
Electronic annex 2c

Optimising conditions for response

The guidelines below provide details to ensure optimal care and management for patients with prolonged disorders of consciousness (PDOC). The medical experts will advise on medication, arousal levels and nutritional requirements.

Positioning of the patient

- 1 Wherever possible, the patient should be positioned safely and comfortably in a wheelchair to minimise potential for contractures and to help optimise the patient's arousal levels and potential to interact with daily stimuli.
 - This will need input and advice from a wheelchair service specialist to ensure that customised seating and pressure relief are provided.
- 2 If it is not possible to position the patient in a wheelchair initially, ensure that the patient has episodes in a good position in bed and or in a comfortable chair.
 - In bed it is better for the patient to be supine, with the bed profiled so they can sit up as much as possible.
 - Ensure that the patient is in a midline position and has opportunity to move their head.
 - Position the arms with pillows and support the knees.
 - Maintain this position for all times when you are providing activity or interacting with the patient.
 - Advice may be sought from the physiotherapist and occupational therapist on optimal positioning.
- 3 The team should try to optimise the patient's sitting tolerance in the bed and chair so that the patient can be sat up for acceptable periods of time, in order to ensure normal sitting positioning for as long as possible. This will normalise their opportunity to interact with environmental stimuli.
- 4 Also allow the patient to lie flat on their sides as required to ensure optimal pressure relief.

Care of the patient

- 1 Ensure that the patient's eyes are well cleaned to optimise potential for eye opening.

- 2 Provide good care for the hands, cleaning in the palm and between the fingers.
 - Keep the nails cut short.
 - Use soft splints where required and regularly check palms of hands for any tissue breakdown if contractures are present.
- 3 Ensure good oral hygiene and care, which will also have the benefit of desensitising the mouth.

Approach to the patient

- 1 Treat the patient as you would wish to be spoken to. Ensure that all communication is age-appropriate and respectful. Find out from the family how the patient would like to be addressed.
- 2 Always ensure that the whole team takes a consistent approach to the issue of communication with the patient. It may be of benefit to put these reminders up above the patient's bed.
 - Speak to the patient as if they understand everything you are saying.
 - Keep information simple and in short sentences.
 - If you are speaking to the patient try not to touch them or move them at the same time if at all possible to avoid overstimulation.
 - Try to tell the patient who you are, where they are, what day it is and the time as often as possible.
 - Tell the patient what you are going to do before you do it, eg 'I am going to move your leg'.
 - Ensure only one person speaks at one time.
 - When you are leaving, tell them you are leaving but will come back (detail). Then remind them what you have done, your name, date, time and location.

Observing the patient

Take time to observe the patient **at rest** in different positions.

- If possible keep a record of movements you have seen, and record by each movement whether you feel it was meaningful or not.
- Look at eye movements and body movements.
- Ask others to do the same.

Structuring the day

- 1 Take care not to overstimulate the patient. For example:
 - Do not leave the music on while talking and touching the patient at the same time – present only one stimulus at a time.
 - Do not leave televisions and radios on for long periods during the day or during their rest periods.
- 2 Ensure that you structure the day for the patient. Create a programme with clear rest periods prior to activity/stimulation periods.
- 3 Provide a programme of activities, interspersed with rest periods. The patient will ideally benefit from a rest period immediately before and after all activities, such as activities of daily living like dressing and showering.

- 4 Establish what interests the patient had, ie hobbies, character type, TV and radio preferences, music taste. This will help to ensure that the programme for the day is in keeping with their personality type.
- Find out what the patient's interests were and bring in appropriate stimulation materials to meet their individual needs.
 - Also have familiar photos and belongings in their environment.

Family involvement

If the family are present, guide them on approach, regulating stimulation and suggest activities that they could be involved in; for example reading the newspaper, changing the environment with short walks, using photos, talking about family news etc.

Keeping a diary

It might be useful to keep a diary of events to allow visitors to refer to the details regarding their visits.

The diary can contain: the date, who was with the patient, what happened, and responses from the patient. For example, *the patient laughed when his friend David was talking about a funny event [describe]*.

Ideas for activities and stimuli

- 1 Ideas for activities to include in their programme are:
- activities of interest, ie magazines of hobbies, TV
 - music
 - go to different environments, eg outside the room, different areas of the unit, outings, activity sessions with other patients etc
 - time with family and friends.

Ensure that the patient has a range of activities during the day with short sessions rather than long periods, focusing on one activity each time.

- 2 Ideas for stimuli to include are shown below.

Vision	Photographs, magazines, pictures and objects patients are familiar with.
Sound	CDs of their favourite music, iPod, familiar sounds from home, work.
Touch	Items they are familiar with, eg toys, fabrics, eg leather jacket etc, material they will be familiar with through work or leisure pursuits and interests.
Smells	Any familiar aftershave or perfume, toiletries, familiar smells, favourite foods' smells, eg marmite etc.
Tastes	Only consider this if it is deemed safe to give the patient a small taste on a Q-tip applied to the tongue. Liaise with the speech and language specialist.
Movement	Bring in any item that the patient may use, eg pen, hairbrush, to link in with their previous interests.

Observing the patient's movements and behaviours

It is important to look out for the type of responses exhibited to the daily programme. Please inform the lead physician or team lead if you see any response of interest.

The responses to look out for are as follows:

- **no movement** observed to certain stimulation
- general **reflexive** movement observed; for example, the whole body demonstrated a startle or strong pattern of movements
- head or arms movement **away** from, eg, touch
- head or arms or eyes move **towards** stimuli, eg the patient looks at a magazine or towards someone entering the room
- client **discriminates** by looking at one stimulus or another when asked, or follows instruction; eg 'close your eyes', 'move your head', or shows a meaningful expression.

Keeping a journal of the record of responses

You may wish to keep a record identifying:

- the date and time and location
- what was happening before the response occurred
- what the patient did – for example reflexive or movement towards stimuli
- what stimuli facilitated the response
- who was present during the stimuli
- how often it has happened.

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