

Disorders of Consciousness



ACRM



The American Academy of Neurology, or AAN, is the world’s largest association of neurologists and neuroscience professionals and is dedicated to promoting the highest quality patient-centered neurologic care. Neurologists are doctors who identify and treat diseases of the brain and nervous system.

Experts from the AAN, American Congress of Rehabilitation Medicine, or ACRM, and the National Institute on Disability, Independent Living, and Rehabilitation Research, or NIDILRR, carefully reviewed the available scientific studies on diagnosing and caring for people with disorders of consciousness, or DoC. This guideline looked at the evidence mainly for people with a DoC lasting 28 days or longer.

The following information is a summary of the evidence from those studies and other key information.

Overview

Consciousness is a state of being awake and aware of one’s self and surroundings. A conscious person is aware of things through thoughts and the five senses: sight, hearing, smell, taste, and touch. A person with a DoC has trouble being awake, or being aware, or both.

Some people with a DoC might benefit from available tests and treatments. For them, an incorrect diagnosis can lead to inappropriate care decisions and poor health outcomes.

People who have had a DoC for 28 days or longer after a brain injury need ongoing specialized health care provided by experts. For these patients, health outcomes differ greatly. Some of these people may be permanently unconscious. Many will have severe disability and need help with daily functions. Others will eventually be able to function on their own, and some will be able to go back to work.

Causes of DoC

A person can have a DoC because of a severe brain injury. This is an event that causes serious problems with the brain’s ability to sense, understand, and respond to the person’s internal feelings and surroundings.

There are two main types of severe brain injury:

- Severe brain injury from trauma—This happens because of physical injury. Examples are falls, car accidents, and head injuries in sports.
- Severe brain injury from disease or illness—This happens when a health problem affects important systems in the body. This sometimes limits or stops oxygen from reaching parts of the brain. Examples of these health problems are difficulty breathing, heart attack, stroke, and brain bleed.

Diagnosing DoC in Adults

Diagnosing a DoC accurately can be difficult. But an accurate diagnosis early after the brain injury is very important. It may help to understand better what care your loved one needs and what health outcomes to expect over time.

To get the correct diagnosis, the clinician should do a thorough evaluation. Then, the clinician should repeat the evaluation several times early in recovery—especially during the first three months after brain injury.

In fact, evaluations should be repeated until your loved one’s condition becomes stable. Then, your loved one’s condition should continue to be retested and watched over time.

Predicting Health Outcomes for DoC in Adults

This guideline looked at the evidence mainly for people with a DoC lasting 28 days or longer after a brain injury. For these people, health outcomes differ greatly.

Some people with DoC will never recover or will recover only a basic level of conscious awareness. An example of basic awareness is when someone is only able to hold eye contact with other people in the room.

Some of those who are severely disabled early after injury and need some help daily will regain some ability to function normally. This includes being able to communicate, do self-care activities, and interact with others.



Guideline Findings for What Predicts Recovery

Some characteristics of DoC help predict better or worse recovery over time. This information is based on moderate evidence:

- A person in a minimally conscious state, known as MCS, has a better chance of recovery than a person in a vegetative state, known as VS.
- A person with a brain injury from trauma has a better chance of recovery than a person with a brain injury from another cause.
- A person who has been in a DoC for a longer time has a smaller chance of recovery than a person who recently had a brain injury.

For DoC linked to any cause, there is a low level of evidence for these findings:

- A better chance of recovery one year after brain injury with MCS diagnosis than with VS/UWS diagnosis.
- A higher risk of disability that gets worse over time when VS/UWS lasts longer than one year.

For information on the AAN's levels of evidence, see the Key to Evidence Levels at the end of this summary.

Severe Brain Injury from Trauma

For people with this DoC type, most will recover consciousness but will have severe disability. They will continue to need help from others for basic activities such as dressing and eating.

Approximately one person in five will recover to the point that they can live at home and care for themselves without help.

Planning for Possible Long-term Disability

It can be difficult to hear that a loved one with a DoC will likely have severe disability going forward. If this is the case for your loved one, be sure to get help with long-term planning.

Talk with the care team about how to get help with these tasks:

- Completing a health directive.
- Receiving guidance in applying for disability benefits.
- Starting to plan for estate needs, caregiver help, and long-term care.

Whether or not disability is likely, be sure to tell the care team early on what your loved one would want for ongoing health care. That information can guide your decisions with the care team.

Managing the Care of a Person with a DoC

There are rehabilitation programs that offer specialty care for people with a DoC. Be sure to talk with your loved one's clinician about the benefits of these programs and whether insurance covers them.

Very few treatments for DoC have been carefully studied. There is moderate evidence that the medicine amantadine can help speed up recovery of function when taken one to four months after injury. This evidence applies only to people in MCS or VS/UWS caused by trauma.

Some people with DoC have health conditions that will not allow them to try amantadine. Also, the evidence is unclear about whether this treatment improves health outcomes over time. Check with the care team to see whether this treatment is appropriate for your loved one.

Few treatments for DoC have been carefully studied. Thus, clinicians will sometimes try treating the person with therapies that the US Food and Drug Administration has not approved for use. All treatments have risks and can cause harm. Be sure to discuss treatment options and risks with experts who know how to care for people with DoC.

Often, the condition of a person with DoC improves early in recovery. It can be impossible to know whether the person's condition improved because of specific treatments or as part of the normal recovery process.

Children with DoC Lasting 28 Days or Longer

As with adults, children with a DoC lasting 28 days or longer need an accurate diagnosis to get the right care. To get the right diagnosis, the clinician should do a careful evaluation. The evaluation should be repeated several times early in your child's recovery.

It is not known how much recovery can be expected for children with a DoC lasting 28 days or longer. There is not enough evidence available to help clinicians predict specific health outcomes for individual children.

Also, there are no therapies with enough evidence showing that they help children with DoC.

More research is needed to understand better how to predict health outcomes and treatment of children with DoC.

If you have a child with a DoC, make sure you discuss the available options with the care team early in the recovery process.

Table: Terms Related to DoC

DoC	Definition
Coma	A state of being completely unconscious. The person is not awake, and the eyes remain constantly closed. Also, there is no behavior suggesting the person is aware of self or surroundings.
Vegetative State, or VS Unresponsive Wakefulness Syndrome, or UWS Post-coma Unawareness, or PC-U	A state of being awake, with eyes open, and of not showing signs of behavior suggesting the person is aware of self or surroundings.
Persistent Vegetative State, or PVS	A VS or UWS that lasts for more than a month.
Minimally Conscious State, or MCS	A state in which the person has definite signs of behavior showing awareness of self or surroundings. Often, these behaviors may not be obvious or may not happen regularly.
Emergence from MCS, or EMCS	A state where the person can communicate in a way that can be understood. Or the person can recognize and use familiar objects. <ul style="list-style-type: none"> To show communication, the person can answer yes or no to questions. The answers may be said aloud, written down, or shown with movements. Examples of these movements are head nodding or shaking, or thumbs pointing up or down. The answers must be correct and consistent when repeated. For object use, the person can show that he or she knows how to use at least two different everyday objects, such as a cup or a comb.
Recovery of Consciousness	A change in behavior that clearly shows the person is recovering awareness of self or surroundings. Recovery of consciousness happens when the health status of someone in a coma or VS/UWS improves to MCS.

To read the full guideline, visit AAN.com/guidelines.

This practice guideline update was co-developed by the American Congress of Rehabilitation Medicine and the National Institute on Disability, Independent Living, and Rehabilitation Research. The guideline was endorsed by the American Academy of Physical Medicine and Rehabilitation, by the American College of Surgeons Committee on Trauma, and by the Child Neurology Society.

With the mission of improving lives of those with disabling conditions through interdisciplinary rehabilitation research, the American Congress of Rehabilitation Medicine curates and disseminates world-class rehabilitation research: in person at ACRM.org/meetings; in print at ARCHIVES-PMR.org; and online at ACRM.org.

NIDILRR is the federal government’s primary disability research agency. NIDILRR’s mission is to generate new knowledge and to promote its effective use to improve the abilities of individuals with disabilities to perform activities of their choice in the community, and to expand society’s capacity to provide full opportunities and accommodations for its citizens with disabilities.

<p>Key to Evidence Levels</p> <p>After the experts review all of the published research studies, they describe the strength of the evidence supporting each recommendation: Strong evidence = Future studies very unlikely to change the conclusion Moderate evidence = Future studies unlikely to change the conclusion Low evidence = Future studies likely to change the conclusion Very low evidence = Future studies very likely to change the conclusion</p>
<p>This document is a summary of the American Academy of Neurology (AAN), American Congress of Rehabilitation Medicine (ACRM), and the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) co-sponsored practice guideline “Disorders of Consciousness.”</p> <p>This research was supported through a memorandum of understanding between the AAN, ACRM, and NIDRR. In 2014, NIDRR was moved from the US Department of Education to the Administration for Community Living of the US Department of Health and Human Services (HHS), and was renamed the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). This article does not reflect the official policy or opinions of NIDILRR or the HHS and does not constitute an endorsement by NIDILRR, the HHS, or other components of the federal government.</p>
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American Academy of Neurology, 201 Chicago Avenue, Minneapolis, MN 55415

ACRM, 11654 Plaza America Drive, Suite 535, Reston, VA 20190-4700. Phone: (703) 435-5335 | Fax: (866) 692-1619 | Email: info@ACRM.org

National Institute on Disability, Independent Living, and Rehabilitation Research, US Department of Health and Human Services, Administration for Community Living, 330 C Street Southwest, Washington, DC 20201

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