

A Family Caregiver Guide to Selecting Rehabilitation Programs for Persons With Disorders of Consciousness (DoC)

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<https://msktc.org/tbi/factsheets>

TBI Factsheet

This factsheet explains the medical and rehabilitation care needs of persons with disorders of consciousness (DoC). It discusses the questions to ask when searching for the right program for your loved one with a DoC.

The Traumatic Brain Injury Model System Program is sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research, Administration for Community Living, U.S. Department of Health and Human Services. (See <https://msktc.org/tbi/model-system-centers> for more information).

Background and Overview

This factsheet is intended for use by family caregivers of persons with DoC. This may include family members, partners, friends, or other caregivers. A person with DoC is not aware of their own self or surroundings. They can't stay awake or interact with others. DoCs include coma, unresponsive wakefulness syndrome (also called the vegetative state), and the minimally conscious state. A detailed description of these conditions and the recovery that follows can be found at <https://msktc.org/tbi/factsheets/facts-about-vegetative-and-minimally-conscious-states-after-severe-brain-injury>.



After a severe traumatic brain injury (TBI), a person may have a DoC that lasts a long time. If your loved one has a DoC but is ready to leave the hospital or acute care unit, they will still need close monitoring and expert care. As a family caregiver, you are an important part of the care team. Family caregivers should be involved in all phases of care and discharge planning.

Persons with DoC may benefit from rehabilitation, also sometimes called rehab. But, not all rehab programs are a good fit for persons with DoC. Some programs don't have the skilled staff, knowledge, or services needed to provide quality care to your loved one. A lack of expertise may lead to inappropriate care decisions and poor outcomes.

A group of expert clinicians and researchers from the American Congress of Rehabilitation Medicine and the TBI Model Systems specializing in DoC developed recommendations for programs that provide rehab to persons with DoC. The recommendations are based on evidence from research, best practices, and expert agreement. They may help you learn what is needed to best manage your loved one's care needs. This factsheet can help you find the right rehab program for your loved one with a DoC. It can help you figure out whether a specific program may meet your loved one's needs. The sections that follow cover the topics: Rehab Program Staff, Rehab Program Goals, Caregiver Training and Support, and Getting Ready for the Next Level of Care.

I. Rehab Program Staff

The care team should include experts from a range of healthcare specialties. A doctor (internist, hospitalist, or attending physician) should be on-site at least 5 days a week. When they aren't on-site, there should be an on-call



provider available to care for patients. For patients on ventilators, a pulmonologist (lung specialist) should also be available on-site. The program should have a way to get timely consults from experts who are not on-site. The care team on site should also include (but may not be limited to):

- A rehab physician
- A nurse
- A respiratory therapist
- A nutritionist
- A physical therapist
- An occupational therapist
- A speech-language pathologist
- A neuropsychologist or a psychologist
- A case manager or social worker
- A spiritual support person

II. Rehab Program Goals

The program should focus on overall goals of evaluating level of consciousness, promoting health and well-being, enhancing recovery, and monitoring for changes in level of function. Family caregivers should be involved in all phases of rehab goal setting.

A. Evaluation

To determine level of consciousness in patients with DoC, programs should use procedures designed for persons with DoC and recommended in clinical practice guidelines. There are rating scales designed to determine a person's level of consciousness. Current guidelines recommend using rating scales repeatedly over a period of days or weeks to establish a correct DoC diagnosis.

Family caregivers may want to ask:

1. Will the evaluation process include rating scales designed for persons with DoC? If so, how often will they be given?

Recommended rating scales include:

- The Coma Recovery Scale-Revised (CRS-R)
- The Sensory Stimulation Assessment Measure (SSAM)
- Wessex Head Injury Matrix (WHIM)
- The Sensory Modality Assessment and Rehabilitation Technique (SMART)
- The Western Neuro Sensory Stimulation Profile (WNSSP)
- Disorder of Consciousness Scale (DoCS-25)

If rating scales are used, the evaluation should be repeated to avoid misdiagnosis.

2. What types of behaviors are evaluated by rating scales for persons with DoC?

- The ability to stay awake, pay attention, and follow directions (cognitive function)
- The ability to understand and communicate in any way possible (language function)
- The ability to move the body (motor function)
- The ability to see, hear, and feel (sensory function)
- The way the environment affects behavior (noise, temperature, lighting, time of day)

3. What other information and tests will the program use to determine level of consciousness?

The program should also use information from other sources to help determine level of consciousness. This includes results from recent tests of the brain, such as CT scans, MRIs, and EEGs.



B. Promoting Health and Well-Being

The program should use procedures to help maintain your loved one's general health, address problems that may arise, and promote overall health and well-being.

Strategies to Maintain General Health

The following procedures can help maintain overall health and level of function:

- Repeated evaluation of the lungs, skin, bones, muscles, bowel, bladder, and sleep pattern.
- Ongoing review of medicines. Medicines should be reviewed often. The program should take steps to reduce or stop medicines that can cause drowsiness and slow recovery.
- The program should review patients' care routines and body systems on a regular basis. This can help to quickly find and treat common problems such as infections, seizures, or hydrocephalus (a build-up of fluid on the brain).
- The program should have procedures (e.g., positioning schedules, passive range of motion) to help prevent problems that can occur due to lack of movement.
- The program should have procedures in place to quickly transfer patients to a nearby hospital for emergency care when needed.



C. Enhancing Recovery

While medicines, environmental management strategies, and assistive technologies may help support recovery, no treatment can cure a DoC. Treatment strategies may focus on:

- Staying awake during the day and sleeping through the night
- Reducing physical discomfort and distraction
- Moving around and performing self-care tasks (brushing their hair and teeth, washing their face, eating)
- Communicating (talking, writing, or use of gestures)
- Initiating and maintaining social interactions

Family caregivers may want to ask:

1. *What medicines does the program use to improve a patient's ability to stay awake and respond to directions and questions?*

- Amantadine hydrochloride can speed up the recovery process when given between 4 and 16 weeks after TBI in persons with DoCs. Clinical practice guidelines suggest that the program should consider this medicine unless your loved one's doctor thinks they should not take it based on medical reasons.
- Zolpidem may improve alertness and behavioral responsiveness in a small percentage of persons with DoCs. The program may consider this medicine unless your loved one's doctor thinks they should not take it based on medical reasons.
- When medicines are recommended, ask about the expected benefits and potential side effects. You may also want to ask how your loved one's doctor will know the medicine is working.



2. What steps does the program take to provide a safe, comfortable environment and reduce physical discomfort and distraction?

The program should change the patient's environment to help with rehab efforts. For example, the program can:

- Make sure your loved one is positioned comfortably in the bed or wheelchair
- Reduce bright lights and distracting noises
- Make sure the room is not too hot or cold
- Remove splints, braces, or other physical restraints that may make it hard to move



3. What types of technologies do you use to help with communication and make it easier to initiate and maintain social interaction?

Programs should have a process in place to find out if an assistive device may help your loved one. Programs should also have a process to help select the best device based on your loved one's needs and abilities. Such devices may be high tech or low tech. Examples include:

- Switches and touch pads
- Picture or letter boards
- iPads and tablets
- Paper and pencil or dry-erase boards
- Eye-tracking systems (computer systems that track eye movements to assist with communication and environmental control)



D. Monitoring for Changes in Level of Function

The program should have a doctor or other provider on staff with relevant knowledge, training, and experience to determine and communicate information about a person's level of consciousness and potential for recovery. The DoC practice guidelines include factors that have been used to predict recovery. You can find a family-friendly version of these guidelines at: <https://www.aan.com/Guidelines/home/GuidelineDetail/926>.

The program should monitor your loved one's response to treatment efforts and progress over time. The program should also monitor program performance and your needs as a family caregiver.

Family caregivers may want to ask:

1. How and when will information about my loved one's diagnosis and potential for recovery be shared with the family?

- Shortly after admission to the program, a care plan meeting should be held to provide information about your loved one's current level of consciousness, rehab goals and expected length of stay in the program.
- Discussions should address the questions and outcomes that you feel are most important.
- The program should give you updates any time there is a change in your loved one's clinical status that results in a change in the treatment plan or rehab goals.
- The program should give you clinical information in language that is easy to understand.

2. How will you know if the treatment efforts are working?

- The program can use the rating scales specially designed for persons with DoC (CRS-R, SSAM, etc.) to monitor treatment response and progress over time.
- The care team should meet regularly to consider whether changes in the treatment plan are needed.



3. How does the program evaluate its success overall? Does the program have reports they can share?

You may be able to obtain information about the outcome measures used and program performance. Examples include:

- Scores or information about the program's performance on behavior rating scales
- Benchmarks or criteria used to determine the length of stay in the program
- Data or information about overall program performance
- Data about how many DoC patients were admitted to the program in the last year and where they were discharged to
- Information about how the program meets family caregivers' needs



4. What type of education and training activities are provided for staff involved in the care of persons with DoC?

The program should provide ongoing education and training for staff to help make sure they are skilled in evaluating, treating and measuring changes over time.

III. Information, Training and Support Services for Family Caregivers

The program should provide tailored education, hands-on training, and individual or group support to family caregivers. The program should also offer guidance to help family caregivers deal with ethical questions that may come up during treatment.



Family caregivers may want to ask:

1. Are educational materials and hands-on training available to family caregivers?

The program should address:

- Tools and resources to improve your knowledge about DoC and common care needs
- Financial matters related to insurance and long-term care planning
- Hands-on training so you can understand and take part in in everyday care when needed. This may include how to perform basic stretching, turning, and positioning; and how to interact with your loved one.

2. What kind of social, financial, and legal support services are available through the program? Is there someone available who I can talk to about finding community-based programs and resources?

The program should provide support services to family caregivers. This should include information and help finding:

- Community-based social support services, programs, and resources
- State and community-based agencies to help with legal and financial needs



3. Who do I talk to if I have concerns about the care my loved one is getting and the providers responsible for administering care?

The program should have a process in place to help family caregivers if concerns or differences in opinion arise with the care plan, treatment team, or program.



IV. Getting Ready for Your Loved One's Move to the Next Level of Care (Facility or Home)

The care team should help you understand why your loved one may need a transition to a different level of care (more or less intensive care setting). They should also talk to you about the options that may be available.

Family caregivers may want to ask:

1. How often will the team meet with the family to talk about progress, future care needs, and discharge options?

Periodic meetings should be held with the team and family caregivers to discuss your loved one's care plan, progress, transition, and discharge options.

2. How will program staff know when my loved one is ready to move to the next level of care?

- Your loved one may eventually be ready to take part in rehab activities that require more active participation. This may be the case if they improve in their ability to communicate clearly and interact with others.
- Sometimes results from assessment and treatment suggest that a patient may not improve or may improve more slowly. In this case, a move to a less intensive setting with a focus on maintaining general health, supporting slow recovery where possible, and maximizing quality of life may be best.



3. When it is time to move to the next level of care, what information should be passed on to other health care providers and family caregivers to support ongoing care needs?

Information that can help support the next level of care includes:

- Current level of consciousness.
- Level of help needed to take care of basic care needs. This includes the number of people and hours needed to help with eating, using the toilet, and grooming. This also includes level of supervision needed to keep your loved one safe.
- Likelihood of further improvement in physical and mental abilities.
- Active health problems and treatments.
- Current medicines.
- Equipment needs.
- Caregiver education and training needs.
- Recommendations for follow-up (when, where, who).

More Resources on Severe TBI and DoCs

American Congress of Rehabilitation Medicine. (n.d.). *Publications*.

<https://acrm.org/publications/>

CARF International. (2022). *CARF® accreditation focuses on quality, results*. <http://www.carf.org/home/>. This website includes consumer resources that may help you assess the quality of a program's services and decide if any given rehab program is a good fit for those with severe TBI.



Giacino, J. T., Katz, D. I., Schiff, N. D., Whyte, J., Ashman, E. J., Ashwal, S., Barbano, R., Hammond, F. M., Laureys, S., Ling, G. S. F., Nakase-Richardson, R., Seel, R. T., Yablon, S., Getchius, T. S. D., Gronseth, G. S., & Armstrong, M. J. (2018, August 8). Practice guideline update recommendations summary: Disorders of consciousness. *Archives of Physical Medicine and Rehabilitation* (99)9, P1699–1709.

<https://doi.org/10.1016/j.apmr.2018.07.001>. Factsheet for family caregivers that includes a summary of practice recommendations for diagnosing and providing care to persons with DoCs. These guidelines include factors that have been used to predict recovery.

Model Systems Knowledge Translation Center. (2017). *Severe traumatic brain injury*.

<https://msktc.org/tbi/factsheets/Severe-Traumatic-Brain-Injury>. Consumer factsheet about what to expect for your loved one's care in the first days and weeks after the injury. Also includes suggested questions to ask, information about care options, and tips on how you can help support your loved one's recovery.

Model Systems Knowledge Translation Center. (2020). *Facts about the vegetative and minimally conscious states after severe brain injury*. <https://msktc.org/tbi/factsheets/facts-about-vegetative-and-minimally-conscious-states-after-severe-brain-injury>. Booklet designed for families that describes each of the DoCs that can occur after brain injury. Also includes information about patterns of recovery, moving to different levels of care and advice on what to look for when choosing a place of care for your loved one.

Authorship

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