

Electronic Annex 3b

The role of team members working with patients and families in prolonged disorders of consciousness

Assessment and management of patients in prolonged disorders of consciousness (PDOC) requires coordinated input from a range of professionals working in an interdisciplinary manner. However, service providers and commissioners are often confused about why this should be necessary. This annex summarises briefly the key skills and expertise each discipline brings to the programme.

The team as a whole

All team members contribute to informal assessment of the patients and any appropriately trained individual may carry out formal assessments of awareness (CRS-R, WHIM, SMART).*

All team members have a role in supporting family and will participate in discussions about carrying out interventions in the patient's 'best interests', in the absence of an Advance Decision to Refuse Treatment (ADRT) or Lasting Power of Attorney for Health and Welfare (Welfare LPA).

Contribution of individual disciplines

Doctors

Patients with PDOC present with a range of different aetiologies and comorbidities. Doctors are primarily responsible for diagnosis, prognostication and optimising the patient's medical condition.

* CRS-R = Coma Recovery Scale – Revised; SMART = Sensory Modality Assessment and Rehabilitation Technique; WHIM = Wessex Head Injury Matrix.

Their role includes:

- > anticipating, identifying and managing all clinical scenarios
- > **liaising with relevant clinical teams from other specialties** for investigation, timely opinions and treatment to manage the brain injury and other comorbidities,
 - including for example neurosurgery, maxillofacial surgery, orthopaedics, cardio-respiratory, ear, nose and throat (ENT), gastroenterology etc.
- > **assimilating clinical information to prognosticate and predict outcome** both in terms of improvement / deterioration and expected survival
- > **providing information and support to family members** and enabling contemporaneous discussion on the appropriateness of clinical treatments.

In the absence of an ADRT or Welfare LPA, the senior consultant has **overall responsibility for best interests decision-making**, including decisions regarding escalation of treatment and life-prolonging interventions.

Consultant specialists in PDOC are specialists in the medical, legal, ethical and public interest in the condition. Together with others, they are responsible for the **development of services**, contribution to guidelines, policies and case law, and for education and training in the field.

Nursing staff

Nursing staff carry out **holistic 24-hour care of patients** in PDOC to maintain clinical stability, manage the patient's personal care and ensure their comfort.

As well as providing for the patient's day-to-day care needs, the nursing staff:

- > monitor for deterioration,
- > maintain **hygiene and skin integrity** by carrying out 24-hour postural management programmes
- > develop a predictable **continence** routine to aid management
- > are involved in **tracheostomy management** and weaning
- > **monitor levels of arousal** and provide an appropriate sensory environment including regular rest periods.

They provide **out-of-hours support to the family**, and coordinate communication and referral with families and the wider health care team, including pharmacy, safeguarding and infection control practitioners, as appropriate.

Physiotherapists

Physiotherapists (PTs) provide **physical interventions to maximise comfort, prevent secondary impairment and maintain respiratory and bodily functions**. This facilitates passive function to enable care needs such as, positioning in a hoist sling, washing and putting on continence pads.

- > An important contribution is the development and provision, with the other key team members (eg nurses, occupational therapists (OTs)), of a **24-hour postural management programme**.

- > Assessment of awareness is assisted by placing the person in varied postures and positions, which may improve arousal.

PTs also contribute to respiratory management, tracheostomy weaning, spasticity management and seating.

Occupational therapists

OTs assess responses using **structured stimuli and functional activities** to establish level of awareness. This can include assessing **access to technology**.

Working closely with other members of the MDT, they help to

- > establish a **regulated environment** and create routines that can help a person to respond
- > identify any sensory and perceptual deficits
- > assess for **cognitive and communication** possibilities within the context of severe impairment
- > identify any behavioural and emotional difficulties that may arise
- > prevent and correct physical deficits, and manage complications such as contractures. This is addressed through the provision of **specialist equipment such as wheelchairs, splints and postural supports** such as bed positioning. OTs also contribute to the development and provision of a 24-hour postural management programme.

Speech and language therapists

Speech and language therapists (SLTs) assess for **communication and advise on how impairments such as aphasia, apraxia and dysarthria could impact on assessments**, to improve their accuracy, validity and reliability.

They work to:

- > develop **functional communication** in patients who are emerging, including the use of **augmentative and alternative communication (AAC)** where appropriate
- > assess **swallowing** to provide information on the management of saliva for **tracheostomy weaning**, including assessment with fiberoptic endoscopic evaluation of swallowing (FEES)
- > if appropriate, will carry out **oral trials** to assess awareness and communication in a functional context.

They contribute to discussions on whether continuing and extending oral intake in patients in PDOC is appropriate and in an individual's best interests.

Psychologists

Psychologists assess **emotion-related behaviours** such as tearfulness, grimacing and laughter to establish whether responses are reflexive, spontaneous or related to particular stimuli. This may include developing **personalised methods for monitoring**, particularly if a trial of a neurostimulant, a behavioural modifier or antidepressant medication is considered.

They also:

- > assess any **challenging behaviours**, such as patients dislodging feeding or tracheostomy tubes or smearing faeces
- > **support families and teams** to understand and manage these behaviours. If a patient is showing signs of emergence, they will assess cognitive function
- > provide **psychological support to families and friends** who have a relative in PDOC
- > have an important role in leading and delivering **staff support** strategies.

Dietitians

Patients in PDOC are usually fully reliant on enteral feeding tubes for nutrition, hydration and medication. **Dietitians are responsible for ensuring the enteral feed provided meets the individual's complete nutrition requirements.**

They also:

- > advise on the timing and rate of feeds and the implication for optimising diurnal rhythms
- > work closely with the nursing staff to ensure **optimal hydration** and to manage feeding tubes and with the medical team to manage any **electrolyte disturbances**
- > advise on the **placement, changing or removal of feeding tubes.**

Music therapists

Music therapists are not available in every programme but, where present, they **use music in the assessment and therapy** for patients in PDOC.

- > They can use music and musical instruments to provide a preferred stimulus, encourage arm or leg use and monitor for change in responses.
- > They may carry out the MATADOC (Music Therapy Assessment for Awareness in Disorders of Consciousness) to contribute to diagnosis.

Social workers

Social workers provide vital **support to the patient and family/advocate** by identifying key social and legal issues.

- > They can **liaise with external agencies** on behalf of / or with families, including social services departments, clinical commissioning groups, embassies, courts, housing departments, the Department of Work and Pension and advocacy services.
- > The aim to **enable, promote and safeguard wellbeing** and **empower families and advocates.**
- > They have a role in **coordinating the continuing healthcare process for funding and discharge planning.**
- > Social workers support families and the MDT with discussions relating to the patient's diagnosis and wellbeing, and **manage any conflict/disagreements within families** and friendships by providing a **safe environment for further discussion.**

Chaplain and pastoral care

Chaplains offer both spiritual and pastoral care and seek to give as much support as is appropriate to patients and their families. This includes providing ministers of different faiths, chapel-based religious services, and times of prayer and ward-based spiritual support.

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