ON WITH LIFE

BRAIN INJURY + STROKE + NEURO

Disorders of Consciousness

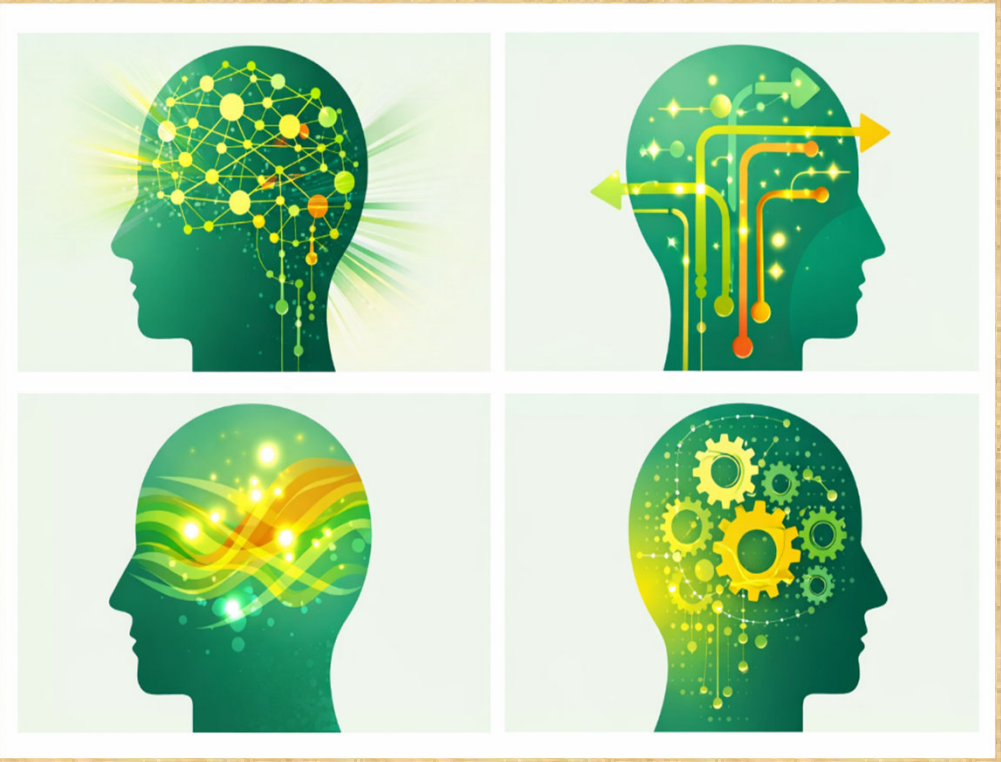
Interventions, Protocols, and Tools to Maximize Outcomes

January, 2026

SMALL STEPS. GIANT STRIDES.

Objectives

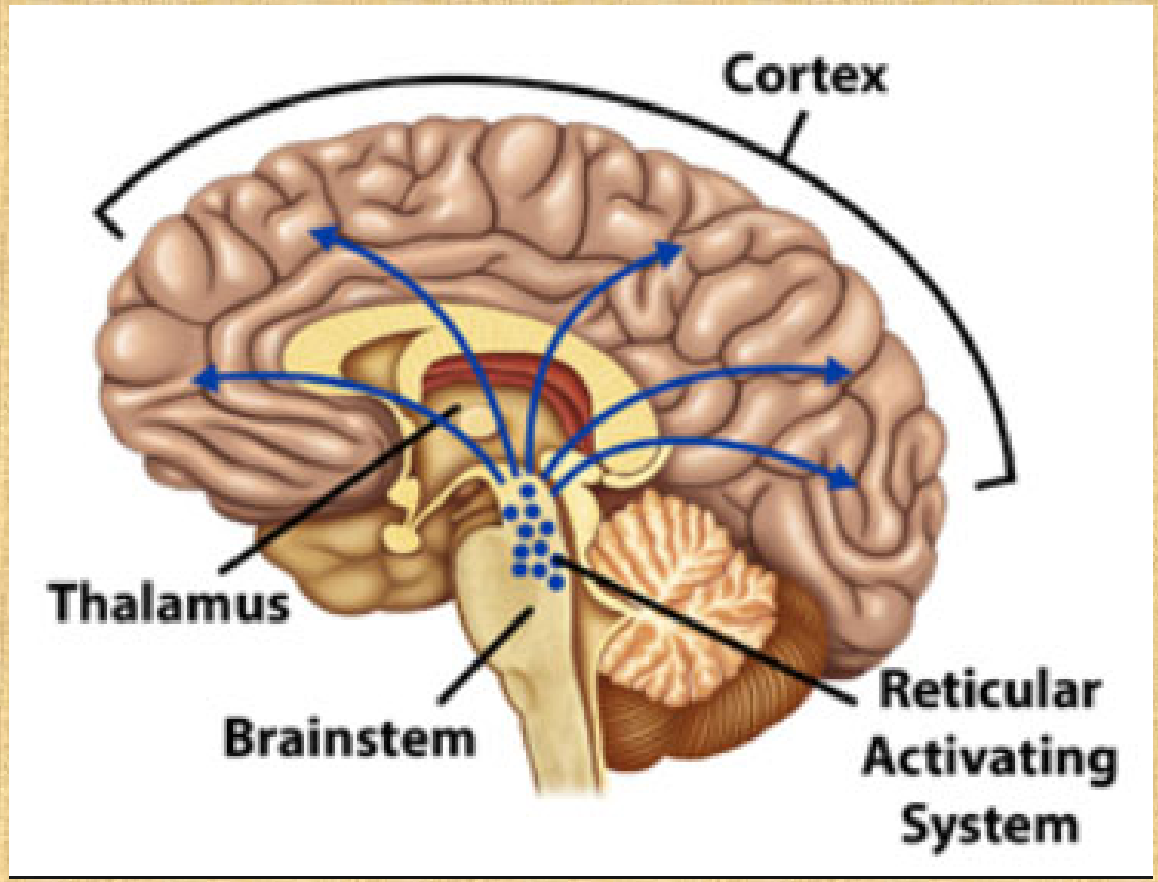
- Following this presentation, you will be able to:
  - Define the generally accepted subcategories of disorders of consciousness (DoC)
  - Describe unique medical management, diagnostic, prognostic and treatment considerations for individuals who present with DoC.
  - Gain an understanding of both practice guidelines and minimum competency standards for rehabilitation providers who serve individuals with DoC and their families.
  - Recognize and understand indicators of progress for individuals with DoC.



Arousal & Awareness

Arousal

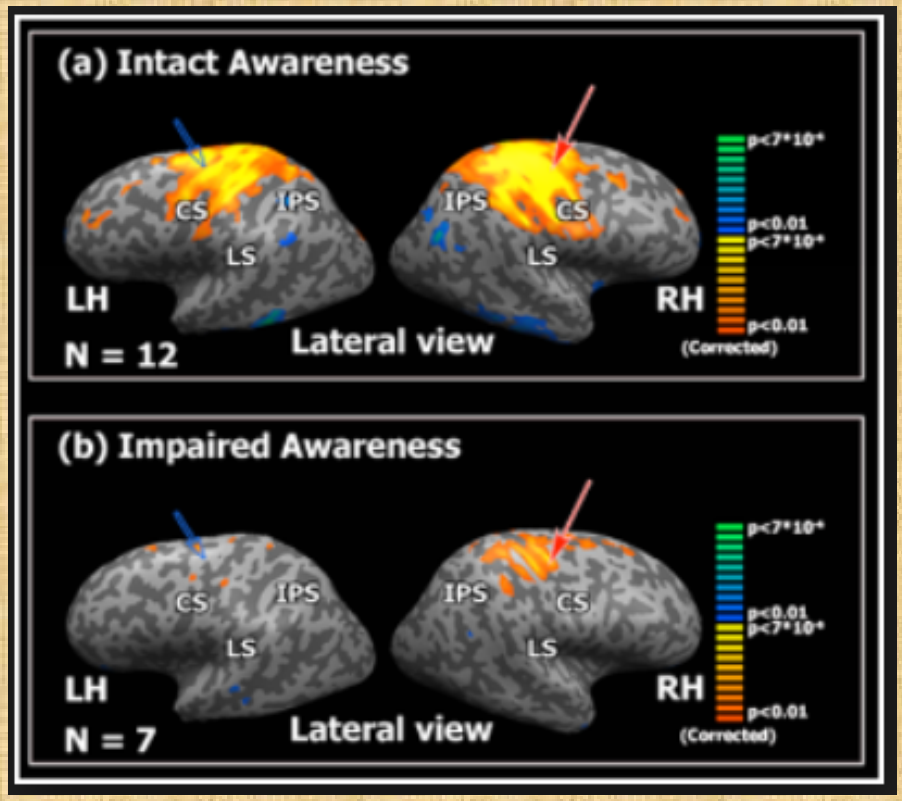
- primitive
- involuntary responsiveness to the world
- reflex (generalized) responses to internal and external stimuli.
- Mediated by the brainstem / reticular activating system



Arousal & Awareness

Awareness

- receive and process sensory information
- Use sensory information to relate to world
- Intentional
- Required for voluntary responses
- Mediated by the cortex.



Classification Systems

The Disorders of Consciousness:

Coma (-arousal, -awareness)

Vegetative State(+arousal, -awareness)

- *Unresponsive Wakefulness Syndrome* (UWS)
- *Post-Coma Unawareness* (PC-U)

Minimally Conscious State (+arousal, **+/-** awareness)

- *MCS –*
  - absence of signs of preserved language function (intelligible speech or command following)
- *MCS +*
  - presence of signs of preserved language function (intelligible speech or command following)

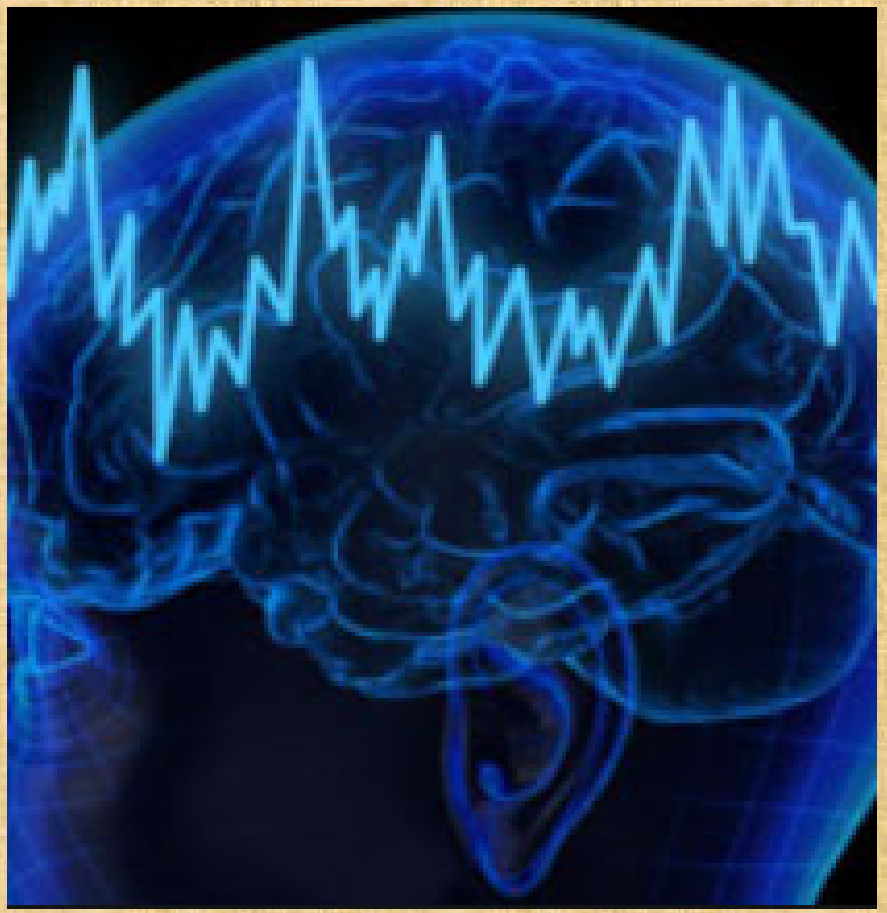
Additional Terms:

Prolonged DoC = lasting at least 28 days

Chronic VS/UWS = 3 months for NTBI or 1 year for TBI

The term “permanent” is no longer used.

Post-Traumatic Confusional State = A period of attentional compromise immediately following traumatic brain injury which may or may not include impaired orientation and varying degrees of amnesia.

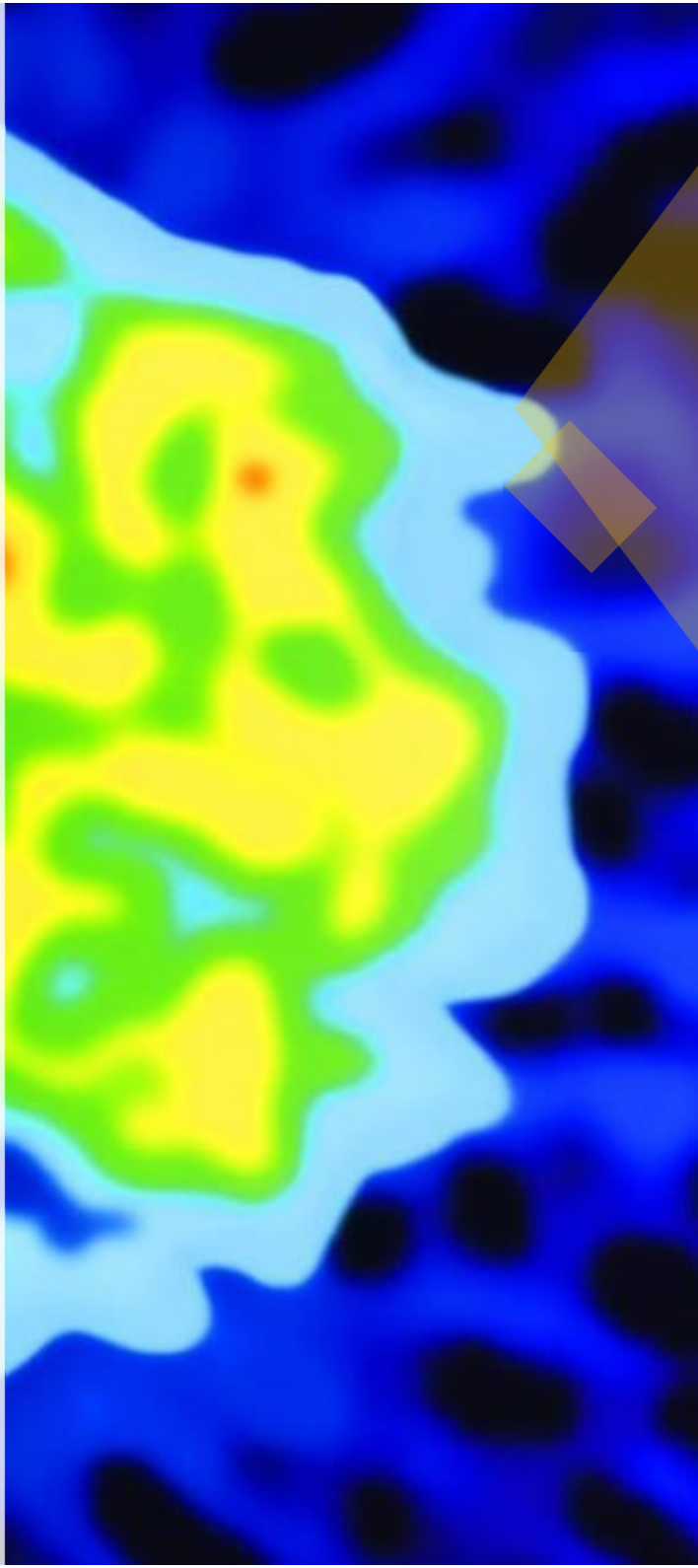


What is Coma?

- No behavioral evidence of arousal or awareness.
- Reflexive responses may be observed minimally
- No eye opening or evidence of a sleep/wake cycle.
- Resolves in 2-4 weeks…survivor either passes away or moves to a higher level.
- *Tends* to correlate roughly to Rancho Los Amigos Level 1

What is a Vegetative State (UWS)(PC-U)?

- Behavioral evidence of arousal, but not awareness.
- Preserved capacity for spontaneous or stimulus-induced arousal.
- Evidence a sleep/wake cycle and inconsistent eye opening (given intact motor pathways to allow eye opening)
- Rule of thumb…responses tend to be subcortical (reflexive / automatic / nonspecific)
- *Tends* to correlate roughly to Rancho level 2



What is a Minimally Conscious State?

- Behavioral evidence of arousal
- **Fluctuating**, but reproducible behavioral signs of awareness
  - Smiling / crying
  - Localization
  - Verbalization
  - Simple directive following (not consistently reproducible)
- Rule of thumb…responses require cortical activation

Seminal Works in DoC

› Arch Phys Med Rehabil. 2020 Jun;101(6):1072-1089. doi: 10.1016/j.apmr.2020.01.013. Epub 2020 Feb 20.

Minimum Competency Recommendations for Programs That Provide Rehabilitation Services for Persons With Disorders of Consciousness: A Position Statement of the American Congress of Rehabilitation Medicine and the National Institute on Disability, Independent Living and Rehabilitation Research Traumatic Brain Injury Model Systems

Joseph T Giacino [1], John Whyte [2], Risa Nakase-Richardson [3], Douglas I Katz [4], David B Arciniegas [5], Sonja Blum [6], Kristin Day [7], Brian D Greenwald [8], Flora M Hammond [9], Theresa Bender Pape [10], Amy Rosenbaum [11], Ronald T Seel [12], Alan Weintraub [13], Stuart Yablon [14], Ross D Zafonte [15], Nathan Zasler [16]

Affiliations + expand

PMID: 32087109 DOI: 10.1016/j.apmr.2020.01.013

Practice Guideline › Arch Phys Med Rehabil. 2018 Sep;99(9):1699-1709. doi: 10.1016/j.apmr.2018.07.001. Epub 2018 Aug 8.

Practice Guideline Update Recommendations Summary: Disorders of Consciousness: Report of the Guideline Development, Dissemination, and Implementation Subcommittee of the American Academy of Neurology; the American Congress of Rehabilitation Medicine; and the National Institute on Disability, Independent Living, and Rehabilitation Research

Joseph T Giacino [1], Douglas I Katz [2], Nicholas D Schiff [3], John Whyte [4], Eric J Ashman [5], Stephen Ashwal [6], Richard Barbano [7], Flora M Hammond [8], Steven Laureys [9], Geoffrey S F Ling [10], Risa Nakase-Richardson [11], Ronald T Seel [12], Stuart Yablon [13], Thomas S D Getchius [14], Gary S Gronseth [15], Melissa J Armstrong [16]

Affiliations + expand

PMID: 30098791 DOI: 10.1016/j.apmr.2018.07.001

DoC Guidelines + Minimal Competencies: Who Should Treat?

Multidisciplinary teams are recommended. This should include (at least):

On Site	Procedures In Place for Consultations	
Physician (at least 5d/wk)	Internal Medicine	Gastroenterology
Psychology	Physiatry	Ophthalmology
PT	Neurology	Otolaryngology
OT	Urology	Infectious Disease
SLP		
Nursing		
Social Work		

Assessment:

Standardized neurobehavioral assessment should be used

Review > Arch Phys Med Rehabil. 2010 Dec;91(12):1795-813. doi: 10.1016/j.apmr.2010.07.218.

Assessment scales for disorders of consciousness: evidence-based recommendations for clinical practice and research

American Congress of Rehabilitation Medicine, Brain Injury-Interdisciplinary Special Interest Group, Disorders of Consciousness Task Force;
Ronald T Seel, Mark Sherer, John Whyte, Douglas I Katz, Joseph T Giacino, Amy M Rosenbaum, Flora M Hammond, Kathleen Kalmar, Theresa Louise-Bender Pape, Ross Zafonte, Rosette C Biester, Darryl Kaelin, Jacob Kean, Nathan Zasler

PMID: 21112421 DOI: 10.1016/j.apmr.2010.07.218

Guidelines + Minimal Competencies: Therapy

There are three primary categories of rehabilitation in DoC:

- Facilitation of Increased Responsiveness
- Clinical State Management
- Family Education and Counseling

Overarching goals should include:

- Enhancing the health of the individual
- Mobility
- Self-care
- Communication
- Participation

Goal-Setting Considerations: **Tolerance-Based**

Base the goal on the level of tolerance exhibited by the individual for a given intervention (see signs of distress in the ADS section of this presentation). If the individual exhibits signs of distress after a given intervention has been administered for 5 minutes, a logical goal might be to progress tolerance to 10 minutes.

Goal-Setting Considerations: **Response-Based**

Base the goal on the response types exhibited by the individual (no response/ generalized response / localized response). If the individual currently responds to auditory stimuli in a generalized way, the logical goal progression would be to the localized response level.

Goal-Setting Considerations:
Risk Management-Based

There are a number of interventions designed to reduce risk for physical complications (see “physical management” section of this presentation). Goals based on these interventions are very appropriate for individuals with DOC.

Goal-Setting Considerations:
Caregiver Education-Based

Goals related to the education and training of caregivers within the individual's support system are integral in ensuring person-centered care. Some examples might include training in the appropriate administration of sensory stimulation, monitoring for signs of distress, and follow-through with physical management interventions such as range of motion.

Primary Categories of DoC Rehabilitation

- Standardized testing
- Facilitation of Increased Responsiveness
- Clinical State Management
- Family Education and Counseling

Standardized Testing

- Our protocol for testing
- CRS-R (Giacino et al., 2014)
- DOCS-25 (Pape et al., 2005)
- OWL scale

Post-Acute DoC Rehabilitation

- Individual, co-treat, group sessions
- Average of 3 hours of therapy per day
  - Increased as tolerated
- Inclusion of family as much as possible
- Monitoring for dysautonomia and pain
- Arousal/alertness
  - Consider sleep
  - Stimulants
  - Ambien trial protocol
- Philosophy on interaction style

Facilitation of Increased Responsiveness

Sensory Modality	Intervention examples
Gustatory	Lemon swabs, suckers, various flavors on cotton-tipped applicator
Olfactory	Spices, fragrances such as shampoo, cologne/perfume, lotions
Tactile	Varity of textures (e.g. silk, cotton, sandpaper, hairbrush) and temperatures (e.g. cool vs. warm clothes on skin)
Proprioceptive/vestibular	Positional changes, wheelchair movement/dancing
Auditory	Preferred music, environmental sounds, familiar voices (in-person or recorded)
Visual	Localization and/or tracking of objects, mirror, familiar photos, familiar people.


Multisensory Interventions

FAST protocol

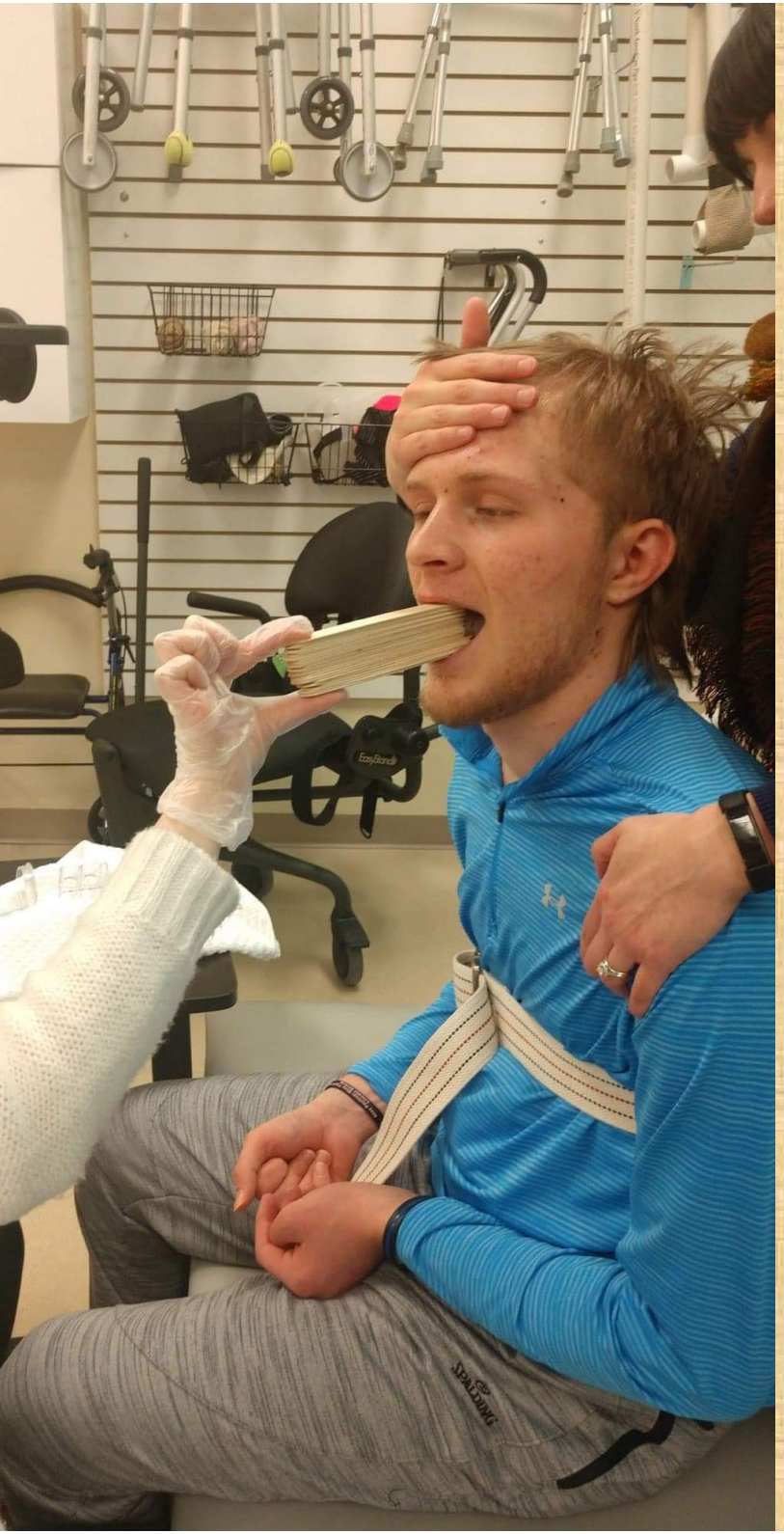
- Familiar Auditory Sensory Training
  - Sensory stimulation-based intervention
  - Recording of familiar voices
  - Shown to improve attention, awareness, and auditory language skills (Pape et al. 2015)
  - Study shown to alter structural and functional connectivity of targeted neural networks (Pape et al. 2020).

Early Communication

- Command following
  - Using any volitional movement
- Low tech AAC
  - Writing
  - Pointing
  - Yes/no

Physical Movement

- **Upright tolerance**
  - Tilt table v. standing frame
    - Upright tolerance needs to be gradual
    - Vitals
    - General rule: once tolerating tilt table for up to 20-30 minutes at 50-60 degrees= progression to standing frame
  - Seated tolerance
    - Edge of mat
    - Postural retraining
    - Righting reactions
- **Seating and positioning**
  - Tilt in space wheelchairs
  - Pressure relieving cushions
    - Pressure mapping
  - Head positioning-strapping, specialized head rests
- **Splinting and bracing**
  - Preserve ROM for future function!
- **Co treats**
  - Maximizing therapeutic benefits with more hands available
  - Positioning for work on command following, and communication



Splinting and Bracing

- 95% of Persons Served in DoC will have spasticity
  - 52.7% in all 4 extremities
  - 72.6% shoulder internal rotators
  - 59.8% plantar flexion
  - Zhang, DiTommaso, O'Brien (2020)
- Early interventions for spasticity are important!
  - Improve accuracy of testing
  - Decrease burden of care
  - Reduce potential for other complications
  - Maximize motor response potential
  - Improve long term management
- Spasticity can mask active movement that can prove alertness or consciousness

Splinting and Bracing

- Early intervention
  - Serial casting
    - Low load, prolonged stretch
    - Series of casts to both gain and maintain ROM at a single joint
    - From bed or seated
    - At least 2 sets of hands
    - Start proximal and move distally(UEs)
    - One joint at a time, 2-3 days depending on tolerance
    - If bilaterally involved:
      - One side at a time, alternate
      - Create bi-valve after casting to maintain ROM
    - Safety considerations:
      - Tolerance
      - Pain
      - Movement
      - Pressure points
      - Education of nursing staff to maintain circulation checks
    - Once desired ROM is achieved at joint- bivalve can be made to maintain
  - Bracing
    - Following serial casting, Orthotist can cast and make AFO, elbow splints
    - OTS vs. custom
    - Gutter splints or custom orthotics can be made for UE joints
  - Wearing schedule

Medical Management of Spasticity

- Early interventions:
  - Don't be afraid to advocate for and be aggressive with treatments
    - Average onset of spasticity following injury in DoC
      - first 4 weeks
      - Can you maintain ROM, prevent loss?
  - Botox/phenol injections combined with serial casting positioning, and splinting
    - Initiating consults!
  - Baclofen pump placement [2]
    - Expert panel opinion:
      - When spasticity interferes with comfort, function, activities of daily living, mobility, positioning, or caregiver assistance, patients should be considered for intrathecal baclofen (ITB) therapy.
- Medication management
  - Don’t forget!
    - Sedating side effects- manage pros/cons

Family Education and Involvement

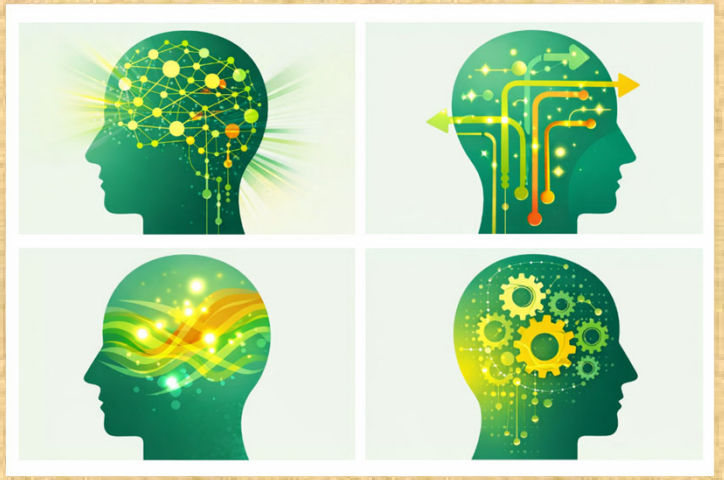
- Support as active participant in rehabilitation
  - Educate re: dysautonomia and removal of stimulation
  - Training re: care routines, ROM, multisensory interventions
- Gain insights into individual preferences and interests
- Help them to remain well-informed as they are faced with many decisions
- Education regarding financial and legal assistance, community resources, and long-term planning

Kason

- 18 y/o. MVA the day after HS graduation
- Admitted to Post-Acute Brain Injury Rehabilitation 6/11/2020
- 2.5 months in DoC
- Used OWL scale to establish emergence (EMCS)
- Severe aphasia and apraxia
- Discharged March 5, 2021
- Continued outpatient rehab close to home
- Intensive outpatient aphasia program- Florida

- Currently:
  - Attending college for music therapy
  - Ran varsity cross country
    - Won a national award "The Battle's Won Comeback award" 2022
  - Performing/singing in college choir

References



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