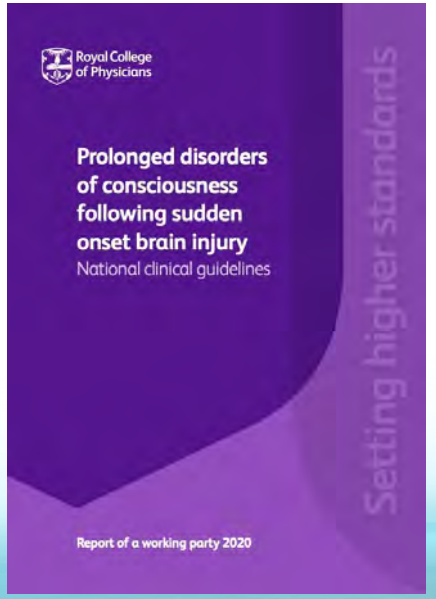
The updated national PDOC guidelines 2020:

What has changed?



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Declarations of Interest

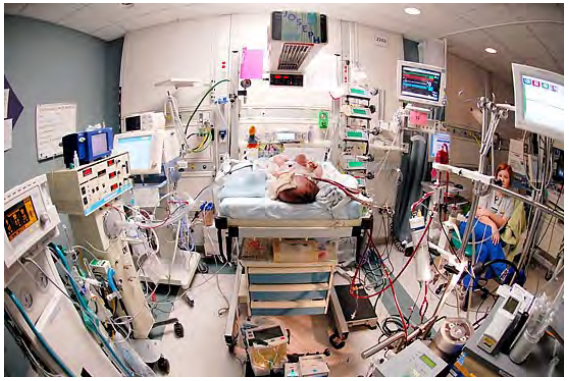
- I am a consultant in rehabilitation medicine, employed full time in the NHS.
  - I am also a a clinical academic Professor of Rehabilitation Medicine at KCL
- Some of the material I will present is derived from the research of my department and/or that of my colleagues
  - It may be declared in my Trust's on Research and Development activity
  - Or by the University in their submission to the Research Excellence Framework.
- Neither I or my family have any personal or financial interest in the content of this presentation

Objectives for this talk

- Take a look at the updated guidelines
  - Why the update was necessary

- We will consider:
  - Some of the key changes - and the rationale for them
  - As the guidelines are no longer that new..
    - Consider some of the challenges to implementation
  - Most important area of change – best interests decision making
    - Still very poorly done, despite being a legal requirement
  - Decisions to continue/ withdraw/withhold life-sustaining treatment
    - Remains one of the most challenging areas of healthcare
  - Main focus for the second half of this talk

Ever better at saving lives

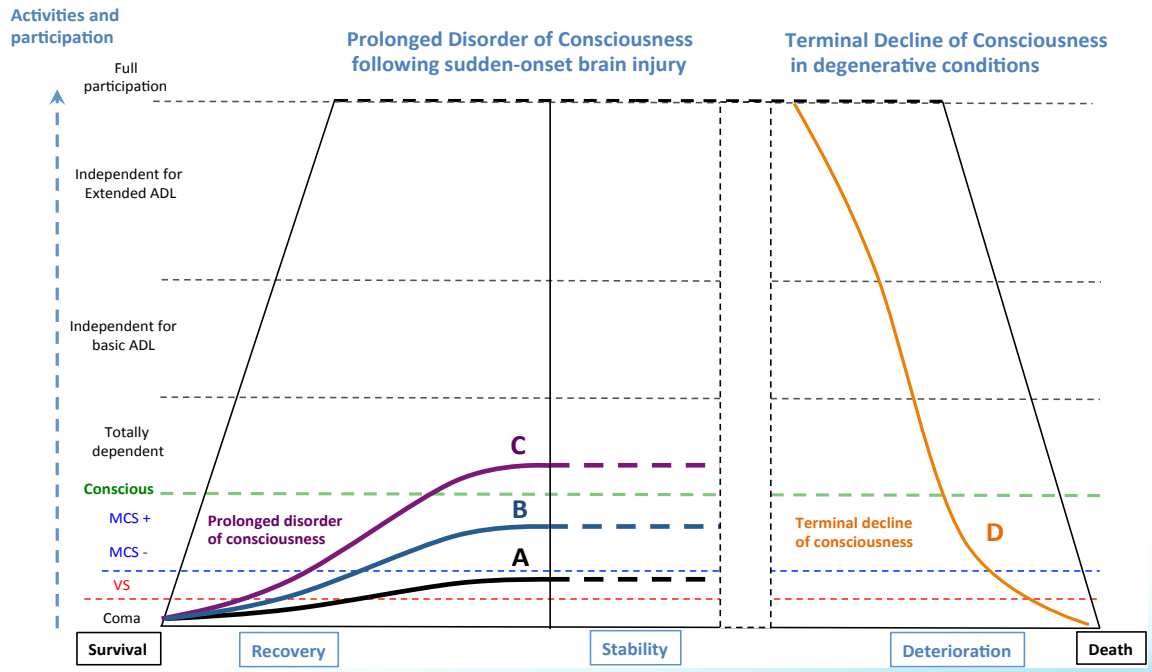


- Better emergency /acute care services
  - Major Trauma Networks
  - Hyper-acute Stroke Units
  - Defibrillators in public places
- Improved outcomes
  - Rescue people who would have died at the scene
    - Seeing increasing numbers of patients in PDOC
      - Following sudden onset brain injury

- Similar issues occur at the other end of life
  - With improved medical care
    - We keep people alive for longer after they drift into unconsciousness
    - How do we manage expectations and difficult decisions?
      - How do we strike the balance between facilitating recovery
      - And humanely and legally discontinuing unwanted further treatments if no longer in P's best interests?

Disorders of consciousness in different stages of life

- PDOC
  - Has received the majority of attention
    - in the media/literature/Courts etc
- TDOC
  - Potentially far greater numbers
    - dementia, Parkinsons', MS,
    - old age etc
- The national guidelines
  - Focus on PDOC
    - But many of the principles apply more widely



Updated PDOC guidelines

- Why was the update necessary?
  - Approach to assessment
    - Further development of assessment measures
      - Need for a more streamlined approach
        - to accommodate increasing numbers
  - Recent Changes in English law
    - Refined interpretation
      - Of the Mental Capacity Act 2005
        - Especially in relation to CANH
  - Publication of other national guidelines
    - US Disorders of Consciousness guidelines
    - UK – Tripartite guidelines
  - Lessons learned
    - From the 2013 guidelines

- Coverage of recommendations
  - Life-long care – from diagnosis to death
    - Definitions and terminology
    - Assessment of the level of consciousness
    - Care and management
    - Ethical and legal framework
      - for best interests (BI) decision-making
    - Practical decision-making
      - Treatment escalation planning
      - CANH
    - End of life care

Terminology

UK Guidelines	Vegetative state (VS)
European consortium	Unresponsive wakefulness syndrome (UWS)
US Guidelines	VS/UWS

- Retained "VS" and "MCS"
  - Clear definitions and people generally know what they mean
    - Only use in the context of PDOC - not in TDOC
    - Only applied after formal evaluation of responsiveness
      - By appropriately trained PDOC assessors/physicians
  - Vegetative – not synonymous with 'being a vegetable'
    - Aristotle described the various faculties of the soul
      - Plants and animals have the vegetative faculty to live and grow
        - Only animals have the faculties for sensation, movement and thought
    - A person in VS can live and grow – but cannot sense or perceive
      - Prognosis – could they return to any 'sapient' or 'cognitive' state?

Emerging from VS/MCS

- MCS – broad spectrum
  - From VS to consciousness
    - Sub-divisions (Bruno et al 2011)
- MCS-minus
  - Visual pursuit responses
  - Localising motor reactions
  - Behave very much like VS
    - But may show signs of pain / distress
- MCS-plus
  - Higher level discriminatory responses
    - Communication
    - Cognitive
      - Evidence of reasoning / problem solving
  - But still <u>inconsistent</u>

- Emerged into consciousness
  - Reliable and <u>consistent</u>
    - discriminatory responses
      - Communication
      - Functional use of objects
    - As defined by Giacino 2002
  - Tightened criteria
    - Must show evidence of intelligent thought
    - Sustainable
      - Most or all of the time when awake
      - In a range of contexts
  - Examples in Annex 1a
    - Simple Yes/No questions
    - Choice-making (if non-verbal)

Definitions and terminology

Revised definitions

'Continuing' VS and MCS

- lasting 4 weeks or more

US guidelines drop 'Permanent VS'

- Use 'Chronic' instead
  - Always had a shorter timespan for 'PVS'
    - Silent on 'permanent' MCS

Our UK Guidelines

- Retain 'Permanent VS/MCS '
  - But based on a lack of trajectory
    - Not just time-scale
  - (No longer critical to EoL decision-making
    - but many families still find this helpful)

Definitions

'Chronic' VS/MCS

- to align with US Guidelines

Aetiology	Anoxic / other metabolic	Traumatic
VS/MCS-minus	>3 months	>1 year
MCS-plus	>9 months	>18 months

Permanent VS/MCS

- Chronic VS or MCS (plus or minus)
  - Confirmed through specialist assessment
- With no further change in trajectory for 6 months
  - As measured by serial application
    - of the Coma Recovery scale (CRS-R)
- May only be diagnosed
  - by an 'Expert PDOC physician'

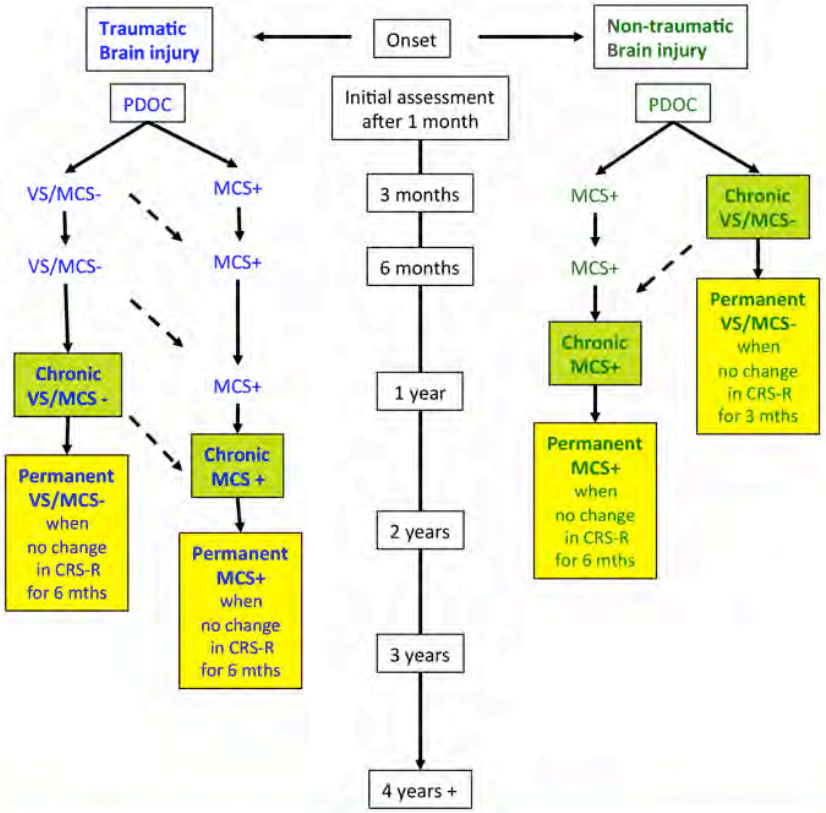
Assessment and diagnosis

- Acknowledgement of spectrum VS/MCS
  - Tight distinction no longer critical to decision-making
    - But overall evaluation of awareness is necessary to judge QoL
      - Requires assessment by experienced PDOC assessors
- Judgement of prognosis and uncertainty
  - Reliant on experience of expert PDOC physician
    - **Trajectory of change** is the most important prognostic indicator

      Requires repeated assessment over time
- Still recommend use of at least one validated tool
  - Coma-Recovery Scale (CRS-R) – serially applied
    - Increasingly accepted as international common language
  - Pragmatic approach
    - Shorter assessments for follow-up
      - Or first time assessment of long-standing VS/MCS

Long term monitoring

- Repeat clinical evaluation
  - ❖ is required over time for
    - Monitoring
    - Treatment planning
  - ❖ Now a legal requirement
    - For BI decision-making
      - Should form a routine part of the review
        - Is continued treatment still in his/her best interests?
  - ❖ Schema for assessment / review:

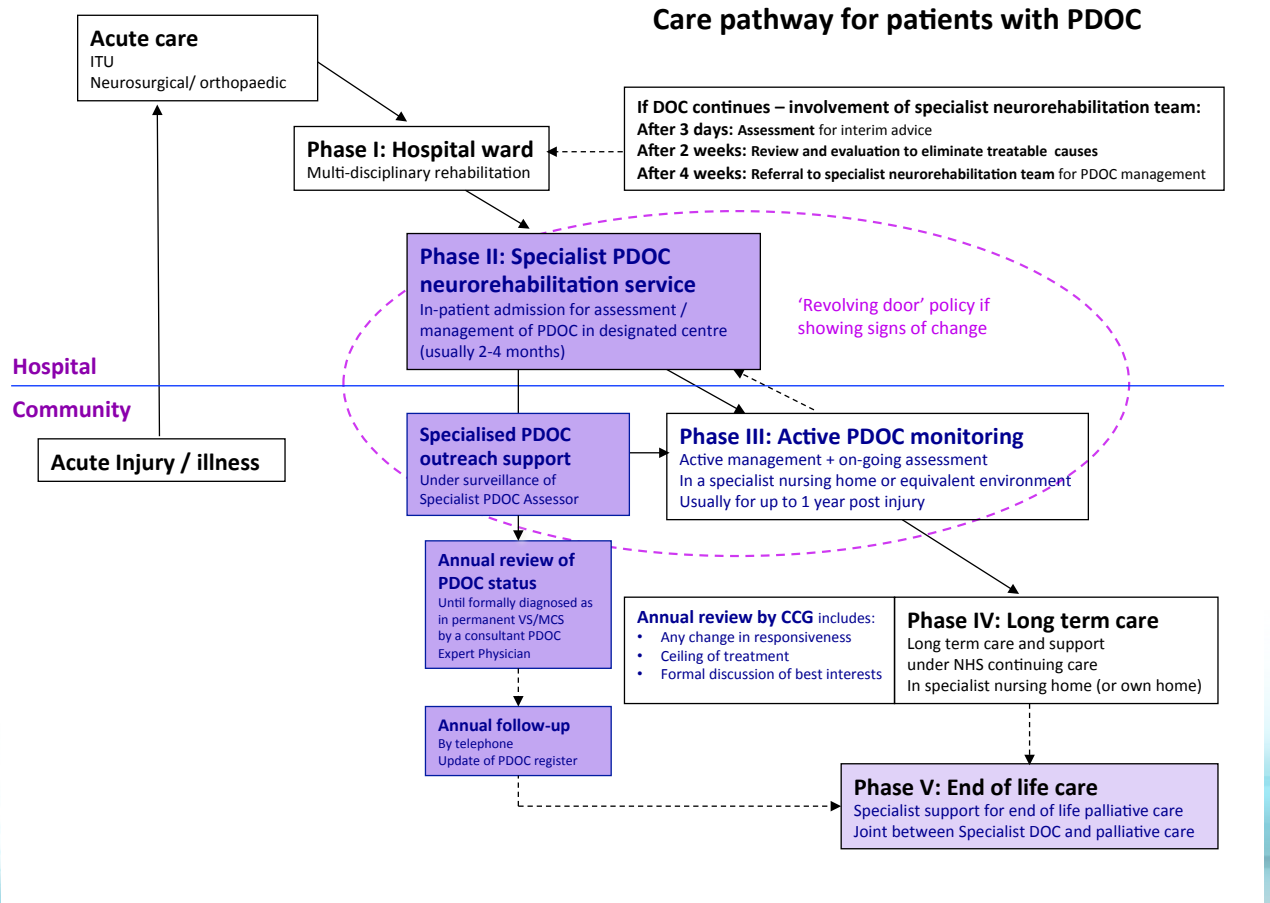


The prognosis for recovery of MCS-minus (MCS-) is generally similar to VS
The timing for assessment for a diagnosis of **permanent MCS+** will depend on
- the nature and severity of the injury,
- any observed trajectory to improved responsiveness on serial testing.

Permanent VS/MCS should only be diagnosed by a PDOC specialist, based on serial assessment of the CRS-R over 6 months.
Best interests discussions should not, however, be delayed until VS/MCS is diagnosed as 'chronic' or 'permanent', but should take place whenever a treatment decision is made.

Pathway of care

- Broadly as before:
  - 5 phases
  - Emphasise the role
    - Of specialist outreach
      - Support from PDOC centres
    - For annual review
      - Including BI decision-making



Best interests decision-making

Under the Mental Capacity Act 2005

The MCA 2005 sets out

- Statutory principles
  - For making decisions on behalf of patients
    - Who lack the capacity to decide for themselves
  - For weighing up best interests
    - Balance of benefits and harms
- The two-stage test for mental capacity
  - Is there an impairment of the mind or brain?
  - Does this affect their ability to make decisions
    - Understand, retain and weigh up information
    - Or to communicate that decision
- Provisions to support decision-making
  - Allow the individual to influence decisions made on their behalf
    - In the event that they might lose capacity

- Legal execution in England
  - Disputes under the MCA
    - are adjudicated by the Court of Protection
      - For Serious Medical Treatments
  - In those proceedings:
    - CoP Judges are empowered
      - To make best interests decisions
        - Declare that a proposed course of action by a health professional will be lawful
        - Protect them from prosecution
    - The Official Solicitor
      - Is appointed to represent the patient
        - As their 'Litigation Friend'

Who decides what is on offer?

- It is first of all up to the doctors decide what treatment options are on offer
  - There may be a number of reasons why a given treatment may not be on offer including:
    - Risks of the treatment for that particular individual
    - Lack of evidence for effectiveness
    - Resource limitations

- 'Futile' treatment is:
  - A medical intervention that does not lead to improvement in the patient's
    - Prognosis , comfort, well-being or general state of health (including quality of life)
  - All treatments can cause harm
    - Futile treatment has no benefits

- Neither a patient, nor their family - or even the Court of Protection
  - Can demand treatment that is not on offer.
  - They cannot force a doctor/ hospital to deliver treatment
    - for which the harms outweigh the benefits

For treatments that are on offer

- For treatments that are on offer
  - A patient (who has mental capacity) can decide whether to accept this or not
    - Before losing capacity:
      - People can plan ahead:
        - Advance Decision to Refuse Treatment (ADRT)
        - Lasting Power of Attorney – Heath & Welfare (including life sustaining treatments)
    - Or after losing capacity
      - The Court can appoint a Welfare Deputy to make decisions on behalf of a patient
        - Excluding life-sustaining treatments
- If none of the above are applicable:
  - Responsibility for BI Decision-making
    - Ultimately lies with the senior clinician on the treating team (ie the consultant)
  - But any treatment given to a patient who lacks capacity
    - Must be given on the basis of their best interests
    - Based on the balance of benefits and harms
      - Taking into account their likely wishes, so far as these can be known

What exactly does this mean?

- Doctors should have a reasonable expectation that
  - Treatment will do more good than harm,
  - **AND** that the patient him/herself would want to have it

- It is the giving, not the withdrawing of treatment
  - That needs to be justified*
    - Just because you can, does not mean that you should..

- Decision-making must take into account
  - What the patient would have wanted
    - So far as this can be established
  - Only the family/friends can give insight into this
    - Must be involved in best interests discussions

*Supreme Court judgement: Aintree vs James 2013

What is the role of family/close friends?

- Within the role:
  - Family/friends are best placed to know patient
    - Their prior beliefs and values
      - What they might have wanted if they could say
  - The question to them is:
    - In your opinion would he/she want to accept
      - The proffered treatment?
        - (Not, should it be withdrawn..)

- Not in the role:
  - To indicate what <u>they</u> want for the patient
    - Or what they would want in that condition
  - Cannot demand treatment that is not on offer
  - They are not the decision-makers
    - no right of consent / refusal

- This is not easy for them
  - Families often feel that they are being asked to make the decision..
    - Aware that what they say will influence the decision
    - Sense of responsibility

Range of treatments to consider

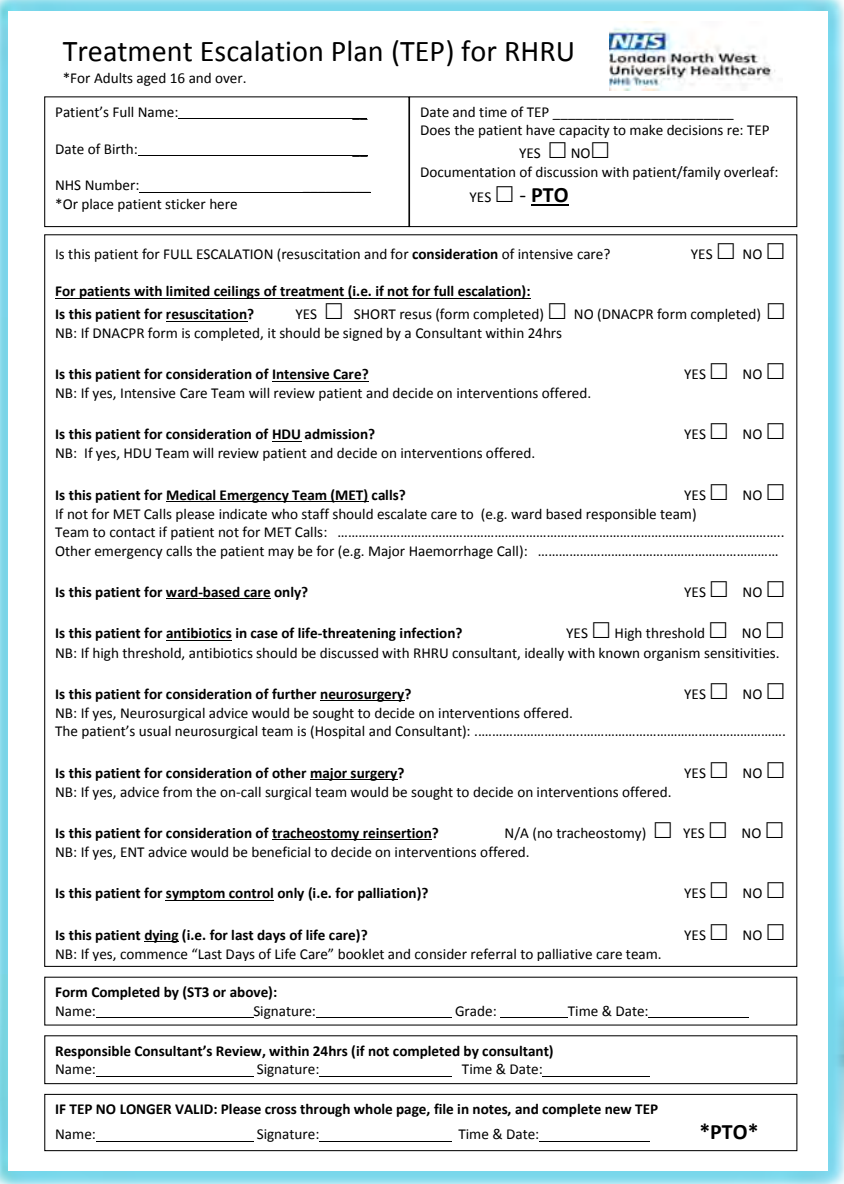
- Escalation of unplanned interventions
  - Cardiopulmonary resuscitation (CPR)
    - In the event of a cardiac arrest
  - Escalation to intensive care
    - Or high dependency unit
  - Acute medical treatments
    - Antibiotics / fluid resuscitation
      - in the case of a life-threatening infection
  - Acute surgery
    - Eg for bowel obstruction
  - Decisions often have to be made out of hours
    - By teams who are unfamiliar with the patient
      - Treatment Escalation Plans

- Elective medical interventions
  - Designed to prolong or sustain life
    - Prophylactic treatments eg
      - Thrombo-prophylaxis
      - Vaccination
    - Screening eg
      - For cancer
    - Long term treatments eg
      - Insulin for diabetes
      - Dialysis for renal failure
      - Tracheostomy / assisted ventilation
    - Tube feeding (via NG or PEG)
      - Given through a medical device
        - "Clinically assisted nutrition and hydration"

Challenges of decision-making

- Clinicians programmed to save lives
  - To give a certain treatment
    - Is relatively straightforward
      - Weigh up balance sheet
        - of benefits versus harms
- To withdraw / withhold treatment
  - Can be more emotive
    - Especially when life-sustaining treatment
      - Cardiopulmonary resuscitation (DNACPR)
      - Escalation to ITU/ HDU
      - Antibiotics for infection
  - Many families
    - Have high expectations for recovery
    - Hope/pray for a miracle
      - Feels like taking away their last chance..
- DNACPR decisions
  - CPR is rarely appropriate in PDOC
    - Futile and often harmful
      - (Hypoxia, broken ribs etc)
  - Must be discussed with the family
    - Even if this will cause distress..
  - Ceiling of treatment
    - Should be established early during admission
      - Families may already be highly distressed
        - Seems like giving up on the patient
  - Clinicians reluctant to add to their burden
    - Take the easy way out
      - Leave for full escalation
      - Exposing the patient to treatment
        - That is against their best interests
          - and potentially harmful (‘abuse or battery’)

- Resuscitation Council:
  - ReSPECT process
    - Personalised recommendations
      - For an individual's future emergency care
- Good clinical practice
  - 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
    - Prominently displayed - front of the notes
    - Review regularly
      - In weekly MDT round



Treatment Escalation Plan (TEP) for RHRU

NHS London North West University Healthcare NHS Trust

*For Adults aged 16 and over.

Patient's Full Name:_____

Date of Birth:_____

NHS Number:_____

*Or place patient sticker here

Date and time of TEP _____

Does the patient have capacity to make decisions re: TEP YES ☐ NO ☐

Documentation of discussion with patient/family overleaf: YES ☐ - **PTO**

Is this patient for FULL ESCALATION (resuscitation and for **consideration** of intensive care? YES ☐ NO ☐

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 ☐

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

Is this patient for consideration of HDU admission? YES ☐ NO ☐

NB: 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)

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 ☐ NO ☐

NB: 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 ☐

NB: 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 ☐

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

Is this patient for consideration of tracheostomy reinsertion? N/A (no tracheostomy) ☐ YES ☐ NO ☐

NB: 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 ☐

NB: If yes, commence "Last Days of Life Care" booklet and consider referral to palliative care team.

Form Completed by (ST3 or above):

Name:_____ Signature:_____ Grade: _____ Time & Date:_____

Responsible Consultant's Review, within 24hrs (if not completed by consultant)

Name:_____ Signature:_____ Time & Date:_____

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

Name:_____ Signature:_____ Time & Date:_____ ***PTO***

CANH – particularly emotive

- Patients will inevitably die within 2-3 weeks
  - Food and fluid feels like part of basic care

❖ Even if everyone is agreed that P would not want to be kept artificially alive
  - Families are concerned about mode of death
    - The length of the dying phase
    - Will they suffer hunger / thirst?
  - Often ask about lethal injection
    - Not legal in England
    - Can only provide optimum palliative care

❖ Until recently - decisions to withdraw CANH in PDOC patients
  - Required an application to the Court of Protection
    - But the law has recently changed…

Evolving case law in CANH withdrawal

Case	Details	Outcome
Permanent Vegetative State (VS)		
1994 Airedale vs Bland	Tony Bland in PVS for 4 years	House of Lords - Withdrawal allowed on grounds of 'futility' But no legal precedent - all future cases should come to the court
Thereafter > 70 cases of PVS		Once diagnosis of 'Permanent VS' was agreed, allowed on grounds of 'futility'
Minimally Conscious State (MCS)		
2011 W vs M	Permanent MCS (7 years)	First case in MCS – Withdrawal <u>not</u> allowed – but appropriate to consider.. Judgements based on balance of benefits and harms
2013 Aintree vs James	Permanent MCS (18 months in ICU)	Withdrawal of all life sustaining treatments allowed (not specifically CANH) Supreme Court judgement - Focus should be not be on level of consciousness but on the <u>quality of life</u> that the patient himself would value It is the giving, not the withdrawing, of treatment that needs to be justified
2016 Briggs vs Briggs	MCS (still improving)	Withdrawal allowed – even though not permanent MCS "Could never recover a quality of life that he would value"
2018	NHS Trust vs Y	Supreme court – no longer need an application to Court of Protection Provided all parties in agreement and guidelines are followed

Sections 4 and 5 of the guidelines

- Following changes in the law
  - Set out practical guidance
    - For responsible decision-making by clinicians
      - Including decisions to withdraw CANH, without the need for an application to the Court
- Concerns had been expressed by some healthcare providers
  - How do we know when we have done it right?
- Guidelines provide
  - Practical tools to support *best interests* discussions and documentation
    - Normalising discussions with families
      - Treatment escalation planning (DNACPR, antibiotics, ITU)
      - Clinically Assisted Nutrition and Hydration (CANH)
    - Proforma for documentation of decision-making process
  - Palliative and End-of-life care
    - Protocols for palliative care following CANH withdrawal

Discussions with family

- Start early – 1st week of admission
  - Before major decisions required
  - Explain process for decision-making
    - Is there an ADRT or LPOA?
      - If so obtain a copy
      - Confirm validity and content
    - If not, decisions lie with treating team
      - Explain role of family / friends
        - They can help to provide the patient's view
          - Not to press their own
        - They are <u>not</u> responsible for the decisions

- Get a picture of the patient
  - Character before the injury
    - Values and beliefs
      - Religious / spiritual
      - Living with disability
        - anything they may have said
    - Key elements of quality of life for them
- Get a picture of the family
  - Their various values and beliefs
    - Understanding of brain injury
      - expectations for outcome
    - Any conflicts of interests eg
      - Financial
      - Conflicting beliefs / religion

Explain – and share written information

- The nature of the brain injury
  - Process and timescale for any recovery
    - Patient's current condition
- Unpick confusing terminology
  - Prognosis may mean different things
    - Life expectancy
    - Improved awareness (Recovery)
  - Recovery can also mean different things

Consciousness	Functional independence	Pre-injury condition And lifestyle

  - Tease out the family's understanding

- Discuss
  - The range of decisions
    - that will need to be made:
  - Who will make them
    - How the family will be involved
  - Likely timescale for decisions

Discuss the range of treatments

- Explain matter-of-factly
  - Treatments that are not on offer
  - Treatments that we will clearly give anyway
    - Eg all supportive and symptomatic care
  - Treatments that may be offered depending on
    - The likelihood of success
    - P's likely wishes
  - Establish treatment escalation plan
- Explain that BI decision making is an on-going process
  - A journey we will take together through regular dialogue
  - Any immediate thoughts they may have..
    - When we will meet formally again
      - Leave the door open for discussion at any time

Life-sustaining treatments

- Key questions to consider for elective decisions
  - What is P's current condition?
    - Awareness of the world around them?
  - What is their quality of their life?
    - Positive experience
      - Is there any enjoyment in their life?
        - If so, how can this be maximised?
    - Negative experience
      - Do they experience pain and/or distress
        - If so, is it appropriately managed?
  - What is their prognosis
    - Best- and worst-case scenario for recovery
      - Would that represent a quality of life that they would value?
  - What would happen if treatment were to be withdrawn
    - What end-of-life care would be provided and where?

- The three key principles
  - Start from the presumption that it is in the patient's best interests to prolong life
    - But can be rebutted if there is evidence
      - that the patient would not want this
  - The decision no longer rests
    - on whether they will regain consciousness
    - But whether they could regain a quality of life
      - that they themselves would value
  - It is the giving, not the withdrawing of treatment
    - that needs to be justified

1. *PL v Sutton Clinical Commissioning Group & Anor* [2017] EWCOP 22. 29. http://www.bailii.org/ew/cases/ EWCOP/2017/22.html

Decisions regarding CANH

- Requirements for decisions with withdraw CANH without an application to the court
  - **Formal assessment of consciousness**
    - Has been conducted in line with the RCP guidelines
    - And the prognosis established by an Expert PDOC physician
  - **Best interests discussions**
    - Have been properly conducted and documented
    - Involving all the relevant members of the family/ friends
      - Informed of best- and worst-case scenario for recovery
  - **All parties are in agreement**
    - About P's best interests in relation to CANH
  - **A second opinion has been obtained**
    - From an independent consultant
      - Not previously involved in the patient's care
  - **There is a clear plan for palliative care**
    - Following withdrawal of CANH
      - Where and how this will be managed

Ideally use the proforma to document this

- Prognosis and uncertainty
  - **Life expectancy**
    - Some might live for many years
      - Others have only days/ weeks
  - **Recovery**
    - Future condition
      - Very certain in some
        - Low-level or long-standing VS/MCS,
        - Deteriorating condition, co-morbidity /frailty
      - Less certain in others
        - Higher level MCS, short duration or upward trajectory
  - External scrutiny required
      - To replace scrutiny by the Court
    - The level of scrutiny depends on
      - The degree of certainty
        - about P's condition and prognosis

PDOC guidelines

- Set out six Categories requiring different levels of external scrutiny
  - Based on prognosis and the level of certainty about that (Table 4.2 – RCP Guidelines p114)

PDOC guideline category		Independent external scrutiny
0	Valid and applicable ADRT or LPoA	Review document to confirm validity and content Valid ADRT is legally binding – no BI dicussion required
1	Death is imminent (eg within hours or days) • CANH is contraindicated for clinical reasons • Or withdrawn as part of established EoL programme	Second consultant, not directly involved with patient's care
2	Comorbidity / frailty unlikely to live > 1 year	Second consultant, not from same department (Can be from the same organisation)
Elective CANH withdrawal: Previously healthy PDOC patients likely to live > 1 yr		
3	High certainty about prognosis for recovery of consciousness (eg low level VS/MCS or long-standing PDOC)	• Senior consultant outside of organisation. • At at least one is a PDOC Expert physician • The guideline requirements have been met • All parties are in agreement about P's best interests • A written palliative EoL care plan is in place
4	Less certainty about prognosis for recovery of consciousness (eg higher-level MCS, or shorter duration) – but agreement that P could never recover a QoL that they themselves would find acceptable	
5	Significant disagreement about P's best interests, at the end of the decision-making process	Application to the CoP

Palliative care planning is often inadequate

- Patients are likely to die differently
  - Depending on the nature of the life-threatening condition
    - When treatment is withdrawn

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

  - Palliative care planning must take account of
    - The likely nature of symptoms and the expected timescale
      - Category 1 – usually die within a few days – managed through conventional palliative care programmes
      - Categories 2-5 - may require more specialist EoL care planning

Dying following withdrawal of CANH

- 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
    - Dry mouth
      - Can be managed with meticulous mouth care
    - Some may develop 'physiological hyper-reactivity'
      - Sweating, tachycardia, hyperventilation
      - Increased spontaneous movement / vocalisations
      - Acidosis may cause compensatory over-breathing
        - Can appear distressed even if unaware
    - Reduced tissue perfusion
      - Affects absorption of subcutaneous medication
        - Erratic response – particularly in late stages – we prefer the IV route

- Potential burden of witness
  - Anticipate and manage symptoms
    - Proactive prescribing
  - Families and care staff
    - should be advised what to expect
    - supported throughout the process

Palliative care protocol

- Principles
  - Even though probably not very distressing
    - Important to reassure all concerned that P is not suffering
  - Provide sedation and analgesia
    - With the aim of keeping the patient in 'calm coma'
      - Use minimum required, but escalate as needed
  - 4-stage protocol
    - Delivered by continuous infusion – IV or SC
      - Prefer IV route – more precise
        - better overall control with lower doses
    - Small background dose over 24 hours
      - Bolus doses as required – 10-20%
        - for predicted needs (eg turning) or breakthrough symptoms
      - Review each 24 hours
        - Re-prescribe total doses for last 24 hours as 'background'
    - If boluses are not effective progress to next stage

- 4-stage Protocol
  - **Morphine/midazolam**
    - Start 10 mg each/24 hours
    - Up to 100mg each
      - Or bolus no longer effective
  - **Levomepromazine**
    - 50 mg/hours
  - **Phenobarbitone**
    - 200-600 mg/24 hours
    - Up to 2400 mg
  - **Self ventilating anaesthesia**
    - eg propofol – rarely required
  - **NB - Higher doses than usual in palliative care**
    - Drugs normally work through cortical suppression
    - In the absence of cortical function, often quite resistant

Commissioning and monitoring

- Phase II - Initial specialist assessment and management
  - And Phase V neuropalliative EoL care
    - Covered by NHSE Specialist Rehabilitation contract
    - Circa 360 cases per year - probably a minority
      - (Turner-Stokes et al 2022 https://pubmed.ncbi.nlm.nih.gov/35546561/)
- Phases III-IV - Ongoing assessment and review
  - Proactive BI decision-making
    - Reliant on PDOC expert opinion
  - New requirement for specialist outreach support for local teams
    - Service specification in preparation
- PDOC registry due for launch Summer 2022
  - Within the UKROC national clinical database
    - For tracking and monitoring of patients
      - Commissioning activity monitoring

How does this work in practice?

Our Service

- The Regional Hyperacute Rehabilitation Unit (RHRU)
  - The only Level 1a hyperacute rehabilitation unit in London
    - Take patients directly from ICUs all over London and South-East England
      - Severe brain injury – still medically unstable
    - Increasingly, tertiary referrals for BI decision-making
      - Largest experience of providing EoL care in this context

  - Approximately 50% of our patient caseload
    - Is in PDOC on admission
      - Of which about a third emerge into consciousness
  - Between April 2014 and 2022 – 8 years
    - 728 admissions – 320 in PDOC
      - Of whom 80 (25%) died on the unit – 69 of these (86%) had un-survivable brain injury
      - CANH is not routinely removed during EoL care,
        - But may be reduced or stopped if the patient is unable to tolerate it;
        - Or if it is decided to be in the patient's best interests to do so

Learning points

- Elective CANH withdrawal is still comparatively rare
  - Even in a tertiary centre that takes patients for specifically this purpose
- Best interests decision-making
  - Can be done responsibly and in a timely manner
    - Without the need for court intervention
- It is an iterative process
  - Often takes place over several week/months
    - As the patient's condition evolves/clarifies
    - When the issue of CANH is first raised
      - 85% of families simply request a bit more time to see what will happen
    - Perfectly acceptable - so long as BI decision-making is actively followed through
      - In our experience, the large majority will resolve through discussion over time

Leaning points 2

- When CANH is withdrawn
  - Families report a great sense of relief and gratitude
    - For supporting a dignified and peaceful death
  - Staff conscientious objection
    - Very few, once P's best interests and likely wishes have been established
    - GPs have quite often been reluctant to engage actively due to workload
      - but willing to refer to others
  - Concerns about hunger and thirst:
    - Managed through meticulous mouth care and proactive palliation using the RCP protocol
  - Dying following CANH withdrawal
    - more peaceful than in many other situations, such as respiratory deaths.

Hospice care

- Some hospices are starting to take on these patients
  - Our experience has been mixed
    - When well managed – excellent care
      - Exemplary support for families
  - Staff preparation is critical
    - As well as support on hand
  - Less good experience
    - Hospice staff did not understand VS/MCS
      - Were expecting a patient in ‘coma’
        - Shocked at how ‘alert’ they looked – eyes open / partially responsive
          - Two cases transferred to local A/E
          - Distressing and emotive interaction with family members

Recent experience of court cases

- Paradoxically - more cases coming to court
  - Perhaps because more BI discussions are taking place
  - North West London Clinical Commissioning Group & GU [2021] EWCOP 59.
    - GU aged 70 - 7 years in VS
      - Hospital criticised for delay in taking a disputed case to court
  - Two recent cases
    - Timely application to the court – as soon as dispute was evident
      - Prolonged court process
      - Hijacked by issues other than CANH withdrawal
        - Lawyers attempted to get court to demand a treatment that was not on offer
        - Involvement of the court in issues that would not usually come to court
    - Enormous amount of clinical time
      - Very expensive – legal bills in excess of £50,000K – falls to treating unit
    - Need to make appropriate funding arrangements
      - So that these cases do not impact on clinical care of other patients

Summary

- Updated guidelines now published for 18 months
  - Impact uncertain
    - Some local examples of good practice
  - No evidence of commissioning
    - For follow-up reviews
  - Some evidence of BI discussions taking place
    - Not systematically and not universal
- More work to be done
  - Development of training
    - Understanding responsibilities
      - Normalising difficult discussions
  - Appropriate systems for Court applications
    - Where these are necessary

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