

## Electronic Annex 3a

# The clinical management of people with PDOC – an overview

People with prolonged disorders of consciousness (PDOC) may initially be managed in many different settings such as intensive care wards, cardiology wards (after cardiac arrhythmias causing hypoxic brain injury), cardiac surgery wards, neurosurgical wards, respiratory wards, neurological wards and so on. These wards are usually able to manage patients who are comatose successfully for a few days or weeks but often will have little experience of longer-term management.

Therefore, this annex outlines some general principles and clinical needs that must be particularly considered in any patient who is left comatose or minimally responsive.

It does not consider the specific management of any underlying or incidental disease, nor does it consider ventilation where this is still needed. Furthermore, this annex does assume a basic level of professional knowledge and skill, and does not cover the general aspects of management.

A person whose brain damage is such that their level of consciousness is still disturbed at 4 weeks post-injury will inevitably require specific management of one or more of the following problems.

1. The person will not be able to control or undertake basic **bodily functions** which will need support or management:
  - > maintaining fluid and food intake
  - > controlling swallow, including drooling and/or aspiration into the chest of saliva
  - > control over micturition
  - > control over defaecation.
2. The person will usually be **immobile**. This leads to all the risks associated with immobility and lack of active movement:
  - > skin pressure ulceration
  - > chest infections
  - > contractures of joints, and loss of range of movement.

3. Many (but not all) people will have considerable increase in **muscle tone** (spasticity) sufficient to cause loss of range of movement at joints. This may lead to the development of fixed deformities (contractures) and may cause increased difficulty in maintaining hygiene and a reasonable appearance. It may lead to quite abnormal posture.
4. A wide range of other particular clinical problems may occur including:
  - > unstable control over temperature, blood pressure, pulse and respiration usually due to mid-brain damage
  - > grinding of teeth
  - > seizures
  - > infections, usually in the bladder or chest.
5. Finally, although the person may be unaware, as far as an external observer can tell, nonetheless it is still important to consider the following, especially if the patient is in a minimally conscious state:
  - > pain
  - > social stimulation
  - > communication and treating with respect
  - > pleasure.

## Evidence

1. There is no good evidence on the frequency or severity of these problems, and no evidence to guide recommendations on assessing or treating most of these problems. What evidence there is relates usually to other conditions.
2. The evidence behind many of the general and specific recommendations can be found in other guideline documents for:
  - > stroke<sup>1</sup>
  - > multiple sclerosis<sup>2</sup>
  - > head injury<sup>3</sup>
  - > long-term neurological conditions.<sup>4</sup>
3. In addition, the following problems have some specific evidence that has been used:
  - > prevention of skin pressure ulceration<sup>5, 6</sup>
  - > treatment of skin pressure ulceration<sup>7, 8</sup>
  - > stretching of joints to prevent or treat contractures<sup>9</sup>
  - > plaster casts for contractures<sup>10, 11</sup>
  - > nutritional support.<sup>12</sup>
4. Thus, the recommendations made below are primarily based on consensus and generally accepted good practice.

## Recommendations

These recommendations apply to all patients who remain in a PDOC after the acute phase of their illness/injury.

*All clinical management should be informed by 'best interests' discussions involving the relevant parties (see Section 4 of the main guidelines).*

- *If the patient has a relevant and applicable Advance Decision to Refuse Treatment (ADRT) this must be followed.*
  - *If the patient has a Welfare Lasting Power of Attorney (LPA) or court-appointed Deputy whose powers cover the decision in hand, they may have the power to refuse treatments in the best interests of the patient.*
1. All care interactions with the patient should be undertaken acting as if the patient were aware, informing the patient of what is being undertaken.
  2. Every patient should have a clear, documented plan for hydration and nutrition:
    - > nasogastric tubes should be used initially
    - > a percutaneous endoscopic gastrostomy tube (or equivalent) should be put in place once it is agreed that return of an ability to swallow is unlikely within a few weeks; the patient should have fluid intake and output monitored
    - > the patient should be weighed regularly
    - > the patient's nutrition should be planned and monitored by a dietitian.
  3. Any patient who has problems with controlling their saliva, for example drooling or aspirating, should have salivation reduced using anticholinergic drugs such as hyoscine patches or atropine drops. If hypersalivation persists, treatment such as glycopyrronium or injection of the salivary glands with botulinum toxin (BoNT-A) should be considered.

*NB. Whilst BoNT-A can be effective, it needs to be repeated every few months.*

- > *There are significant logistical challenges in getting patients in PDOC to outpatients for injection every few months, or providing injection on a visiting outreach basis.*
- > *Thus, it is mainly appropriate for inpatient management in the acute stages for transitory hyper-salivation, but is less likely to be a viable option for long-term management in this context.*

4. All patients should have a documented active plan to manage urinary excretion, avoiding catheterisation if possible.
5. All patients should have a documented active plan and bowel regimen to manage their bowel activity and incontinence.

6. All patients should have an **active documented plan to monitor skin care** and integrity and to minimise the risk of skin pressure ulceration:
  - > Every patient should be nursed on a high specification foam mattress or an alternating-pressure air mattress designed for reducing the risk of skin pressure ulceration.
7. Every patient should have a **plan to prevent and manage chest and urinary tract infections** including:
  - > consideration of **whether treatment is in the patient's best interests**
  - > regular changes in position.
8. All patients should have a **documented plan to maintain posture and joint movement**:
  - > unless there are specific contraindications, every patient should be sat out of bed for at least 2 hours every day in a suitable chair appropriately chosen to maintain an appropriate posture and to reduce the risk of skin pressure ulceration.
  - > The only exceptions should be when the medical state renders this practice unsafe or impractical.
9. Any **patient who has spasticity** (hypertonia) affecting limbs sufficiently to cause loss of range of movement despite full regular passive movements should have one or more of:
  - > **a trial of an oral antispasticity drug** (baclofen, gabapentin, tizanidine) starting at a low dose and increasing slowly, monitoring both spasticity and level of responsiveness to determine both effectiveness and adverse effects
  - > **intramuscular botulinum toxin, if focal management is appropriate** (eg to avoid imminent contracture, or if spasticity is localised to 1–2 joints)
  - > **splints (orthoses) and/or plaster casts** applied to the affected limbs/joints to maintain the joint in the most appropriate position possible, monitoring skin carefully for pressure ulceration.
10. All patients should be **monitored for signs and symptoms of pain** and should have pain managed appropriately.
11. The **drugs being prescribed to and given to patients should be reviewed regularly** (every 4–8 weeks) **to determine whether it is still appropriate to use them**. Particular attention should be given to:
  - > any drug that may reduce awareness and arousal such as anticonvulsants, antidepressants and opiates
  - > any drug being given for prophylactic reasons, especially if the benefit is small and will only have an influence years in the future
  - > any drug that causes pain or carries significant risk without obvious benefit
    - for example, the risks of venous thromboembolism are highest in the immediate post-acute period, and **it is generally appropriate to stop subcutaneous heparin by 3 months post-injury**
    - similarly, statins are rarely appropriate.

12. The patient's social contacts with friends and family should be supported, and any decision that might impede continuation of these relationships should be considered very carefully.
13. Activities undertaken with the patient should be expected to lead to pleasure and/or social interaction, and should avoid overstimulation.
14. The patient's need for equipment to facilitate high-quality care, maintenance of a good posture, and mobility out of the bed should be met fully without delays.
15. The patient's clinical state should be monitored by both the treating healthcare team and by the specialist neurological rehabilitation team who should assess at least once a year.
16. The specialist neurological rehabilitation team should be contacted and asked for advice about any problem that is beyond the experience or expertise of the healthcare team caring for the patient; this applies at all times after 7 days.

Specific advice is provided in separate annexes on physical management ([Annex 3c](#)) and tracheostomy care/ weaning ([Annex 3d](#)).

## References

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- 12 National Institute for Health and Care Excellence. *NICE Clinical Guideline CG 32 Nutrition support in adults*. <sup>117</sup>~~SEP~~ *Oral nutrition support, enteral tube feeding and parenteral nutrition*. London, 2006.
- 13 Royal College of Occupational Therapists and Association of Chartered Physiotherapists in Neurology. *Splinting for the prevention and correction of contractures in adults with neurological dysfunction: Practice guideline for occupational therapists and physiotherapists*. London, 2015.
- 14 National Institute for Health and Care Excellence. *Xeomin (Botulinum Neurotoxin Type A) for treating chronic sialorrhoea*. NICE Technology Appraisal Guidance [TA605]. London: NICE, 2019.