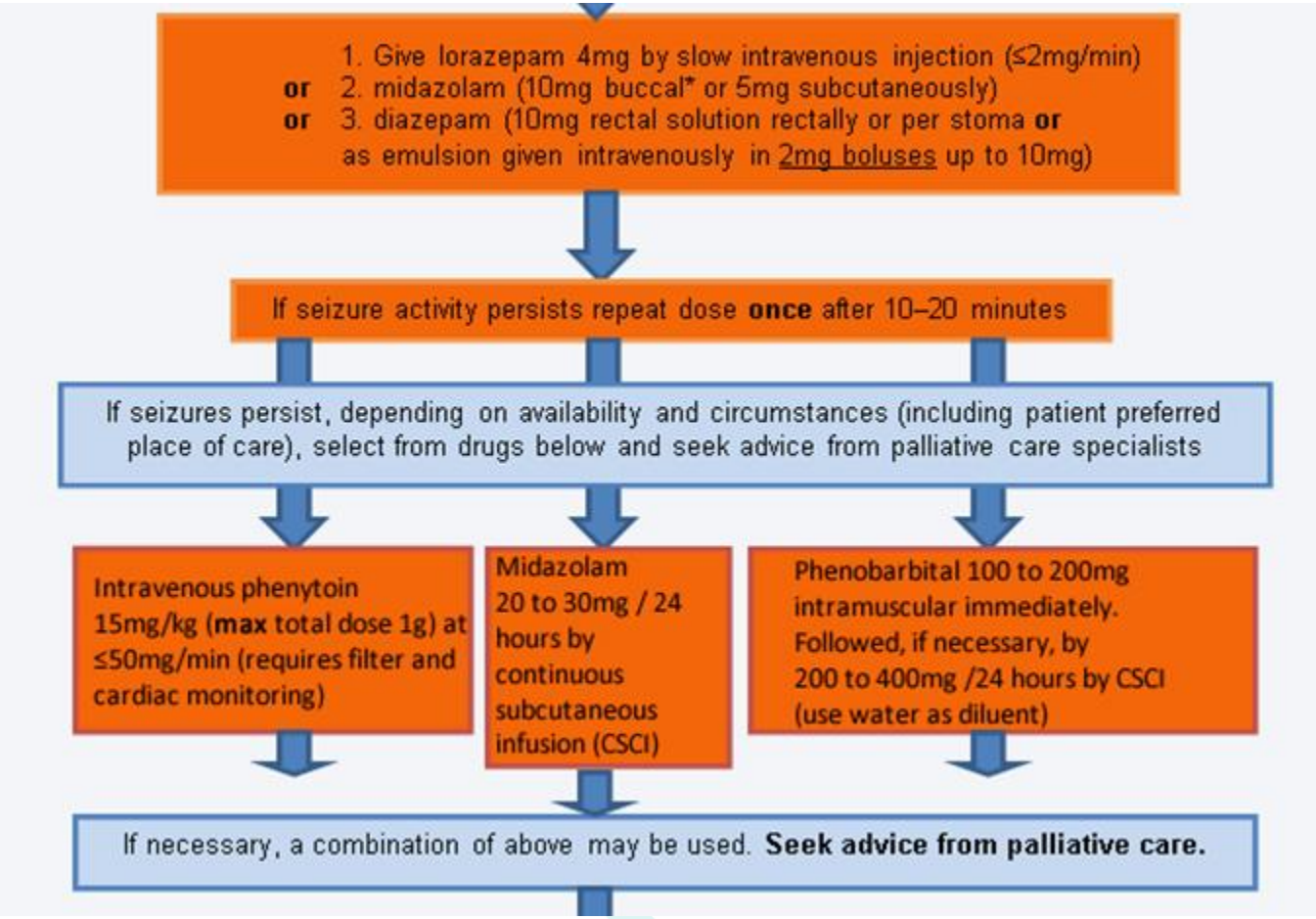
- If frequent episodes for olanzapine 5mg ON and up titration



Challenges

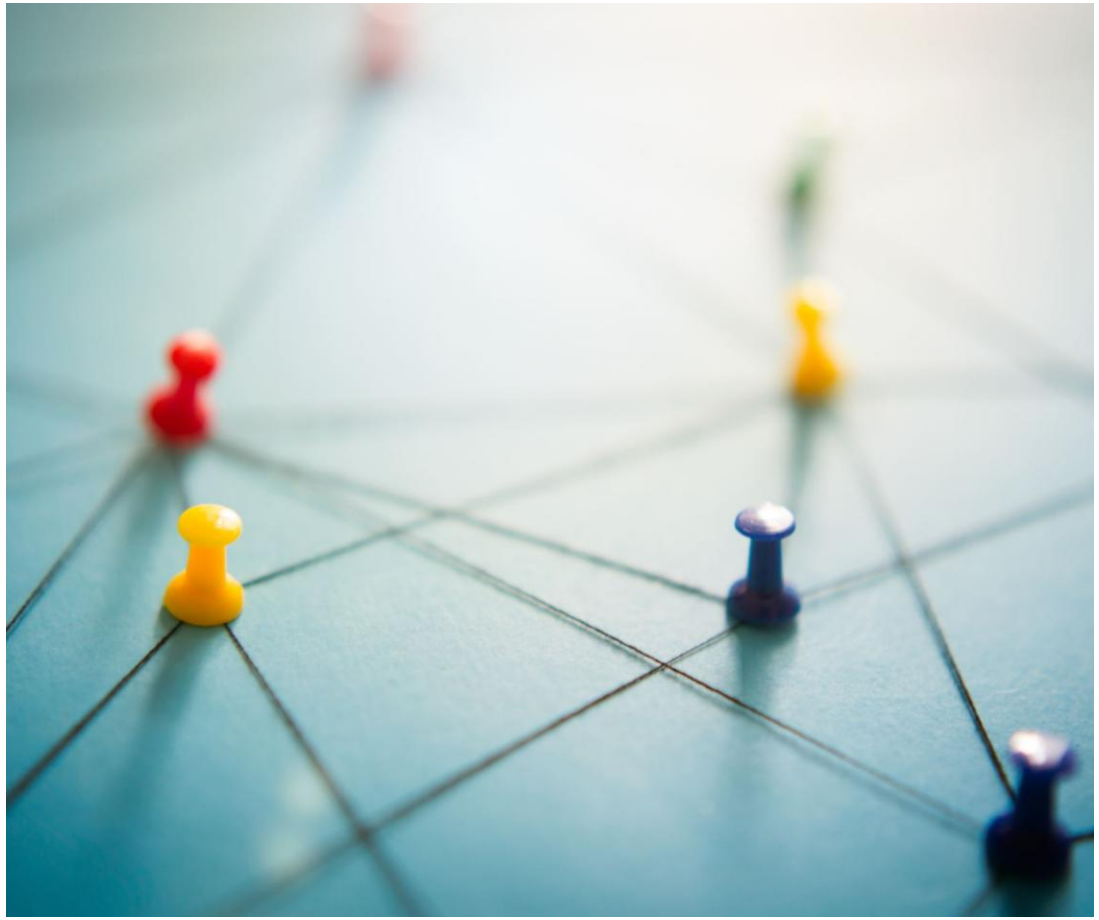
What if he has uncontrollable seizures?

Acute seizures – Scottish Palliative care guidelines



Individualised plan

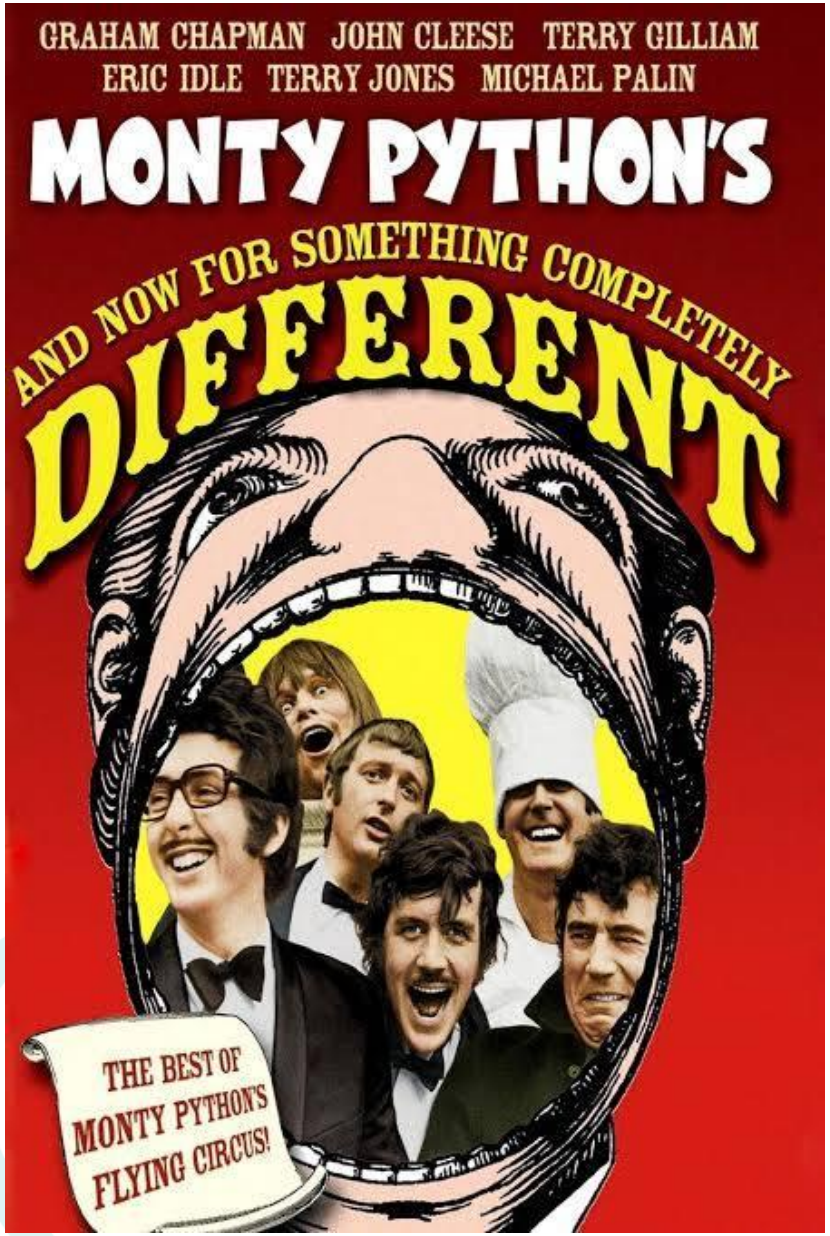
- Focal seizure lasting over 10minutes or cluster of focal seizures within 2 hours – 5mg SC midazolam (repeat at 10minutes)
- Generalised seizures – 10mg SC midazolam (repeat at 10minutes)
- Two doses of SC midazolam 10mg available in 24 hr period
- Ongoing seizures/status despite above – phenobarbital 200mg stat IM, repeat 30minutely up to 600mg (a 10mg/kg loading dose). Discuss CSCI dosing.



Summary of learning

- Fears – some disabling, product of lived experience
- Loss of oral routes – good evidence now for CSCI levetiracetam, some emerging evidence for lacosamide SC but not easy to negotiate. Patients have trusted and non trusted medications
- “Sedation” and other side effect concerns
- Place of care – fraught with emotional and practical difficulties

The case – a peaceful death in the IPU three months later. No seizures in the last three weeks of life. Never received phenobarbital.



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Empower Enable Engage

Caring ● Together ● Respect ● Responsive ● Dynamic

Catastrophic terminal haemorrhage

- What it is (and what it isn't)
- Thankfully rare

Management:

- Identify and manage risk
- Supportive measures
- Sedation

Catastrophic Haemorrhage

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Together we care

PREPARATION FOR THE EVENT

1) Identify patients at risk
i.e. those with:

- Head and neck cancers
- Haematological cancers
- Tumours invading or at close proximity to major vessels

2) Modify risk factors:

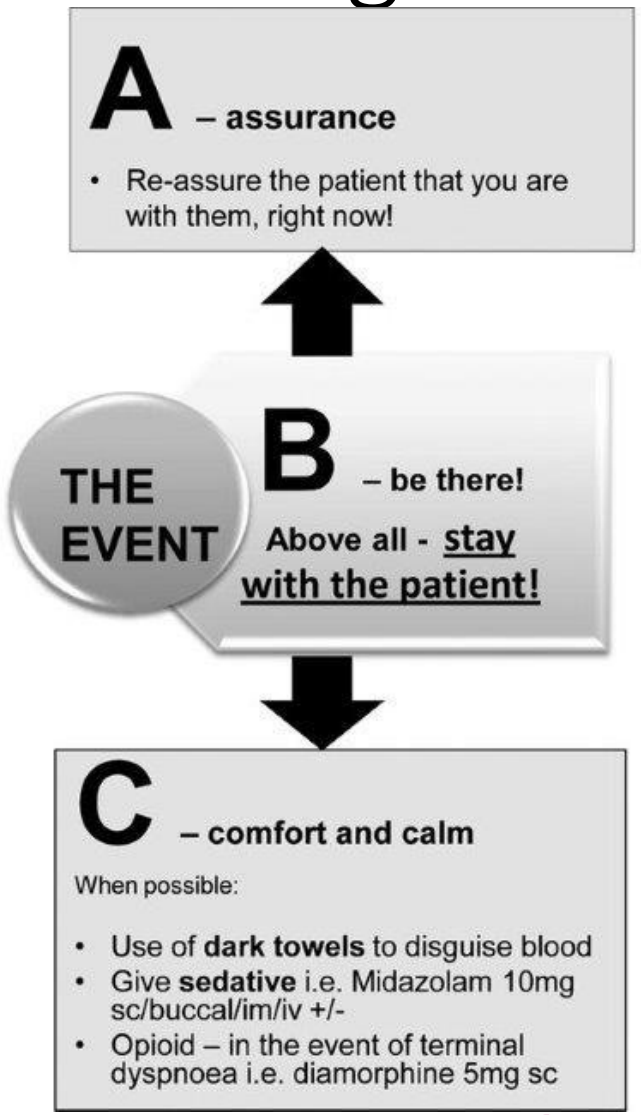
- Identify modifiable factors and implement measures to REDUCE risk i.e. stopping anticoagulant drugs.

3) Engage in sensitive discussions.

When appropriate with:

- Patients and relatives
- Other professionals i.e. palliative care team, GP, district nurses, out-of-hours team, and local ambulance team.

Consider discharge with anxiolytics, opioid, community orders against resuscitation.



AFTER THE EVENT

1) Supportive measures:

- Provide immediate support and reassurance to family, care-givers, and staff present.

2) Disposal of waste:

- Dispose of clinical waste as appropriate – i.e. using yellow bags provided to patient on discharge.

3) Psychological support:

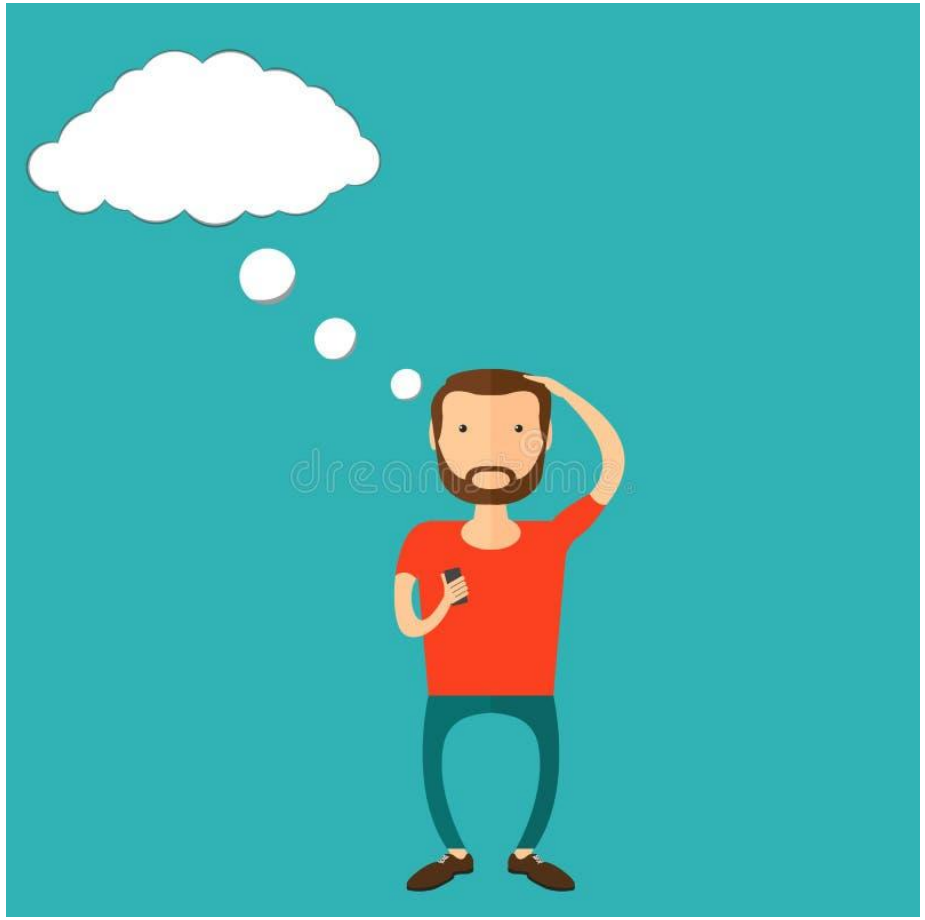
- Offer on-going psychological support, bereavement counselling +/- debrief session for all involved including family, care-givers and staff.

Ubogagu, E. Harris, D.G. (2012)

Communicating and living with risk

- If we know something, should we always advise the patient of it?

- Could you live with the knowledge?



Should you discuss the risk with the patient?

- Pros
  - Easier to prepare practically
  - Children in house
  - Warning bleeds
  - Patient asks
  - Preventative measures may be possible
- Cons
  - Rare events
  - High degree of uncertainty
  - Frightening in prospect
  - May impact quality of life
  - May impact place of care

Pretend you are speaking to your loved one

Interviews with health care professionals

Wadee, T. Noble, S. (2025). From research to reality: a review of three clinical problems in the last days of life. Clinical Medicine. 25 (4).

- Vivid memories of the event
- We are poor predictors of those at risk of haemorrhage
- Death is rapid
- Patients are frequently left alone to get crisis medicine

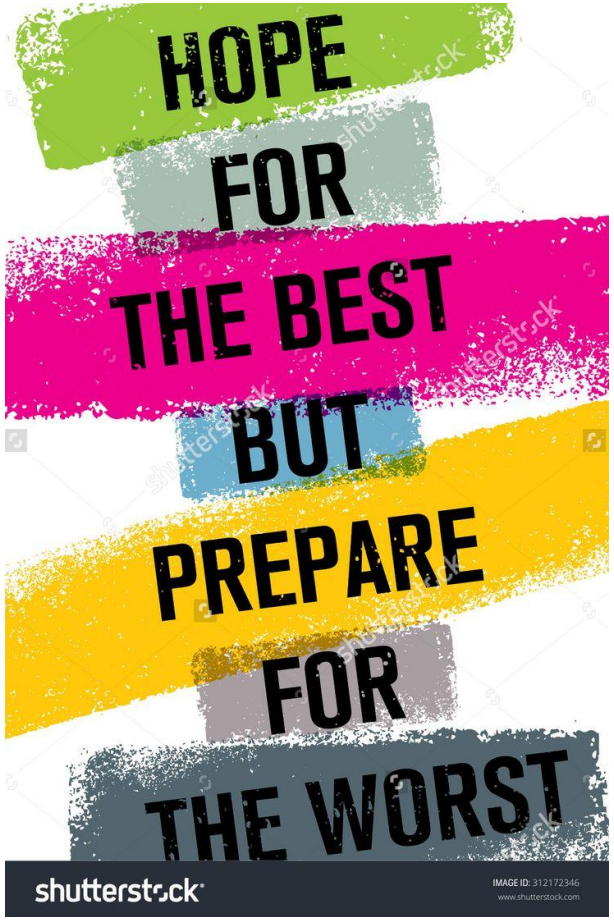
The importance of a team debrief and supportive session cannot be overemphasized.

Conclusions

How can we prepare better – not just for death, but for the crises that can come with dying?

Staying curious as to your motivations: What are the goals here? Who is the main beneficiary? What does good look like? Is it likely to be perfect?

“To cure sometimes, to relieve often, to comfort always” – Hippocrates



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Any questions