Palliative care following withdrawal of life sustaining treatment

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Northwick Park Hospital
Life-sustaining treatments

- Early stages following injury
  - Prognosis for recovery can be hard to predict
  - A range of life sustaining treatments are given
    - In the hope of a good recovery

<table>
<thead>
<tr>
<th>Category</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Escalation of unplanned immediate or urgent interventions for life threatening events that may/may not arise</td>
<td>1. Attempts at Cardiopulmonary Resuscitation (ACPR)</td>
</tr>
<tr>
<td></td>
<td>2. Surgical or other invasive interventions</td>
</tr>
<tr>
<td></td>
<td>3. Escalation to Intensive / high dependency care</td>
</tr>
<tr>
<td></td>
<td>4. Antibiotics in the instance of life-threatening infection.</td>
</tr>
<tr>
<td>Elective medical interventions designed to sustain or prolong life</td>
<td>1. Prophylactic treatments</td>
</tr>
<tr>
<td></td>
<td>• Antithrombotic or seizure prophylaxis, cardio-protective agents,</td>
</tr>
<tr>
<td></td>
<td>implantable pacemakers /defibrillators etc.</td>
</tr>
<tr>
<td></td>
<td>2. Other treatments, screening or preventative interventions</td>
</tr>
<tr>
<td></td>
<td>• (eg bowel or breast cancer screening, immunisation, or treatments for unrelated conditions)</td>
</tr>
<tr>
<td></td>
<td>3. Long-term treatments</td>
</tr>
<tr>
<td></td>
<td>• (eg dialysis, tracheostomy/assisted ventilation, insulin, steroid replacement therapy)</td>
</tr>
<tr>
<td></td>
<td>4. Clinically assisted nutrition and hydration (CANH).</td>
</tr>
</tbody>
</table>
Treatment Escalation planning

- Resuscitation Council
  - ReSPECT process
    - Treatment escalation plans
    
- “Co-ordinate my care”
  - Urgent care plan

- Normalise discussions
  - With both team and family
- Be honest and open
  - Be clear
    - who the decision is for

- Ceiling of treatment
  - ‘Treatment escalation plan’
    - For all patients
  - In front of notes
    - Plastic pocket
      - Next to DNACPR
  - Review regularly
    - In weekly MDT round

https://www.resus.org.uk/respect/

https://www.coordinatemycare.co.uk

Treatment Escalation Plan (TEP) for RHRU

- For Adults aged 16 and over.

<table>
<thead>
<tr>
<th>Patient’s Full Name:</th>
<th>Date and time of TEP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of Birth:</td>
<td>Does the patient have capacity to make decisions re: TEP</td>
</tr>
<tr>
<td>NHS Number:</td>
<td>YES □ NO □</td>
</tr>
</tbody>
</table>

Documentation of discussion with patient/family/overleaf:

<table>
<thead>
<tr>
<th>Is this patient for FULL ESCALATION (resuscitation and for consideration of intensive care)?</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES □ NO □</td>
</tr>
</tbody>
</table>

For patients with limited ceilings of treatment (i.e. if not for full escalation):

- Is this patient for resuscitation? YES □ SHORT resus (form completed) NO □ (DNACPR) form completed |

NB: If DNACPR form is completed, it should be signed by a Consultant within 24hrs

- Is this patient for consideration of Intensive Care?
  - YES □ NO □ |

If yes, Intensive Care Team will review patient and decide on interventions offered.

- Is this patient for consideration of HDU admission?
  - YES □ NO □ |

If yes, HDU Team will review patient and decide on interventions offered.

- Is this patient for Medical Emergency Team (MET) calls?
  - YES □ NO □ |

If not for MET Calls please indicate who staff should escalate care to (e.g. ward based responsible) Team to contact if patient not for MET Calls: Other emergency calls the patient may be for (e.g. Major Haemorrhage Call):

- Is this patient for ward-based care only?
  - YES □ NO □ |

- Is this patient for antibiotics in case of life-threatening infection?
  - YES □ High threshold |

If high threshold, antibiotics should be discussed with RHRU consultant, ideally with known organism sensitivities.

- Is this patient for consideration of further neurosurgery?
  - YES □ NO □ |

If yes, Neurosurgical advice would be sought to decide on interventions offered. The patient’s usual neurosurgical team is (Hospital and Consultant):

- Is this patient for consideration of other major surgery?
  - YES □ NO □ |

If yes, advice from the on-call surgical team would be sought to decide on interventions offered.

- Is this patient for consideration of tracheostomy reintervention?
  - N/A (no tracheostomy) □ YES □ NO □ |

If yes, ENT advice would be beneficial to decide on interventions offered.

- Is this patient for symptom control only (i.e. for palliation)?
  - YES □ NO □ |

- Is this patient dying (i.e. for last days of life care)?
  - YES □ NO □ |

If yes, commence “Last Days of Life Care” booklet and consider referral to palliative care team.

Form Completed by (ST3 or above):

<table>
<thead>
<tr>
<th>Name:</th>
<th>Signature:</th>
<th>Time &amp; Date:</th>
</tr>
</thead>
</table>

Responsible Consultant’s Review, within 24hrs (If not completed by consultant):

<table>
<thead>
<tr>
<th>Name:</th>
<th>Signature:</th>
<th>Time &amp; Date:</th>
</tr>
</thead>
</table>

If TEP NO LONGER VALID: Please cross through whole page, file in notes, and complete new TEP

<table>
<thead>
<tr>
<th>Name:</th>
<th>Signature:</th>
<th>Time &amp; Date:</th>
</tr>
</thead>
</table>
Although the BMA/RCP guidelines focus on CANH

- **Real life decision-making is rarely that simple**
  - Patients are often on multiple life-sustaining treatments
    - Each needs to be considered in its own right
  - It is neither possible nor sensible to separate these entirely

**Different decisions required at different stages**

- **Decisions about ACPR /escalation**
  - Require instant action by unfamiliar clinicians
    - Need to be made in advance from an early stage in pathway
    - Emotive – public perception that CPR is universally life-saving

- **Others can be made as the need arises**
  - But still urgent (eg antibiotics, surgery etc)
    - Element of chance - ‘out of our hands’
    - Less emotive – public less aware, more time to discuss

- **Elective decisions regarding longer term treatments**
  - Can be made over time
    - More emotive again – ‘bigger decision’ - family perceive as their responsibility
    - Requires wider frame of reference
Frequent issues that arise

- **Switch of perspective**
  - **Early stages**
    - Understandably, many families are often keen for everything to be done
    - May become angry at any suggestion of ‘giving up on them’
      - CPR / antibiotics particularly emotive – also CANH
  - **Later on**
    - May reach the conclusion that P would not want treatment
      - Understandably frustrated by the fact that there a process to go through before life-sustaining can be withdrawn - particularly CANH

- **Concern about hunger and thirst after CANH withdrawn**
  - ‘Couldn’t you just give a quick injection?..’
    - No, it is illegal to knowingly give a treatment that would hasten death
  - **But we can provide excellent palliative care**
    - Guidelines offer detailed advice
      - Including a choice of EoL palliative care regimens
Challenges for EoL care

- Process of dying is often prolonged
  - Timing of death is difficult to anticipate
    - Uncertainty when to apply EoL pathways
      - Even after elective withdrawal of L-S treatment

- Complex neurological symptoms
  - Spasticity, involuntary movements
    - Requiring skilled postural handling and specialist equipment
      - Typically not available in hospice settings

- Autonomic dysfunction / reflexive movements
  - May become more pronounced with metabolic disturbance
    - Burden of witness for families and care staff

- Some have underlying painful conditions – especially in MCS
  - Unable to communicate their symptoms

EoL care requires a collaborative approach between specialists in
  - Palliative care
  - Neuro-disability management
## Categories of patient dying in PDOC

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
<th>Mode of dying</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Other co-morbidities / frailty – likely to die in less than 1 year</strong></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Death is imminent within hours or days</td>
<td>Death usually due to other causes or complications</td>
</tr>
<tr>
<td>2</td>
<td>Death not necessarily imminent but weeks or months</td>
<td>Eg bronchopeumonia or other condition unrelated to brain injury</td>
</tr>
<tr>
<td></td>
<td><strong>Stable or upward trajectory – elective decision to withdraw life-sustaining treatment</strong></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Very low level disordered consciousness (VS)</td>
<td>Death due to the brain injury and its complications</td>
</tr>
<tr>
<td>4</td>
<td>Moderate or fluctuating response/awareness (MCS)</td>
<td>Mode of dying depends on the type of treatment withdrawn</td>
</tr>
<tr>
<td>5</td>
<td>Post Court order</td>
<td></td>
</tr>
</tbody>
</table>

- **Patients are likely to die differently**
  - Depending on the nature of the life threatening condition
    - When treatment is withdrawn
  - Palliative care planning must take account of
    - The likely nature of symptoms and the expected timescale
      - Category 1 – usually die within 14 days – managed through conventional palliative care programmes
      - Categories 2-5 - may require more specialist planning
### Some possible modes of dying

<table>
<thead>
<tr>
<th>Treatment withdrawn</th>
<th>Mode of dying</th>
<th>Anticipated timescale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insulin for diabetics</td>
<td>Keto-acidosis / hyper-osmolar coma</td>
<td>Usually within 48-72 hours</td>
</tr>
<tr>
<td>Long term ventilation</td>
<td>Type 1 respiratory failure</td>
<td>Instant, hours or days</td>
</tr>
<tr>
<td>Tracheostomy</td>
<td>Aspiration pneumonia and/or Respiratory failure</td>
<td>Variable</td>
</tr>
<tr>
<td>Dialysis</td>
<td>Uremia / acidosis</td>
<td>Average 1 week (IQR 0-6 weeks)</td>
</tr>
<tr>
<td>CANH</td>
<td>Multi-organ failure secondary to dehydration</td>
<td>Usually 2-3 weeks</td>
</tr>
</tbody>
</table>

### Acidosis / metabolic disturbance

- **Common end-stage in many situations**
  - CANH usually withdrawn at the same time due to risk of vomiting
    - Its continuation could actually hasten death
  - Acidosis may cause compensatory over-breathing
    - With or without involuntary vocalisation
    - May give the appearance of distress, even if the patient him/herself is unaware
CANH withdrawal

- If CANH is withdrawn in otherwise stable patient
  - Develop dehydration and multi-organ failure
    - Renal failure, uraemia, acidosis and electrolyte disturbance
      - Ultimately ending in cardiac arrest
  - Typically takes about 2-3 weeks
    - During which patients visibly lose weight
  - In many cases not inherently distressing
    - Reduced tissue perfusion
      - Affects absorption of subcutaneous medication
        - Erratic response – particularly in late stages
    - Dry mouth
      - Can be managed with meticulous mouth care

Families and care staff should be advised what to expect and supported throughout the process.
Physiological hyper-activity

Many may die peacefully

- Some show a strong physiological reaction
  - to altered homeostatic balance
- Reflex hyperactivity in the brainstem – can be extreme

- Signs may include:
  - Sweating, tachycardia – can be dramatic
  - Hyperventilation secondary to metabolic acidosis
    - If vocal cords partially closed may manifest as groaning
  - Other spontaneous / reflexive movements normally displayed
    - May become more prominent
    - Eg roving eye movements, teeth-grinding, chewing, crying,

These give the appearance of distress

Burden of witness can be profound and should not be under-estimated
Even though rare – this eventuality should be planned for
End of life palliative care regimens

- Standard palliative regimens may not work well
  - Morphine / midazolam etc rely on cortical pathways
  - Absorption of subcutaneous medication erratic in late stages

- RCP guidelines provide EoL regimens
  - Continuous subcutaneous infusion (CSCI)
  - Intravenous infusion (IV)

- Background infusion
  - With bolus doses as required
  - 4 stage regimen – careful but sufficient escalation
    - Stage 1 is often sufficient
    - But occasionally up to stage 3
      - Must have a back-up plan for delivery of higher stages in case required
IV regimens

- Hard to provide outside of a hospital setting
  - Nursing homes and palliative care teams
    - Generally not trained in IV management
  - Requires a mid- or long line

- In hospital – IV often preferable
  - Reliable absorption
    - Especially in the late stages
  - Bolus doses are much easier – just press the button
    - Do not have to check and draw up separately
    - Rapid action – within 2-3 minutes
    - Can give low dose and repeat if necessary
      - Accurate titration to need
      - Overall doses may be lower
# 4-stage protocol

<table>
<thead>
<tr>
<th>Stage</th>
<th>Agent</th>
<th>Dosing</th>
<th>Titration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 1</td>
<td>Morphine</td>
<td>Start at 10mg/24 hours each</td>
<td>Each 24 hours: Re-prescribe infusion dose to total required in previous 24 hrs</td>
</tr>
<tr>
<td></td>
<td>Midazolam</td>
<td>Bolus doses: • 10% for short interventions (eg turning) • 20% for symptom control</td>
<td>Up to maximum • Midazolam 10-20 mg/hr • Morphine 10 mg/hr Or until bolus dose no longer effective</td>
</tr>
<tr>
<td>Stage 2*</td>
<td>Levomepromazine</td>
<td>Add Levomepromazine 50mg/24 hours Bolus doses: 12.5-25 mg</td>
<td>Up to maximum 150mg/24 hours Or until bolus dose no longer effective</td>
</tr>
<tr>
<td>Stage 3</td>
<td>Phenobarbitone</td>
<td>Replace Levo with Phenobarbitone 200-600 mg/24 hrs in a separate syringe Bolus doses 100-200 mg</td>
<td>Titrate up to 2400mg per 24 hours</td>
</tr>
<tr>
<td>Stage 4</td>
<td>Self-ventilating IV anaesthesia – eg propofol</td>
<td></td>
<td>With the support of ITU trained staff supervised by consultant anaesthetist</td>
</tr>
</tbody>
</table>

- Slight variations for SC and IV administration
  - If reach stage 3 SC – consider transfer to IV
- Sedation is often the principal requirement
  - Beware of morphine-induced agitation
    - Option to skip stage 2 and move direct to phenobarbitone
Tracheostomy

- Often not considered
  - Clinical teams anxious about weaning tracheostomy
    - Fear of aspiration / RTI / immediate suffocation

- But long term tracheostomy creates problems
  - Often limits choice of nursing home placement
  - Requires monthly change
    - Logistics depending on risk
  - Risk of infection, erosion, bleeding

- ‘Risk weaning’
  - Recent experience suggests we are often too cautious
    - But palliative care plan requires careful consideration
Impact for clinical teams

Many challenges

- Ethical concerns
  - Trained to care for and treat patients – “we have a duty of care”
    - “Withdrawal of treatment = neglect
      - Rather than giving unwanted treatment = abuse
  - Religious concerns
    - Against their own personal creed
    - Conscientious objection
- Distressed and challenging families
  - Sometimes with disparate views
- Difficulty managing death (especially in rehab settings)
  - What is the therapist’s role – not sure what to do
    - Structured goal setting for PDOC
  - Grieving for a patient they have got to know
    - What to say to the family after death
Experience to date

- Regional Hyper-acute Rehabilitation Unit (RHRU) Northwick Park Hospital
  - One of two designated PDOC specialist services in London

- Providing neuro-palliative care for >10 years
  - Including elective CANH withdrawal

- Share our experience of managing EoL care for patients in PDOC
  - Since introduction of the BMA/RCP guidelines – December 2018

NB: These data are pre-publication and confidential at present
- PLEASE DO NOT TWEET..!
Deaths

12 PDOC patients

- Have died on the RHRU since December 2018
- CANH was withdrawn in 8
  - 4 patients had elective withdrawal within scope of the Guidelines

<table>
<thead>
<tr>
<th>Category</th>
<th>No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outwith the scope of the BMA/RCP guidelines</td>
<td></td>
</tr>
<tr>
<td>CANH not withdrawn – died of other conditions</td>
<td>4</td>
</tr>
<tr>
<td>CANH not possible/ contra-indicated (Admitted from Trust for palliative EoL care)</td>
<td>1</td>
</tr>
<tr>
<td>Imminently dying from other conditions within hrs/days CANH withdrawn as part of EoL care pathway</td>
<td>3</td>
</tr>
<tr>
<td>Elective CANH withdrawal within scope of the BMA/RCP guidelines</td>
<td></td>
</tr>
<tr>
<td>Category 2: With other Co-morbidities/Frailties</td>
<td>3</td>
</tr>
<tr>
<td>Category 3: Otherwise healthy VS/MCS</td>
<td>1</td>
</tr>
</tbody>
</table>
## Case Details – all 12 pts

<table>
<thead>
<tr>
<th>Case</th>
<th>Cat</th>
<th>Decision pathway</th>
<th>Days to death</th>
<th>Mode of death</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td><strong>CANH not withdrawn</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>0</td>
<td>Died from other condition</td>
<td></td>
<td>Bronchopneumonia</td>
</tr>
<tr>
<td>2</td>
<td>0</td>
<td>Died from other condition</td>
<td></td>
<td>HAP + AKI + LVF</td>
</tr>
<tr>
<td>3</td>
<td>0</td>
<td>Died from other condition</td>
<td></td>
<td>Bronchopneumonia</td>
</tr>
<tr>
<td>4</td>
<td>(3) 0</td>
<td>Died from other condition</td>
<td></td>
<td>Bronchopneumonia</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>CANH withdrawn as part of palliative care programme</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>0</td>
<td>No route for feeding, admitted for pall care</td>
<td>14</td>
<td>Bowel perforation/sepsis</td>
</tr>
<tr>
<td>6</td>
<td>0</td>
<td>Pall care – death expected within hrs/days</td>
<td>2</td>
<td>Bronchopneumonia</td>
</tr>
<tr>
<td>7</td>
<td>0</td>
<td>Pall care – death expected within hrs/days</td>
<td>7</td>
<td>Chronic aspiration pneumonia</td>
</tr>
<tr>
<td>8</td>
<td>0</td>
<td>Pall care – death expected within hrs/days</td>
<td>6</td>
<td>Type 1 Respiratory failure</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Elective / semi-elective CANH withdrawal</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>2</td>
<td>Co-morbidities / frailty</td>
<td>4</td>
<td>Pneumonia / Ca Bronchus</td>
</tr>
<tr>
<td>10</td>
<td>2</td>
<td>Co-morbidities / frailty</td>
<td>7</td>
<td>Multiple abdo pathology</td>
</tr>
<tr>
<td>11</td>
<td>2</td>
<td>Co-morbidities / frailty</td>
<td>6</td>
<td>Inoperable hydrocephalus</td>
</tr>
<tr>
<td>12</td>
<td>3</td>
<td>Previously healthy PDOC</td>
<td>17</td>
<td>Multi-organ failure following CANH withdrawal</td>
</tr>
</tbody>
</table>
Audit of performance against standards

Standards

- Patients should have had:
  - Specialist assessment of level of responsiveness/awareness
    - In accordance with RCP guidelines
  - Formally documented best interests meetings
    - with all relevant members of family/ close friends
  - A second opinion from an independent consultant
    - Not previously involved in the patient’s care
  - Where CANH is electively withdrawn in otherwise health pts
    - Should have the RCP/BMA recommended proforma completed

Acknowledgement Dr Verity Thakur for assimilating the data
Summary of pts covered by guidelines

<table>
<thead>
<tr>
<th>PDOC assessment</th>
<th>Best interests meetings</th>
<th>2nd opinion</th>
<th>Proforma</th>
<th>Place of death</th>
<th>Mode of death</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Internal Palliative care consultant</td>
<td>N/A</td>
<td>RHRU</td>
<td>RIP in 4 days Bronchpneumonia</td>
</tr>
<tr>
<td>Category 2 – Co-morbidities / frailty</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td>RHRU</td>
<td>RIP in 6 days – Inoperable hydrocephalus</td>
</tr>
<tr>
<td>2</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td>N/A</td>
<td>RIP in 4 days Bronchpneumonia</td>
</tr>
<tr>
<td>3</td>
<td>✓</td>
<td>✓</td>
<td>✓ Legal case</td>
<td>RHRU</td>
<td>RIP in 7 days Abdo pathology</td>
</tr>
<tr>
<td>Category 3 – Previously healthy PDOC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td>✓ RHRU</td>
<td>CANH withdrawn</td>
</tr>
<tr>
<td>5</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td>✓ RHRU</td>
<td>Died of pneumonia whilst waiting for Trust approval</td>
</tr>
<tr>
<td>6</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td>✓ Nursing home</td>
<td>CANH withdrawn elsewhere</td>
</tr>
</tbody>
</table>


Review of 42 deaths since 2012

Demographics
- Mean age 49
- Mean time onset of ABI to death 16 months

Aetiology
- Hypoxic/Diffuse - 55%
- Traumatic - 19%
- Haemorrhagic CVA - 24%

CANH withdrawn
- Yes - 45%
  - 83% in guidelines category 1
    - death expected within hours/days, so outwith the guidelines
- No - 55%
# Palliative care dose ranges

<table>
<thead>
<tr>
<th></th>
<th>CANH withdrawn N=19</th>
<th>CANH not withdrawn N=12</th>
<th>All N=30</th>
</tr>
</thead>
<tbody>
<tr>
<td>Protocol stage</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>84%</td>
<td>83%</td>
<td>84%</td>
</tr>
<tr>
<td>2</td>
<td>5%</td>
<td>17%</td>
<td>10%</td>
</tr>
<tr>
<td>3</td>
<td>5%</td>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td>Symptom control*</td>
<td>Good</td>
<td>68%</td>
<td>67%</td>
</tr>
<tr>
<td></td>
<td>Difficult</td>
<td>26%</td>
<td>33%</td>
</tr>
</tbody>
</table>

## Maximum dose (mg per 24 hours)

<table>
<thead>
<tr>
<th></th>
<th>Mean (95%CI)</th>
<th>Range</th>
<th>Mean (95%CI)</th>
<th>Range</th>
<th>Mean (95%CI)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Morphine</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mean (95%CI)</td>
<td></td>
<td>Mean (95%CI)</td>
<td></td>
<td>Mean (95%CI)</td>
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<td>Range</td>
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<tr>
<td></td>
<td>50 (29, 74)</td>
<td>10-200</td>
<td>53 (24, 93)</td>
<td>10-240</td>
<td>51 (36,72)</td>
<td>10-240</td>
</tr>
<tr>
<td><strong>Midazolam</strong></td>
<td></td>
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<td>Mean (95%CI)</td>
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<td>Mean (95%CI)</td>
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<tr>
<td></td>
<td>Range</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>38 (27, 51)</td>
<td>10-100</td>
<td>33 (18, 51)</td>
<td>5-100</td>
<td>36 (27, 76)</td>
<td>5-100</td>
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</table>
## Symptoms difficult to control (n=9)

<table>
<thead>
<tr>
<th>Pt ID</th>
<th>Aetiology</th>
<th>PDOC diagnosis</th>
<th>CANH with-drawn</th>
<th>Route</th>
<th>Protocol Stage</th>
<th>Morphine</th>
<th>Midazolam</th>
<th>Additional Medications</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Hypoxic</td>
<td>MCS</td>
<td>No</td>
<td>CSCI</td>
<td>1</td>
<td>50</td>
<td>10</td>
<td></td>
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<tr>
<td>2</td>
<td>Hypoxic</td>
<td>MCS</td>
<td>No</td>
<td>CSCI</td>
<td>1</td>
<td>30</td>
<td>30</td>
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<tr>
<td>4</td>
<td>CVA</td>
<td>MCS</td>
<td>No</td>
<td>IVI</td>
<td>1</td>
<td>40</td>
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<tr>
<td>6</td>
<td>Hypoxic</td>
<td>Not fully assessed</td>
<td>No</td>
<td>IVI</td>
<td>2</td>
<td>240</td>
<td>80</td>
<td>Levomepromazine 12.5mg sc prn x1.</td>
</tr>
<tr>
<td>8</td>
<td>Hypoxic</td>
<td>MCS/VS</td>
<td>No</td>
<td>IVI</td>
<td>2</td>
<td>200</td>
<td>100</td>
<td>Levomapromazine 25mg IV bolus x1</td>
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</tr>
<tr>
<td>3</td>
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<td>MCS</td>
<td>Yes</td>
<td>IVI</td>
<td>1</td>
<td>80</td>
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<tr>
<td>5</td>
<td>Hypoxic</td>
<td>VS</td>
<td>Yes</td>
<td>IVI</td>
<td>1</td>
<td>100</td>
<td>100</td>
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</tr>
<tr>
<td>7</td>
<td>Traumatic</td>
<td>VS</td>
<td>Yes</td>
<td>IVI</td>
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<td>100</td>
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<td>Levomepromazine 25mg IV prn bolus x3 in 48hrs prior to death.</td>
</tr>
<tr>
<td>9</td>
<td>Hypoxic</td>
<td>VS</td>
<td>Yes</td>
<td>IVI</td>
<td>3</td>
<td>125</td>
<td>10</td>
<td>Levomepromazine 50mg/24hrs IV, Phenobarbitone 600mg/24hrs IV,</td>
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</tbody>
</table>

**Conclusions**

- 78% hypoxic brain injury
- 63% MCS
  - (or borderline VS/MCS)
- 44% CANH withdrawn
In our experience

- **CANH withdrawal**
  - Initially approached with some trepidation
    - Bringing staff and hospital management on board
      - Concerned about press coverage etc
  - In reality less problematic than we feared
    - With appropriate planning in place for more difficult deaths

- **Other causes of death**
  - Symptom control can be more problematic
    - Respiratory failure
    - Abdominal catastrophe
  - Definitely want IV regimen
    - And anaesthetic backup
Summary

- Although CANH is highly emotive
  - **Isolated withdrawal is comparatively rare**
    - Particularly with sensible treatment escalation planning
  - **Symptom control may be more challenging in respiratory failure**

- Palliative care planning needs to be holistic
  - **Collaboratively managed**
    - Between specialist palliative care and neuro-disability teams
      - Anticipating all the likely scenarios

- The majority of cases may be relatively straightforward
  - **But some are more difficult**
    - As yet it is difficult to predict which – but ? MCS > VS
  - **It is wise to have back-up plans in place for escalation if needed**

- The PDOC registry may be a useful vehicle
  - To gather systematic data in the future
Open discussion