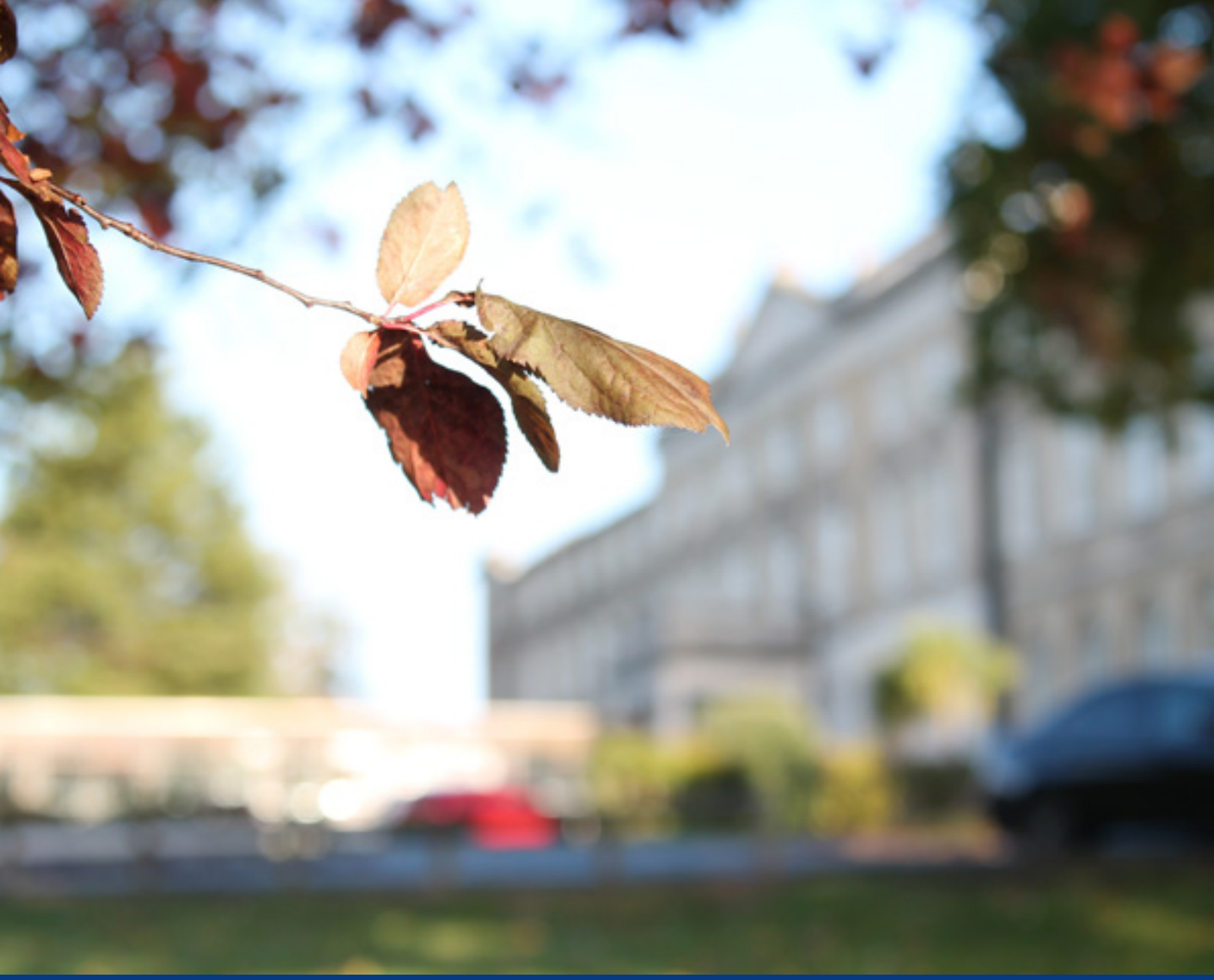

Guidelines for Speech and Language Therapists working with adults in a Disorder of Consciousness (DOC)

developed by a UK-wide group of Speech and Language Therapists at

ROYAL COLLEGE OF SPEECH & LANGUAGE THERAPISTS

Royal Hospital for Neuro-disability

NHS

Leeds Teaching Hospitals NHS Trust

Northwick Park Hospital, London North West University Healthcare NHS Trust

The Walton Centre NHS Foundation Trust

The Royal Wolverhampton NHS Trust

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Guidelines for Speech and Language Therapists working with adults in a Disorder of Consciousness (DOC)[1]

Development of the Guidelines

A DOC is the result of a severe brain injury and is a relatively rare but complex condition. SLTs are increasingly likely to come across this patient population, as advances are made in lifesaving treatment immediately following injury. It is difficult to establish prevalence in the UK, but Wade (2018) estimates a prevalence of 17-38 per million. Since the creation of Major Trauma Centres (MTCs) in 2012, patients with severe traumatic injuries are increasingly surviving. A report from the Trauma Audit and Research Network (Moran et al., 2018) confirmed the development of MTCs was associated with a significant 19% increase in the odds of survival for trauma victims who reached hospital alive. However, with increasing survival comes increasingly complex injuries and a higher incidence of individuals surviving in a DOC. In addition, as populations age, an associated increase in cardiac arrests may be linked to an increase in patients with DOC due to hypoxic brain damage (Pichler & Fazekas, 2016, Van Erp et al., 2015). This population require expert care to have the best chance of optimising recovery and preventing further complications.

In 2019 the Royal College of Physicians updated the Prolonged Disorders of Consciousness National Clinical Guidelines, which emphasise the role of the multidisciplinary team in working with this population. Speech and Language Therapists have a key role in the assessment and management of patients in a DOC.

These guidelines and associated competency framework are designed to be used by SLTs working with adults in a DOC due to a sudden onset injury, at any point in the care pathway from critical care to community long-term care. They have been written to support the practice of SLTs working with this specialist and complex patient population. Evidence for working with adults in DOC comes from a range of sources, but there is often a lack of research specific to SLT intervention. Roberts and Greenwood (2019) carried out a Delphi survey of experienced SLTs in order to determine a consensus opinion on SLT best practice with this patient group. The findings from this study were used as basis for these guidelines, which are the result of a piece of collaborative work involving specialist SLTs, working with adults in DOC across the UK. They were written by a working party of experienced SLTs employed in a range of settings, including Critical Care, rehabilitation and community. A final draft was sent to a wider group of expert SLTs across the UK in order to ensure that they reflect current practice within the profession.

The SLT working party acknowledges that these are guidelines only and may need to be adapted for the service in which the SLT works.

1 DOC refers to a Disorder of Consciousness. After 4 weeks patients are considered to be in a Prolonged Disorder of Consciousness (PDOC). Throughout this document the term DOC will be used, reflecting that SLTs should be involved from the early stages in Critical Care. See the RCP Guidelines (2019) for more detail on definitions.

These guidelines should be read in conjunction with other key documents:

- Royal College of Physicians, (2019). Prolonged disorders of consciousness National Clinical Guidelines (and any subsequent updates). **https://www.rcplondon.ac.uk/guidelines-policy/prolonged-disorders-consciousness-national-clinical-guidelines**
- British Medical Association/Royal College of Physicians (2019) Clinically Assisted Nutrition and Hydration (CANH) and adults who lack the capacity to consent Guidance for Decision making in England and Wales. **https://www.bma.org.uk/advice/employment/ethics/mental-capacity/clinically-assisted-nutrition-and-hydration/clinically-assisted-nutrition-and-hydration-canh-guidance**
- Mental Capacity Act 2005 **https://www.gov.uk/government/collections/mental-capacity-act-making-decisions**

Patients in DOC have suffered a profound brain injury. They will have significant and complex cognitive, communication and physical impairments so SLTs should be involved in their assessment and management as part of a Multi-Disciplinary Team (MDT). SLTs will also work closely with the families and friends of patients in DOC.

By definition, patients in DOC lack the capacity to make decisions about their care, and decisions may be made on the basis of their best interests in accordance with the provisions of the Mental Capacity Act 2005. SLTs will be involved in best interests decision making as part of the MDT in the absence of a Lasting Power of Attorney for Health or Advanced Decision to Refuse Treatment.

Adults in DOC are a complex and challenging population to work with due to the profound level of disability involved. This is life-changing for both the patient and their families. SLTs and managers must ensure robust supervision procedures are in place in order to provide support for staff working with patients, who may only give no or minimal responses, and families who will be suffering from distress.

Further training may be available through study days and support can be accessed by contacting the relevant RCSLT Advisors. In addition, authors of theses guidelines who have included their email address have agreed to be contacted to provide advice. There are also other online resources:

> The Coma and Disorders of Consciousness Research Centre at Cardiff University has developed free e-learning to support health care students and staff.
> **http://cdoctraining.cdoc.org.uk/**
>
> Healthtalk.org provides further information and resources from the perspective of family members.
> **http://www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/topics**

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Assessment of awareness and communication in patients in a Disorder of Consciousness

Introduction:

Speech and Language Therapists possess key skills to carry out formal and informal assessments to contribute to a diagnosis for patients at all points on the continuum of consciousness. SLTs have particular skills and knowledge that should be utilised when assessing any patients showing communicative behaviours. SLTs are able to choose appropriate assessment materials based on psycholinguistic principles and highlight to other team members the potential impact of aphasia, apraxia of speech, dysarthria and cognitive impairments on assessment. SLTs should have a key role in the assessment, management and monitoring of communication in patients in DOC due to the emphasis on communication behaviours in the definitions used to determine MCS and emergence (Giacino et al. 2002, RCP Guidelines 2019).

Key points:

These guidelines should be read in conjunction with the RCP guidelines (2019) and any subsequent updates, which give further details on recommended assessments and factors to take into account before commencing assessment.

- It is important to have a good understanding of the definitions associated with DOC and which communicative behaviours are associated with each state on the continuum of consciousness (RCP 2019, Giacino et al. 2002, Bruno et al. 2011).
- SLTs should be involved in carrying out both formal and informal assessments to obtain information on responses in a range of contexts, for example a quiet room, in the physio gym, in a café with family.
- The three most commonly used DOC assessments are: the Wessex Head Injury Matrix (WHIM, Shiel et al., 2000); the Sensory Modality Assessment and Rehabilitation Technique (SMART, Gill-Thwaites, 1997) and the Coma Recovery Scale-Revised (CRS-R, Giacino, Kalmar, & Whyte, 2004). The RCP guidelines (2019) recommend that one or more of these tools should be used, but emphasise that none will provide an accurate diagnosis if used alone.
- SLTs should be involved in administering formal assessments. WHIM and CRS-R can be used by anyone following training from an experienced assessor, but SMART requires attendance at a specific training course. SLTs working with DOC patients should be able to carry out WHIM and CRS-S and may choose to undertake SMART training if appropriate to their service.
- Other assessments such as the Sensory Tool to Assess Responsiveness (STAR) are being developed (Stokes et al. 2018) and SLTs should be aware that other tools may become available and undertake training as appropriate.
- SLTs should be aware of the pros and cons associated with each assessment (RCP, 2019, Stokes et al., 2018, Pundole & Crawford, 2018, Seel et al. 2010) and be involved in team discussions about which formal assessments are most appropriate for an individual patient.
- It is important to be aware of when it is optimal to start assessment, considering relevant factors, e.g. posture, nutrition, medical stability, sensory/perceptual issues and medications that may impact on arousal.
- Assessment should start early on when the patient is in Critical Care, although consideration should be given to which assessments are most appropriate in this setting.

- Due to the complex nature of patients in DOC, team working is vital. Joint sessions should be arranged with appropriate physiotherapy and occupational therapy colleagues to ensure positioning is optimised to facilitate responses, appropriate movements to assess command following are identified and to provide a range of postures in which to carry out assessment (e.g. sitting versus standing on a tilt table).
- It is also useful to carry out both formal and informal assessments with another team member to reach a consensus on whether observed behaviours are intentional or not. It may sometimes be useful to film patients and consider behaviours as a whole team.
- In order to differentiate between behaviours that are reflexive or spontaneous and occur without a stimulus and those which occur intentionally, it is vital to observe the patient at rest. Quiet periods of behavioural observation are integral to CRS-R and SMART but should be carried at the start of assessment sessions regardless of assessment being used. Simple record sheets are available (Putney PDOC Toolkit, Wilford et. al. 2018).
- SLTs should help families to document behaviours they observe when they are with the patient. This can be done by giving them an observation form (e.g. RCP guidelines, Putney PDOC toolkit) or a separate copy of the WHIM to carry out.
- Family (or any person significant to the patient) should be involved in at least some SLT assessments. This provides an opportunity for education about responses seen and there is evidence that the presence of a familiar person may facilitate a response (Sun et al., 2018).
- SLTs should collect information from family and friends on the patient's social background, likes, dislikes, hobbies etc. to be used in personalised intervention plans.
- SLTs should take a holistic approach to assessment, completing both formal and informal assessments. Assessment should be carried out in a range of contexts and include familiar and emotionally salient stimuli that are more likely to elicit a response (Sun et al. 2018, Perrin et al. 2015, Abbate et al., 2014, Di Stefano et al., 2010).
- SLTs should assess for the presence of communicative behaviours in DOC patients. This includes command following, yes/no responses, choice making, expressing a preference in context, facial expression, gestures, mouthing or verbalising and the use of low/high tech AAC.
- Trained SLT assistants may carry out some WHIM and CRS-R assessments and personalised assessment and treatment programmes under the supervision of the treating SLT if appropriate. Qualified staff must also carry out assessments and be responsible for diagnosis.
- In order to meet the criteria for emergence, patients are expected to demonstrate functional object use or functional communication (Giacino et al. 2002, RCP 2019 Annex 1a). SLTs can contribute to the assessment of functional object use in motivating contexts, such as oral trials, but must take a lead within the team if a patient demonstrates behaviours that could be used for communication.
- Factors such as aphasia, apraxia of speech, dysarthria and cognitive impairment may affect a patient's ability to demonstrate that they have emerged from DOC. SLTs should have a good understanding of how these factors can influence assessment and be able to lead on discussions within the MDT (Marjerus et al. 2009, Schnakers et al., 2015, Pundole & Crawford, 2018)
- SLTs have the relevant knowledge and skills to adapt assessments to compensate for the above factors, using a total communication approach, including where appropriate AAC. It is important to use appropriate and relevant stimuli ensuring they are visually, semantically and phonologically distinct. It may also be necessary to educate other members of the team to ensure they are able to choose appropriate stimuli for awareness assessment.
- SLTs should be involved as an integral part of the MDT and contribute to the diagnosis of level of consciousness and prognosis.

- If a patient remains in DOC, a disability management approach should be taken, i.e. shaping the environment to provide motivating interaction opportunities rather than facilitating communication directly. Families should be provided with interaction/sensory/leisure guidelines to give them ideas of appropriate activities to carry out, which may facilitate communication in future, and to help them to monitor for any change. This could include, but is not limited to, watching short clips of preferred TV programmes together, listening to music, and/or looking at family photos.
- Families and carers should also be given clear guidance on when a referral back to SLT would be appropriate. For example, if a patient in MCS responds occasionally and unpredictably with mouthing or following a command, it would not be possible to set meaningful rehabilitation goals. However, if the patient starts to do this more predictably further 1:1 rehabilitation may be appropriate. When giving specific guidance to families their expectations should be taken into account to ensure patients are referred only at an appropriate time. It may be useful to be prescriptive (e.g. Joe can look to a correct picture from a choice of two on 4/5 occasions and he does this each time you visit him for 3 weeks).

Guidelines:

1. SLTs should be involved in assessment from an early stage post injury in Critical Care and at all points in the DOC care pathway.
2. SLTs should be involved in both formal and informal assessment of patients in DOC to contribute to identifying signs of awareness and communication behaviours.
3. SLTs have a key role in educating the team and families on how communication impairments can affect assessment of awareness.
4. SLTs should lead in the assessment of communication in patients in DOC.

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Use of Augmentative and Alternative Communication (AAC) in patients in a Disorder of Consciousness

Introduction:

The SLT has a key role to play in assessing for any purposeful communication in patients in a DOC. As communicative behaviours in this population are often non-verbal, assessment with low and high technology AAC are an essential part of the SLT's toolkit. Little published research exists on the use of AAC with patients in DOC, with Lancioni and colleagues' dominating the evidence base (Lancioni et al. 2008, 2008, 2009, 2009, 2009, 2010, 2012, 2014). Concerns have been raised in relation to participant numbers, methodological robustness and the quality and rapid speed of peer review in these papers (Bishop 2015; Etchells and Chamber 2015). Despite this, these studies do highlight the possible benefits of assistive communication technology for some patients in a DOC.

Key points:

- AAC assessment and intervention should commence as early as possible (McCurtin and Murray, 2000) irrespective of setting.
- The SLT should examine whether the patient can use everyday gestures (e.g. thumbs up/down, a head nod/shake), or a pen/paper to normalise the communication method used.
- If this is not possible the SLT should consider low tech AAC options and any special equipment needed to access it (e.g. a switch). Given the severity of the brain injury and likely physical, cognitive and communicative impairments in this population, low tech options should always be thoroughly explored before assessment with any high tech AAC is undertaken. These include assessment of non-verbal yes/no through eye, facial or body movements; use of picture or phrase boards; alphabet boards or other low tech AAC e.g. E-tran (eye-transfer) frames.
- Team working is essential for successful implementation of AAC (McCurtin and Murray, 2000). The SLT should work closely with MDT colleagues, particularly from Occupational Therapy to explore pre-requisite skills for switch use. This includes attempts to elicit a purposeful body movement to control the switch as well as exploring the ability of the patient to demonstrate cause and effect. This might be through demonstration of using the switch to turn on/off a radio or television with stations or channels personal to the individual.
- SLTs can refer to the Putney PDOC Toolkit's section 'Command following" (p. 27-28) for further information and practical resources (Wilford et al 2018).
- When looking to develop cause and effect skills, a trial is recommended to establish consistency in switch use. Tasks should be graded, introducing environmental stimulation (Lancioni et al. 2008; 2009; 2010; 2012; 2014) and/or simple games before AAC devices heavily reliant on language processing skills (Beukelman and Mirenda, 1992). The trial should be tailored to the individual but include intensive practise (at least daily) and be of sufficient duration (proposed minimum of two weeks). A review after the first week to establish if new learning or progression is being made is advised, with more frequent reviews for patients making clear advances in their ability to use the chosen AAC method.
- The use of AAC can help with assessment of awareness, and examining any new behavioural responses. This may be particularly applicable in younger patients where the use of technology is more commonplace and appealing.
- Consistent use of AAC equipment may be one possible way for a patient in a DOC to demonstrate emergence.

- Use of Rehabilitation Assistants or discipline-specific assistants is appropriate to ensure intensity of AAC practise. Nursing staff, family and friends may also be involved if deemed by SLT to possess the appropriate skills.
- It is unusual for patients in a DOC to be able to use high tech AAC methods competently due to their significant cognitive and communicative impairments. However, if appropriate, assessments with eye gaze or switch accessible computer systems may be undertaken. Where this is the case SLTs across the rehabilitation pathway are strongly advised to contact their nearest specialised AAC service (https://www.communicationmatters.org.uk/page/assessment-services). These services will support teams to undertake their assessments and provide AAC equipment and support.
- Where AAC is being implemented, it is essential SLTs provide training to staff, family and friends of the person being provided with AAC to enable them to be involved in the delivery of the programme (NHS England/Specialised Commissioning 2016).
- The ability of a patient in a DOC to use AAC should be regularly re-explored throughout the patient journey particularly when new behaviours or meaningful change in performance are observed.

Guidelines:

1. SLT assessment should include assessment of the ability of patients in DOC to use both low and high-tech augmentative and alternative communication (AAC)
2. Assessment and intervention for use of AAC in patients in DOC should commence as early as possible irrespective of setting
3. For DOC patients demonstrating the potential physical ability to use access methods (e.g. via a switch/eye gaze), SLTs should provide bespoke programmes to give patients the opportunity to develop switch skills through games and language activities
4. The trial should be tailored to the individual but include intensive practise (at least daily) and be of sufficient duration (proposed minimum of two weeks)
5. Sessions during an AAC trial for a patient in DOC should initially be delivered by SLT (in conjunction with Occupational Therapy/Physiotherapy as needed) subsequently involving AHP assistants, nursing staff, family and friends if deemed by SLT to possess the appropriate skills
6. SLTs should provide training to staff, family and friends of patients in DOC to enable them use the AAC and to be involved in the delivery of AAC programmes
7. The ability of a patient in DOC to use AAC should be regularly re-explored throughout the patient journey particularly when new behaviours or meaningful change in performance are observed

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Tracheostomy Management in patients in a DOC

Introduction:

The contribution of SLTs to the management of tracheostomy in patients in a DOC is essential. Tracheostomy weaning in patients in a DOC is typically more complicated and prolonged than with conscious patients. However, it has been shown that the Glascow Coma Scale score is not predictive of weaning success (Enrichi et al., 2017; Perin et al., 2017). Research indicates that multi-disciplinary tracheostomy care helps to reduce the total time a patient has a tracheostomy (Speed and Harding, 2013). SLTs are an important member of the multi-disciplinary team, providing specialist expertise in the area of swallowing and saliva management (McGrath and Wallace, 2014) which includes assessment to minimise risk and therapeutic input to accelerate the weaning process (Frank, Mäder and Sticher, 2007).

Key points:

- SLTs working in this area should have completed their basic tracheostomy competencies (RCSLT, 2014) and the more specialist DOC competencies outlined in this document.
- The tracheostomy weaning process should be similar to the weaning process for other neurologically impaired patients with a tracheostomy.
- Tracheostomy weaning, and specifically cuff deflations, should not be delayed purely because the patient is in a DOC. Cuff deflation and one-way valve trials should commence as early as possible, when the patient is still in critical care and may still be requiring ventilation (Seel et al., 2013; GPICS, 2019). As with any patient with a tracheostomy, the longer that the cuff is inflated the greater the desensitisation of the laryngo-pharynx and the greater the disuse atrophy of swallowing musculature (Goldsmith, 2000).
- One-way valves (OWVs) should still be used as part of the weaning process, as their use will enable the redirection of airflow through the laryngo-pharynx facilitating the build-up of subglottic pressure for swallowing (Gross et al., 2015) and cough (Lichtman et al., 1995). OWVs also improve laryngo-pharyngeal sensation which may improve swallowing frequency and function (Suiter, McCullough and Powell, 2003).
- It is important to avoid using the term ‘speaking valve’ with this client group as this can be misleading for family members, giving the impression that the patient will be able to speak once the valve is used. Utilisation of the term ‘one-way valve’ is recommended with patients in a DOC. It is also important to provide early education to family members to ensure that they understand that the tracheostomy is not the cause of communication difficulties and that cuff deflation or decannulation will not result in the patient being able to speak.
- As patients in a DOC are unable to communicate non-tolerance of OWVs, assessment should take place cautiously with close monitoring for signs of air trapping or difficulty breathing. Air trapping can be subtle and not detectable by oxygen saturations alone. Signs and symptoms to watch for include: increased respiration rate, increased heart rate, if ventilated – rising peak pressure, release of air post OWV removal, and signs of hypercapnia (e.g. rising PaCO2).
- If the tracheostomy tube is too large to facilitate OWV use, then it is important to consider a downsize to optimise tracheal and laryngeal airflow (Mitchell et al., 2013), as the sensory benefits of one-way valve are extremely important in this patient group.
- SLTs should work closely with the MDT to formulate a weaning plan, taking into account all rehabilitation priorities and the impact of fatigue from tracheostomy weaning on other aspects of rehabilitation and recovery.
- The use of tracheostomy tubes with a sub-glottic port has been shown to reduce the rate of Ventilator-Associated Pneumonia (VAP) (Ledgerwood et al., 2013). A large proportion of patients in a DOC will have difficulties managing their oral secretions. Therefore, patients in a DOC may be more likely to benefit from the use of these tubes to facilitate the removal of aspirated secretions and prevent pneumonia.

- The use of Fibreoptic Endoscopic Evaluation of Swallowing (FEES) (Hales, Drinnan and Wilson, 2008), or nasendoscopy by ENT, to assess airway patency and saliva management is often beneficial to provide information to guide tracheostomy weaning (RCSLT FEES Position Paper version 2, in preparation).
- As this patient group are more likely to have a tracheostomy in the longer-term, it is important to remain vigilant for signs of complications (e.g. granulation, tracheomalacia and tracheal stenosis) (Engels et al., 2009). SLTs should make onward referrals to request ENT review when required. Fenestrated tubes should only be used with caution and close monitoring due to the high risk of complications, such as granulation (Pandian et al., 2019) (Siddharth and Mazzarella, 1985). If used, the position and patency of fenestrations should be checked regularly (Powell et al., 2011).
- Above Cuff Vocalisation (ACV) is a technique that can be used in patients with tracheostomy. It involves directing an external flow of air through the sub-glottic port and up through the larynx to improve oropharyngeal and laryngeal sensation and allow the patient to vocalise. Research by Kothari et al., (2016) investigated the use of ACV with 10 patients in a DOC (Kothari et al., 2016). They reported increased swallowing frequency and reduced amounts of secretions aspirated from above the cuff. This does suggest potential benefits of ACV in tracheostomy weaning in patients in a DOC. However, given the limited research in this population and potential risks of ACV (e.g. air trapping and subcutaneous emphysema) which would be more complicated in patients unable to express discomfort, ACV should be implemented with caution in this population group until further evidence is available. If used, We suggest referring to ACV as 'External sub-glottic air flow', as per Kothari et al. (2016), to prevent family from having unrealistic expectations about the possibility of vocalisation.
- There is limited evidence for the benefits of capping, or corking, in tracheostomy. However, a survey of clinicians indicated that many consider capping to be an important part of the weaning process and determining readiness for decannulation (Stelfox et al., 2008). Capping may be of benefit, particularly in long-term care or the community, to provide assurance that the patient is ready for decannulation.
- Patients in a DOC may need to be monitored for a longer period of time post-decannulation to ensure that they are adequately managing their oral secretions. If a patient is decannulated after a prolonged period with a tracheostomy there may be issues with stoma healing. SLTs should review saliva management post-decannulation as there may be issues with altered pharyngeal pressures if there is air escape via the stoma. SLTs should liaise with the MDT and/or GP to request ENT referral where needed for consideration of surgical closure of the stoma.
- Once discharged to community or long-term care patients ideally should receive a minimum of an annual multi-disciplinary tracheostomy review. SLTs should contribute to this review. However, many regions across the UK do not have a community/outreach service for tracheostomy. SLTs working in the community should be aware of what services are available in their area and liaise with their MDT/ENT/ GP for onward referrals where needed.
- As a minimum, patients should receive one SLT review once transferred to the community from acute or rehabilitation.
- The frequency of SLT input in the tracheostomy weaning process is likely to vary dependent on the setting and where the patient is on their journey. Frequency of input may vary from daily or twice daily (e.g. critical care) through to annual review (e.g. long-term/community).

Guidelines:

1. SLTs should be involved in tracheostomy weaning as early as possible in critical care
2. SLTs should complete assessment of patients' saliva management and contribute to weaning plans for all patients in a DOC with a tracheostomy
3. SLTs should avoid using the term 'speaking valve' instead using the term 'one-way valve' with this client group
4. SLTs should provide advice, training and education to families, and the MDT, regarding saliva management and tracheostomy weaning in patients with a DOC

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Saliva management in patients in a Disorder of Consciousness

Introduction:

Saliva management issues are common in patients presenting in a DOC and are part of routine clinical management (RCP, 2019). SLTs have specialist knowledge and skills which contribute to effective multidisciplinary team (MDT) assessment and intervention for saliva management issues. The associated risks of poor saliva management, particularly aspiration risk, can severely impact on individual quality of life (Bavikatte et al., 2012). Assessment of saliva management is a key part of the SLT input provided to patients in a DOC and is best provided in an MDT context (Squires et al., 2012; NICE, 2013).

Key points:

- In DOC, saliva management issues occur primarily in the context of oropharyngeal dysphagia and/or orofacial weakness. However, clinicians should also consider hypersalivation which can present in neurological conditions or as a side effect of medication (NICE, 2013). Individuals with tube feeding and/or tracheostomy are at risk of higher secretion levels (Donzelli et al., 2003).
- Individuals with profound sensory dysfunction have decreased recognition of drooling often combined with dysphagia which impedes the ability to manage secretions (Bavikatte et al., 2012).
- SLTs should take a full case history and provide appropriate bedside and/or instrumental assessments to evaluate the type and volume of secretions and the individual's swallowing profile. For individuals with sialorrhea in DOC and oropharyngeal dysphagia or orofacial weakness SLTs should provide a lead role in MDT assessment, care planning and review.
- Within the MDT context, SLTs should work with the team to understand the individual's postural control, levels of wakefulness and awareness as they impact on effective saliva management. SLTs should work alongside respiratory physiotherapy colleagues to provide a full assessment of the type and volumes of oral, pharyngeal and tracheal secretions present.
- Use of published scales for assessment of frequency and severity of drooling, which are rated by carers (e.g. Bavikatte et al., 2012) are applicable to individuals in DOC. Secretion volume can be estimated from 24 hour oral suction collections. For individuals who have a tracheostomy in situ, where there is a sub-glottic tracheostomy port, 24 hour sub-glottic suction collections indicate volume of aspirated oral secretions.
- However, SLTs should review the impact of positioning, tracheostomy size and cuff status on sub-glottic suction volumes, and consider FEES for more detailed assessment. Where individuals are appropriate for FEES, secretions can be rated using validated scales for example, the Secretion Severity Rating Scale (Murray et al., 1996) or the New Zealand Secretion Scale (Miles et al., 2017).
- The saliva management care plan is intended to improve comfort and function of the mouth and reduce tissue viability risks, for example perioral chapping, irritation, maceration and infection of the skin (NICE, 2013). The 'Mouthcare Pack' (Mouthcare Matters, NHS England) is available to provide a baseline assessment and a weekly outcome measure to monitor progress with oral care.
- The MDT should ensure hydration status is optimised with input from medical, nursing and dietetic colleagues. SLTs should liaise with physiotherapy colleagues regarding positioning to optimise head control and oral closure. Individuals in DOC are fully dependent for mouthcare. SLTs should refer to the most appropriate healthcare professional who can advise on frequency of mouthcare and adjuncts such as specialist oral hygiene tools, toothpastes and/or oral saliva replacement products.
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- SLTs should involve family, friends and/or care staff as appropriate to ensure that an accurate assessment is gained of the saliva management issues over the 24 hour period.
- SLTs should ensure that any planned management strategies and interventions are provided with upmost regard to the individual's best interests and previously expressed wishes and incorporate family and carer training where required.
- Providing mouthcare is a functional task that provides an opportunity to monitor for signs of awareness (e.g. anticipatory mouth opening, localising response towards a toothbrush, response to smell and taste of toothpaste).
- Behavioural management strategies for saliva issues are highly unlikely to be appropriate for in individuals in a DOC due to absent or inconsistent awareness.
- SLTs should consider interventions to target pharyngeal and laryngeal sensation, swallow frequency and efficacy. For patients with tracheostomy, this may include early consideration of cuff deflation trials and one-way valves, or external sub-glottic airflow. External sub-glottic airflow has been reported to increase frequency of saliva swallows and reduce volume of secretions aspirated above the cuff (Kothari et al., 2016), however evidence is limited and therefore it should be used cautiously in the DOC cohort.
- Facial Oral Tract Therapy (FOTT) can be considered for prevention and reduction of hypersensitivity (Coombes, 2008). SLTs should review the evidence base and safety aspects of interventions prior to inclusion in a care plan. SLTs should complete training, competencies and have clinical supervision in place to support their practice.
- SLT assessments should inform and support MDT decision making around medications. Medical led interventions include prescription of anti-muscarinic drugs (e.g. hyoscine patches, glycopyrrolate, atropine drops) to reduce secretions (BNF, 2019; MNDA, 2017; NICE, 2013). Where these are not fully effective injection of the salivary glands with Botulinum toxin can be considered within a specialist service as a second or third line treatment (Bavikatte et al., 2012). For management of secretions that are thick or tenacious mucolytics such as carbocisteine and/or nebulisers may be prescribed (BNF, 2019; MNDA, 2017).
- The MDT should review whether any medications are contributing to hypersalivation (e.g. clozapine, baclofen, citalopram) (BNF, 2019).The MDT should ensure there is a robust follow up plan in place to provide long term saliva management, for example if a patient is discharged to community setting and may benefit from repeat Botulinum toxin injections. Community services should involve an SLT if there is a deterioration in saliva management, for example this should be incorporated into Continuing Healthcare Funding reviews in community. The MDT should review whether medications for secretion management are impacting on an individual's cognitive profile (e.g. hyoscine patches) and consider the timing of commencing or changing medications in relation to formal assessments of awareness (e.g. WHIM, CRS-R or SMART-PROFILE).

Guidelines:

1. Individuals in DOC should have a full assessment of mouthcare and saliva management which is reviewed regularly. SLTs should use of assessment scales and/or instrumental assessment of saliva using FEES if clinically appropriate.
2. Families and carers of individuals in DOC should be involved in assessment and care planning for saliva management, to promote interventions that are in the individuals' best interests. SLTs should provide specialist training to families and carers as appropriate.
3. SLTs should provide specialist input into initiating and reviewing the MDT saliva management care plan. SLTs should consider therapeutic interventions that target orofacial, pharyngeal and/or laryngeal sensation and frequency of saliva swallows.
4. SLTs should advise the MDT on aspiration risk in relation to oral secretions following bedside and/or instrumental dysphagia assessments as appropriate.

5. Where there is any form of spontaneous or purposeful behavioural response to sialorrhea – consistent or inconsistent – this should be noted as part of any ongoing formal or informal assessments of level of awareness (for example using the Putney PDOC Toolkit or SMART assessment informs).
6. SLTs should advise on the severity of dysphagia, aspiration risk and the amount and type of secretions to inform selection of appropriate treatments by medical colleagues.
7. MDTs should to consider when to complete informal and formal assessment tools (e.g. PDOC Toolkit, WHIM, CRS-R, SMART) in relation to commencing or changing medications for saliva management acknowledging that some medications may cause side effects that can mask awareness.

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Oral intake in patients in a Disorder of Consciousness

Introduction:

Assessment of response to oral intake is a key part of the SLT input provided to a patient in DOC. A diagnosis of DOC alone should not prevent SLTs from assessing a patient's response to oral intake (O'Neil-Pirozzi et al., 2003; Brady et al., 2006; 2009). However, the best interests of the patient should be carefully considered prior to assessing swallowing or providing therapeutic oral trials (small amounts of oral intake to assess awareness/provide sensory stimulation) as there will be patients for whom assessment of swallowing with oral intake is not appropriate. Families often place high value on eating and drinking and family expectations should be carefully managed through clear discussion regarding the purpose of assessment with oral intake/therapeutic oral trials.

Key points:

- In the critical care and acute setting, where the trajectory of improvement in level of awareness is more varied, patients in DOC may progress more quickly with their eating and drinking than in the rehabilitation or chronic phases.
- Assessment for oral intake in patients in DOC has a different focus from other patients with neurological disorders. The goal with this client group is rarely to achieve full oral intake, or even frequent therapeutic oral trials with nursing staff. In this population, swallowing assessment and therapeutic oral trials are used as tasks to assess for behaviours that indicate awareness or communication and to provide sensory stimulation.
    - Food and drink provide a multisensory, motivating context which may elicit intentional behaviours such as anticipatory mouth opening to a spoon or licking residue from the lips that are not assessed elsewhere.
    - Swallowing assessment and therapeutic oral trials can give additional information on interaction by providing a functional context in which to communicate likes/dislikes (e.g. by gesture/facial expression), make choices or indicate 'more'.
    - If safe, therapeutic oral trials can be a meaningful activity which a patient can be involved in with families to promote social inclusion and a way to monitor for change in awareness over time.
- It is important to ensure family members, friends and nursing staff/carers are aware of the aims of swallowing assessment and of any therapeutic oral trials before commencing.
- A bedside swallowing assessment of response to oral intake is necessary prior to considering instrumental swallowing assessment, as a proportion of these patients will be unable to participate in instrumental swallowing assessment (e.g. due to bite reflex, reduced mouth opening, lack of awareness of a bolus).
- A bedside swallowing assessment of a patient in DOC differs from a standard bedside assessment and should additionally include assessment of:
    - Oral hypersensitivity
    - Primitive or abnormal reflexes/movements (e.g. rooting, sucking, bite, tongue thrust, tooth grinding)
    - Ability to visually focus/track (e.g. of yoghurt pot/spoon) or reach/localise
    - Responses to different smells/tastes/temperatures
    - Ability to follow a command, make a choice or indicate 'more'
    - Ability to hold, manipulate or use an object appropriately

    - Anticipatory mouth opening
    - Responses to touch of spoon/cup to the lips
    - Ability to form appropriate mouth shape for utensil (e.g. cup vs spoon)
    - Response to residue on lips/in mouth

(Wilford et al., 2018)

- Assessment should be repeated on different occasions varying the items given and with familiar people present.
- Input from physiotherapy and occupational therapy can be beneficial for e.g. positioning, posture and use of adaptive cutlery to aid hand over hand feeding.
- Instrumental swallowing assessment should be utilised if appropriate e.g. to inform decision making or if it will affect the patient's ongoing management. Either FEES or videofluoroscopy can be used (O'Neil-Pirozzi et al., 2003; Brady et al., 2006; 2009), dependent on the clinical question to be answered, availability and the patient's presentation.
- There is no published research on Cough Reflex Testing in this client group but it may be considered as an adjunct to assessment.
- If a patient appears safe to have therapeutic oral trials it is vital to carefully consider decisions about continuing and/or extending oral intake, weighing up the risks versus the benefits. Factors to consider include:
    - Evidence of patient engagement/enjoyment in the task
    - Whether the patient is managing the therapeutic oral trials by reflexive movement alone
    - Trajectory of improvement in the patient's level of awareness
    - Reason for wanting to feed the patient e.g. social interaction, monitoring of awareness, nutrition
- Consider the overall risk of assessing with oral intake/therapeutic oral trials in conjunction with the patient's current treatment escalation plan and bearing in mind the complex medicolegal issues regarding withdrawal of clinically assisted nutrition and hydration (British Medical Association/Royal College of Physicians, 2018)
- SLTs should provide specialist opinion during MDT discussions on whether continuing and extending oral intake in patients in DOC is appropriate and in an individual's best interests.
- Families and carers should also be given clear guidance on when a referral back to SLT would be appropriate. For example, if a patient manages a pot of yoghurt with family a few times a week through reflexive movements only, then it may not be appropriate to increase volume or consistency and ongoing input would not be required unless a change is reported. However, if the patient shows signs of increased engagement, for example, indicating 'more' or making a choice about flavours then further SLT input would be appropriate both for further assessment of level of awareness and communication, as well as swallowing.
- It is recommended that SLTs read the Putney PDOC Toolkit's section 'Response to oral intake' (pp. 28-33) for further information and practical resources.

Guidelines:

1. SLTs should complete a bedside assessment of response to oral intake of patients in DOC
2. SLTs should utilise the skills of the MDT when assessing response to oral intake of patients in DOC
3. SLTs should conduct instrumental assessments of swallowing of patients in DOC if clinically appropriate
4. If safe, SLTs should utilise therapeutic oral trials as part of their management plan for patients in DOC but close consideration should be given to the appropriateness of regular therapeutic oral trials and who is best placed to provide those trials
5. SLTs should provide advice, training and education to the whole MDT, including families, regarding oral intake in patients with DOC

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Oral hypersensitivity in patients in a Disorder of Consciousness

Introduction:

SLTs, as experts in communication and swallowing, should assess oral reflexes and identify signs of oral hypersensitivity with the aim of inhibiting undesirable responses and facilitating normal patterns of movement in order to enhance overall function.

Abnormal posture as a result of an increase in muscle tone (spasticity) may lead to sensory loss/disturbance and therefore impact function (RCP, 2019). Depending on the type of neurological injury, spasticity can affect any muscle in the body, including those in the trunk, neck and face. Postural stability and mobility are a basis for the synchrony of oral movements, swallowing and breathing (Oetter et al, 1995).

Individuals who are sensitive to one type of sensory stimuli can often react defensively towards other modalities (Dunn, 2001). It is important to be aware that sensory deprivation linked to touch and kinaesthetic stimulation may lead to increased responses/sensory overload to auditory and visual stimuli.

Key points:

- Many patients with DOC demonstrate a degree of hypersensitivity (RCP, 2019). These hypersensitive responses may include intolerance to touch, withdrawal, increased patterns of flexion, teeth grinding, reflex biting, jaw clenching, lip pursing and facial grimace (Gilmore et al, 2003).
- Individuals with brain injuries can often exhibit hypersensitivity to oral and facial stimulation and can experience increased muscle tone when anything is placed in the mouth (Brown et al, 1992).
- SLTs should take into consideration the effect abnormal posture and positioning can have on the alignment and movement of the body. For example, if the head is extended then selective jaw movements and normal swallowing may be effortful.
- The presence of oral hypersensitivity may lead to:
    - Reduction in the ability to tolerate stimulation within the oral cavity e.g. via use of a toothbrush (Gilmore et al 2003)
    - Poor oral hygiene, which can lead to increased risk of aspiration pneumonia (Langmore et al, 1998)
    - Increased oral infections
    - Limited functional patterns of movement leading to reduced ability to tolerate oral tastes (Gilmore et al, 2003)
    - Increased discomfort as a result of limited movement and poor oral hygiene.
- Ongoing liaison with the multidisciplinary team (MDT) regarding ways to optimise saliva management and oral hygiene should take place.
- From the early stages (e.g. in critical care/acute) SLTs should promote the need to prevent sensory deprivation and the development of hypersensitive responses by aiming to improve tolerance to touch, increase level of awareness and provide opportunities to participate in functional activities (Coombes, 2008).

- Although evidence is limited for SLTs working in this area the following intervention could be considered:
    - The use of a holistic whole body approach such as Facial Oral Tract Therapy (Coombes, 2008; Hansen et al, 2010; Konradi et al, 2015). The SLT should work in conjunction with the MDT to normalise tone, improve base of support and position for function.
    - An oral desensitisation programme can be implemented focusing on head/jaw support grip, distal to proximal tolerance to firm touch and stimulation within the mouth incorporating functional and meaningful tasks, such as teeth brushing. When using this technique it is suggested that a consistent approach is adopted and trialled for a two week period before reviewing the presence of defensive reactions to establish if oral hypersensitivity has changed (Bahr, 2001; Gilmore et al, 2003; Konradi et al 2015).
    - SLTs are integral in ensuring that where possible an interdisciplinary approach is adopted with the aim of incorporating techniques to reduce hypersensitivity into the day-to-day routine. The environment may need to be adapted to reduce sensory overload. The individual should be encouraged to participate via tactile direction and facilitated hand to mouth motions.
    - SLTs should be involved in MDT discussions relating to the consideration of other forms of intervention. The use of devices such as bite guards could be used to reduce the negative effect of abnormal oral reflexes or in some cases a TheraBite could be used to attempt to increase mouth opening (Kamstra et al., 2012). The use of botulinum toxin could be trialled with the aim of alleviating abnormal patterns of movement (Fietzek at al., 2009).
- SLTs will need to provide training and support to the MDT, including family, to ensure consistency and effectiveness in carryover of these techniques.
- Onward referrals should be made to dental and/or maxillo facial teams if required e.g. due to dental complications and repeatedly bitten lips (Millwood et al, 2005).

Guidelines:

1. SLTs should assess and provide oral hypersensitivity programmes for patients in DOC who displays signs of oral hypersensitivity.
2. Assessment and intervention for oral hypersensitivity in patients in DOC should commence as early as possible once the patient is medically stable.
3. SLTs should provide training to staff, family and friends of patients in DOC to enable them to be complete oral hypersensitivity programmes.
4. Oral hypersensitivity needs of patients in DOC should be regularly reviewed throughout the pathway.
5. SLTs should be involved in decision making regarding the use of other forms of intervention for managing oral hypersensitivity.

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Competencies for SLTs working with patients in a Disorder of Consciousness

Introduction

These competencies provide a basis to promote safe and best practice when working with patients in DOC. They have been split into the following domains:

1. Assessment of awareness and communication
2. Augmentative and Alternative Communication
3. Oral intake and oral hypersensitivity
4. Tracheostomy and saliva management

You will require support from your SLT clinical supervisor to complete these competencies. You will require input from an SLT with experience of DOC and you may need to seek this from outside your service if there is no one suitable within your service. Components of the competencies may also be completed with, and signed off by, other appropriate trained MDT members, such as physiotherapists, occupational therapists and clinical psychologists.

Pre-requisite core skills

Generally, it would be expected that management of a patient in DOC would be undertaken by a clinician at band 6 or above who:

- Has read the Royal College of Physicians (2019) Prolonged Disorders of Consciousness National Clinical Guidelines (or any subsequent updates).
- Is familiar with the recommended tools for assessment of DOC as per the RCP guidelines: Coma Recovery Scale – Revised (Giacino, Kalmar and Whyte et al. (2004), the Wessex Head Injury Matrix (WHIM) manual (Shiel, Wilson, McLellan, Horn and Watson, 2000) and the Sensory Modality Assessment and Rehabilitation Technique (SMART, Gill-Thwaites, 1997).
- Understands the criteria for diagnosis of Vegetative and Minimally Conscious States together with the compatible and incompatible features of each.
- Has completed dysphagia competencies and has experience of independently managing patients with dysphagia and communication difficulties of a neurological origin.
- Fully understands the advantages and disadvantages of videofluoroscopy and FEES.
- Has completed the relevant sections/skill levels of NHS Education for Scotland IPAACKS: Informing and Profiling Augmentative and Alternative Communication (AAC) Knowledge and Skills. This document supports the general learning and development of people working with individuals who use AAC.
- Completed the relevant sections of the RCSLT Tracheostomy Competency Framework (2014) where appropriate:
    - The core tracheostomy skills
    - Either the critical care tracheostomy competencies and/or the community and/or long-term tracheostomy competencies dependent on work setting

Competency	Evidence	Date	Signature
Knowledge			
1. Assessment of awareness and communication			
To be able to define VS, MCS (including MCS+ and MCS-) and emergence criteria To demonstrate an awareness of the formal assessments available for the assessment of DOC and the strengths and weaknesses of each To be able to suggest which assessments may be appropriate at each stage in the care pathway To demonstrate an understanding of why additional informal assessments are also required To demonstrate knowledge of how it can be difficult for a patient with a profound brain injury to demonstrate emergence			
2. Alternative and Augmentative Communication			
Demonstrates an understanding of the complexities of cognitive, sensory, physical and linguistic needs when introducing, selecting and trialling AAC systems with individuals in a DOC. Understands when referral to a specialist AAC assessment service is required			
3. Oral intake and oral hypersensitivity			
Demonstrates an understanding of the difference between a standard bedside swallow assessment and an assessment of response to oral intake in a patient in DOC Demonstrates an understanding of primitive oral reflexes and oral hypersensitivity and how to assess for their presence			

Demonstrates an understanding of the key factors relevant to implementing a management plan regarding oral intake for patients in DOC, such as, safety of swallow, medical status, purpose of oral intake, patient enjoyment and social context			
Demonstrates an understanding of when to refer for instrumental swallowing assessment with the DOC client group			
4. Tracheostomy and saliva management			
Demonstrates knowledge of the different pharmacological methods of managing saliva.			
Demonstrate an understanding of the similarities and differences between standard tracheostomy weaning and tracheostomy weaning in a patient in DOC			
Demonstrates an understanding of the importance of avoiding using the term 'speaking valve'			
Demonstrates an understanding of the importance of close monitoring when using a one-way valve as patients are unable to express discomfort			
Demonstrates an understanding of the importance of monitoring closely for tracheostomy complications (e.g. granulation, tracheomalacia and tracheal stenosis)			
Practical Skills			
1. Assessment of awareness and communication			
Is able to carry out and interpret a WHIM assessment			
Is able to carry out and interpret the CRS-R			

Is able to decide on the appropriate timing of assessment			
To initiate joint sessions with relevant team members			
To be able to record observations of a patient at rest			
To be able to choose appropriate stimuli for assessment			
To contribute to team discussion on how communication impairment might impact on assessment of level of awareness			
To include family in assessment sessions			
To provide appropriate information to family and carers on how they can support the patient, and know when it would be appropriate to refer for further assessment/rehabilitation.			
2. Alternative and Augmentative Communication			
Able to adapt assessment procedures to meet individual needs and abilities of those in DOC			
Able to select appropriate piece of AAC equipment based on severity of physical and sensory disability			
Able to include alternative access methods in the assessment process			
Able to identify when it is appropriate to stop an AAC trial			
Able to demonstrate appropriate multidisciplinary working when using AAC			

3. Oral intake and oral hypersensitivity			
Independently complete assessments of response to oral intake in patients in DOC			
Accurately identify the presence of primitive reflexes and oral hypersensitivity			
Able to design and implement an appropriate treatment plan to manage oral hypersensitivity.			
Appropriately implement oral intake management plans for patients in DOC, taking into account a variety of factors, such as, safety of swallow, medical status, purpose of oral intake, patient enjoyment and social context			
Appropriately feed back to the MDT, including families, regarding the outcomes of speech and language therapy sessions focusing on response to oral intake			
Appropriately refer for instrumental assessment of swallow for patients in DOC			
4. Tracheostomy and saliva management			
Complete assessments of cuff deflation and one-way valve use in patients in DOC with appropriate MDT colleagues.			
Accurately identify the non-tolerance of one-way valve in patients in DOC			
Able to contribute to tracheostomy weaning plans and one-way valve use for patients in DOC			
Able to educate family members and the MDT about the impact of tracheostomy on swallowing and the weaning process			
Able to contribute to MDT annual tracheostomy reviews (for long-term patients)			

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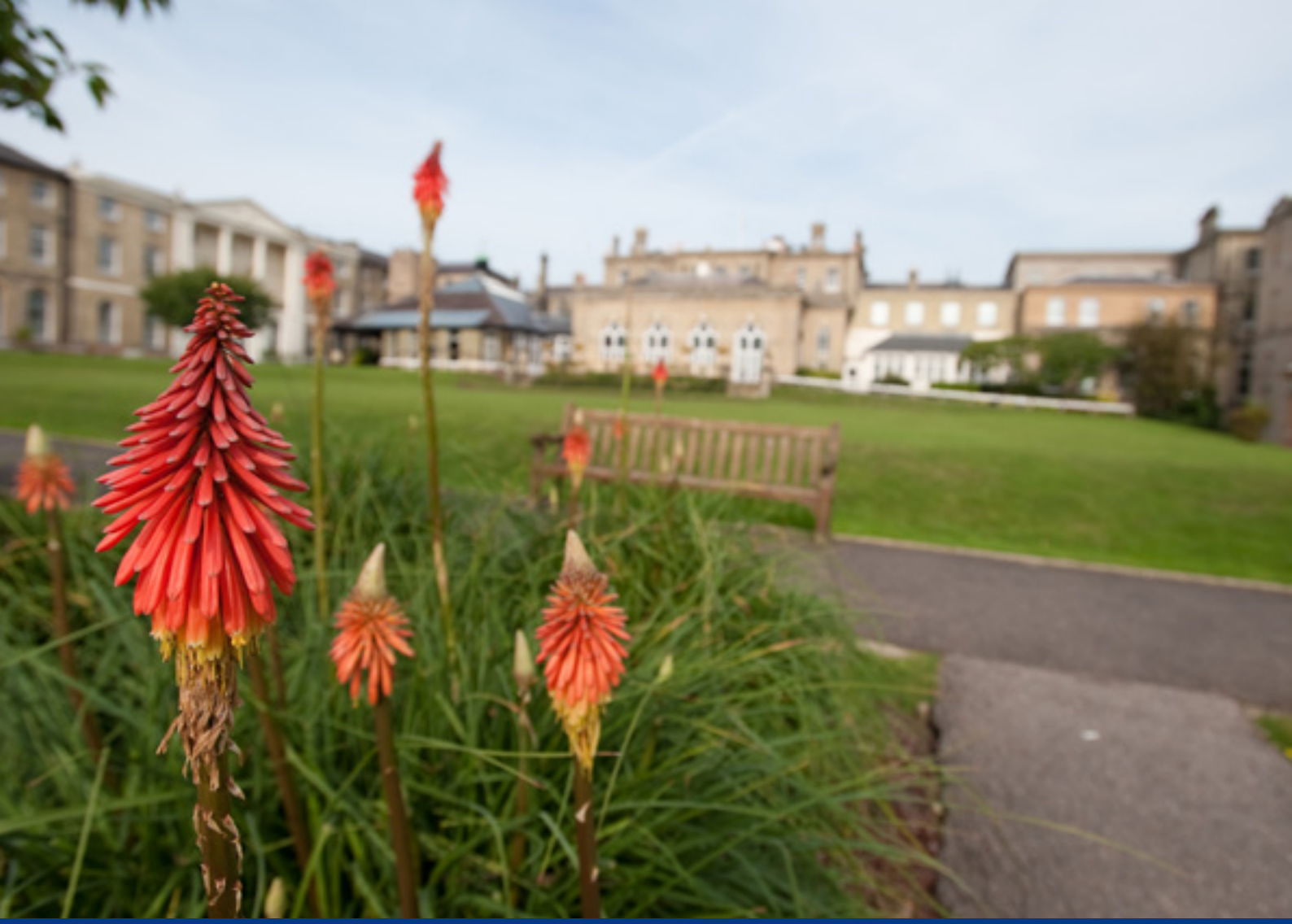

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