

Electronic Annex 2c

Optimising conditions for response

The guidelines below provide details to ensure optimal care and management for the patient with prolonged disorders of consciousness (PDOC) and should be used in conjunction with the guidelines on physical management in electronic Annex 3c.

The medical experts will advise on the optimisation of medication, arousal levels and nutritional requirements, which may impact on the individual's responses.

Positioning of patient

1. Wherever possible the patients should be **positioned safely and comfortably in a wheelchair** to; minimise potential for contractures, help optimise the patient's arousal levels and potential to interact with daily stimuli.
 - > **This may need input and advice from a wheelchair service specialist** to ensure that bespoke 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 in supine position, with the bed profiled so they can sit up as much as possible and have the potential to respond to the environment.
 - > 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 regarding these issues.
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 enable the patient to lie 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 patient

1. **Treat the patient as you would wish to be spoken to.** Ensure 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 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** and in different positions.

- > If possible, keep a record of movements you have seen. 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 to gain a picture of the patient over time and in different environments or people.

Structuring the day

1. Take care not to overstimulate the patient. For example
 - > Do not overstimulate, ie leaving the music on while talking and touching the patient at the same time – present only one stimuli 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 specifically for the patient. Create a programme that includes routines in different environments/situations.
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 TV and radio preferences, music taste, what routines they liked and what would be important in their day. This will help to ensure the daily programme is appropriate and applicable to the person.
 - > Find out what the patient's interests were and have appropriate stimulation materials to meet their individual needs.
 - > Where possible personalise the environment with photos and personal belongings.

Family involvement

If family members are present, collaborate with them to; establish a consistent approach by family and the multidisciplinary team (MDT), to regulate both stimulation and the environment. It may be useful to suggest activities that they could be involved in, for example reading the newspaper, changing the environment with short walks, using photos, talking and establish activities that they may wish to do. Activities with the family can be part of the daily programme. If fatigability is a problem, consider if it is possible to arrange a rest period before family visits to optimise their opportunity to respond to family members.

Keeping a diary / communication book

Particularly when family members visit outside of normal working hours a diary / communication book may help to facilitate communication between the family and treating team about observed responses.

Information may include: 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).*

The family can record changes they have seen or concerns they have, and the MDT can respond to information and include what is happening in sessions or any issues of interest for the family.

Patients sometimes respond more readily with familiar people. It is often helpful if family members record videos of any responses that they see, so that the team can view them and interpret the responses.

Ideas for activities and stimuli

Ideas for activities to include in their programme are:

- > activities of interest, ie magazines of hobbies, specific TV
- > music
- > personal care activities important to the patient, eg manicure, grooming,
- > moving to different environments, eg different areas of the unit, garden, hospital shop, outings, activity sessions with other patients, specific activities with volunteers (pets as therapy dogs etc)
- > time with family and friends.

Ensure that the patient has a range of activities during the day with short sessions of focused activity or longer sessions of more general activity (Table 1).

Table 1 Examples of activities and stimuli

Vision	Photographs, magazines, pictures and objects they are familiar with
Sound	CDs of their favourite music, iPod, familiar sounds from home, work
Touch	Items they are familiar with, ie toys, fabrics (leather jacket etc), materials they will be familiar with through work or leisure pursuits and interest
Smells	Any familiar aftershave or perfume, toiletries, familiar smells, favourite foods, eg Marmite etc
Tastes	Only consider this if it is deemed safe under the guidance of the speech and language specialist
Movement	Bring in any item that the patient may use, eg pen, paintbrushes, hairbrush to link in with their previous interests or routines

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 stimuli, eg touch
- > head or arms or eyes move **towards** stimuli, ie the patient looks at a magazine or towards someone entering the room

- > patient **discriminates** by looking at one stimulus or another when asked, or follows instruction, for example 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 presenting the stimuli
- > how often it has happened.

Prepared by Karen Elliott and Helen Gill-Thwaites on behalf of the PDOC Guideline Development Group (October 2019).