Prolonged Disorders of Consciousness: National Clinical Guidelines

An overview of the new guidelines

On behalf of the
PDQC Guidelines Development Group

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Ever better at saving lives

- Emergency care services
  - Major Trauma Networks
  - Hyper-acute Stroke Units
  - Defibrillators in public places

- Improved outcomes
  - Rescue people who would have died at the scene
    - Some with catastrophic brain injury
      - Prolonged disorder of consciousness

- Similar issues apply at the other end of life
  - Improved medical care
    - Keep people alive for longer
    - after they drift into consciousness
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.)
RCP PDOC guidelines

- Published in 2013
  - Highly influential in their time
    - Relied on by clinicians and the courts
  - Now out of date
    - Update due for publication early 2020

- Purpose of this conference:
  - To provide a preview
    - What they are likely to contain
  - Discussion and feedback

- Caveat
  - Proposed update with RCP council for approval
    - What we share today may yet be subject to change
Key additions

Scope and purpose
- Prolonged Disorders of Consciousness
  - VS/ MCS - Continuing >4 weeks after sudden onset brain injury
    - Specifically not Terminal decline in consciousness (TDOC)

Main areas covered are the same
- More practical advice on implementation
  - Expanded annexes

Guideline development group – 27 members
- Clinicians, lawyers, commissioners
- Patient/family representation

Stakeholder organisations expanded
Stakeholder consultation and feedback

Endorsing organisations
- Association for Palliative Medicine
- British Geriatric Society
- British Psychological Society
- British Society of Rehabilitation Medicine
- Chartered Society of Physiotherapists
- Royal College of Occupational Therapists
- Faculty of Intensive Care Medicine
- Royal College of Nursing
- Royal College of Physicians
- Royal College of Speech and Language Therapists
- Society for Research in Rehabilitation

Supporting organisations
- The Association of British Neurologists
- The British Medical Association
Why was an update needed?

- Recent changes in the law
  - Refined interpretation of the Mental Capacity Act 2005

- Approach to assessment and diagnosis
  - Further development of assessment measures
    - Need for a more streamlined approach to accommodate numbers

- Publication of other guidelines
  - US Disorders of Consciousness Guidelines
  - BMA/RCP/GMC guidance on clinically assisted nutrition and hydration (CANH) in patients who lack capacity to consent

- Experience and lessons learned
  - from implementation of 2013 guidelines
  - Updated literature
**Terminology**

<table>
<thead>
<tr>
<th>UK Guidelines</th>
<th>Vegetative state (VS)</th>
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<tbody>
<tr>
<td>European consortium</td>
<td>Unresponsive wakefulness syndrome (UWS)</td>
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<tr>
<td>US Guidelines</td>
<td>VS/UWS</td>
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Retained “VS” and “MS”

- **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?

UK Guidelines

- Vegetative state (VS)

European consortium

- Unresponsive wakefulness syndrome (UWS)

US Guidelines

- VS/UWS
Definitions and terminology

Set out criteria for
- Vegetative state (VS)
- Minimally conscious state (MCS) – minus and plus
- Emergence into consciousness
  - Tighter definitions
    - Require evidence of intelligent thought and sustainability

Revised definitions
- ‘Continuing’ VS and MCS – lasting 4 weeks or more
- ‘Chronic’ VS/MCS-minus, to align with US Guidelines
  - Chronic MCS-Plus
- Permanent VS/MCS retained in our UK Guidelines
  - Based on a lack of trajectory towards increased responsiveness
    - No longer critical but many families still find this helpful
Chronic and permanent VS/MCS

**Chronic VS/MCS**
- Only diagnosed after formal assessment according to guidelines
  - Approximate time scales

<table>
<thead>
<tr>
<th>Aetiology</th>
<th>Anoxic / other metabolic</th>
<th>Traumatic</th>
</tr>
</thead>
<tbody>
<tr>
<td>VS/MCS-minus</td>
<td>&gt;3 months</td>
<td>&gt;1 year</td>
</tr>
<tr>
<td>MCS-plus</td>
<td>&gt;9 months</td>
<td>&gt;18 months</td>
</tr>
</tbody>
</table>

**Permanent states**
- Chronic VS or MCS (plus or minus)
  - That has been 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
Changes in the law since 2013

- Refined interpretation of the MCA – key legal points
  - The doctors decide what treatments are on offer
    - But any treatment they do offer must be on the basis of best interests
  - It is the giving, not the withdrawing of treatment
    - That must be justified
  - The question is no longer whether they will regain consciousness
    - But whether they will achieve a quality of life that they themselves would value

- Requirement for court application prior to CANH withdrawal
  - Withdrawn in July 2018, provided that
    - The provisions of MCA 2005 and relevant guidance followed
    - There is agreement on the best interests of the patient
Implications for practice

Previous default position - continue CANH
  - ‘Declaratory relief’ was reliant largely on diagnosis of ‘Permanent VS’
    - As defined by time since injury (6-12 months)

Now have to justify giving not withdrawal
  - All decisions to start, re-start, continue or withdraw CANH
    - At any stage post injury
    - Starting early and re-visited over time
  - Emphasis on recovery of quality of life (not consciousness)
    - Clinical judgement – best and worst case scenarios for recovery

Up to clinicians to manage decision-making responsibly
  - Proportionate approach to external scrutiny
    - Based on prognosis and uncertainty
  - Best-interests discussions with family / friends
    - To determine the patient’s likely wishes
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 best interests decision-making

- Should form a routine part of the review
  - Is continued treatment still in his/her best interests?

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 – 5 phases

Care pathway for patients with PDOC

- Phase I: Hospital ward
  - Multi-disciplinary rehabilitation
  - If DOC continues – involvement of specialist neurorehab team:
    - After 3 days: Assessment for interim advice
    - After 2 weeks: Review and evaluation to eliminate treatable causes
    - After 4 weeks: Referral to specialist neurorehabilitation team for PDOC management

- Phase II: Specialist PDOC neurorehabilitation service
  - In-patient admission for assessment / management of PDOC in designated centre
  - (usually 2-4 months)

- Phase III: Active PDOC monitoring
  - Active management + on-going assessment
  - In a specialist nursing home or equivalent environment
  - Usually for up to 1 year post injury

- Phase IV: Long term care
  - Long term care and support under NHS continuing care
  - In specialist nursing home (or own home)

- Phase V: End of life care
  - Specialist support for end of life palliative care
  - Joint between Specialist DOC and palliative care

Acute care
- ITU
- Neurosurgical/ orthopaedic

Hospital

Community

Acute Injury / illness

Specialised PDOC outreach support
- Under surveillance of Specialist PDOC Assessor

Annual review of PDOC status
- Until formally diagnosed as in permanent VS/MCS
- By a consultant PDOC
- Expert Physician

Annual review by CCG includes:
- Any change in responsiveness
- Ceiling of treatment
- Formal discussion of best interests

Annual follow-up
- By telephone
- Update of PDOC register

'Revolving door' policy if showing signs of change
Two sets of guidelines

**BMA/RCP CANH Guidelines**
Published 2018
- Address CANH only
  - In all patients who lack capacity

**RCP PDOC Guidelines**
Update due 2020
- Address wider range of treatments
  - In Prolonged Disorders of Consciousness
Life sustaining treatments

Best interests decision-making

- Starts from the strong presumption
  - That it is in the patients best interests to prolong life
- But cannot simply be assumed
  - Must be balanced against the benefits and harms of intervention
  - Taking into account the patients’ likely wishes
    - And revisited over time

BMA/RCP guidance offers detailed advice for CANH

- On the approach to BI decision-making
  - Involvement of family and friends
  - Obtaining a suitable independent second opinion
  - Documentation
- Broadly similar principles can be applied
  - to other Life sustaining treatments
Treatment escalation planning

- Increased awareness of need for TEP including
  - Cardio-pulmonary resuscitation
  - Escalation of care to ITU/HDU
  - Other intervention incase of life-threatening condition

- Resuscitation Council – ReSPECT process
  - Personalised recommendations
    - For an individual’s future emergency care

- Also important for patients who lack capacity
  - Doctors may make the decision if clinically inappropriate
    - But must inform family/friends even if this will cause distress
End of life care

- End of life care poses a number of challenges
  - The dying process can be prolonged and unpredictable
  - Different categories of patient are expected to die differently
    - Elective withdrawal of CANH is particularly emotive
      - Can be associated with physiological distress
    - Withdrawal of other life sustaining treatments
      - May have different considerations
      - The guidance offers some more specific advice

- Many palliative care teams still unfamiliar with this area
  - Experience with the EoL palliative care regimen
    - Has led to small changes
Commissioning and monitoring

Phase II - Initial specialist assessment and management
- And Phase V neuropalliative EoL care
  - Covered by NHSE Specialist Rehabilitation contract

Phases III-IV - Ongoing assessment and review
- Proactive best interests decision-making
  - reliant on PDOC expert opinion
- New requirement for specialist outreach support for local teams
  - Service specification in preparation

PDOC registry under development
- Within the UKROC national clinical database
  - For tracking and monitoring of patients
  - Commissioning activity monitoring
Questions