The Catatonia Foundation

INFORMATION ABOUT CATATONIA

HOPE. RECOGNITION. RECOVERY.

WHAT IS CATATONIA?

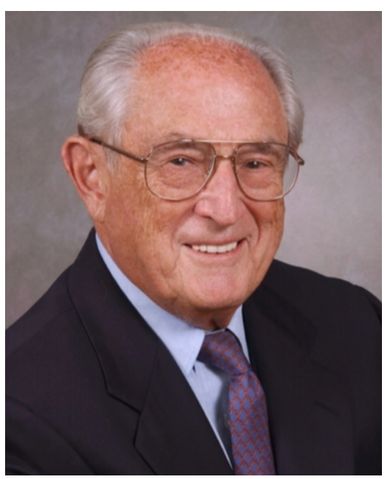
Catatonia is a severe neuropsychiatric syndrome that involves disturbances of movement, speech, behavior, and volition. It may also affect mood, emotions, and autonomic functions (e.g., breathing, heart rate, blood pressure). Catatonia can occur in the context of psychiatric, neurologic, or general medical conditions. If not identified and treated appropriately, it carries a high risk of serious complications and sometimes death.

WHY TIMELY DIAGNOSIS MATTERS

- ***Effective treatments exist.*** Lorazepam and electroconvulsive therapy (ECT) can bring rapid improvement.
- ***The wrong treatment can make things worse.*** Antipsychotic medication may aggravate catatonia.
- ***Delays are dangerous.*** When diagnosis or treatment is delayed, catatonia may become harder to treat. In severe cases, the risk of medical complications or death may rise.

"Any physician who recognizes catatonia has an effective treatment in his hands. And so I would say catatonia is a treatable syndrome."

—Max Fink, M.D., world-renowned catatonia expert with a career spanning more than 65 years. Dr. Fink has published extensively on the topics of catatonia and ECT, and has received numerous awards for his research.



HOPE FOR PATIENTS, FAMILIES, AND CAREGIVERS

The Catatonia Foundation was created by five individuals whose family members or friends suffered with severe symptoms of catatonia and struggled to get a proper diagnosis and access to effective treatment. If Jeff, David, Anja, and Alyssa had not received accurate diagnoses and optimal treatment, the outcomes could have been tragic. Two would likely have died and two would not have been able to care for even their basic needs. Yet their stories have hopeful endings—they are all thriving.

Our wish is that these stories inspire hope—and that our website gives you the tools and resources to help you navigate a complex medical system for better outcomes. You may be searching for information, looking for guidance from people who have been there, or feeling overwhelmed and scared. Our comprehensive website brings together what we wish we had when our loved ones were suffering—relevant and up-to-date information all in one place. It includes the current understanding of diagnosis and treatment, valuable resources, practical advocacy tips, and a growing list of patient-recommended providers experienced in treating catatonia.

Hope, for us, doesn't mean denying the difficulties or expecting every outcome to be the same, as each case of catatonia is unique. It means carrying the light forward for everyone still struggling, through education, advocacy, and connection. Each diagnosis, each informed clinician, each supported researcher brings us closer to a world where recovery from catatonia is the rule, not the exception. Progress happens because people who care refuse to give up. That's the heart of The Catatonia Foundation.

FEATURES AND PRESENTATIONS

Catatonia can affect movement, speech, behavior, and emotion. It may develop gradually or emerge suddenly, and its features can change over time.

Common features include:

- ***Movement changes:*** immobility or rigidity, unusual postures, repetitive or purposeless movements, or sudden agitation without clear cause
- ***Speech and behavior changes:*** minimal or absent speech, repeating others' words or actions, social withdrawal, or reduced eating and drinking
- ***Emotional and physical changes:*** flat or inconsistent affect, ambivalence, or changes in heart rate, blood pressure, or temperature

Patterns of presentation:

- ***Stuporous:*** immobility, mutism, and withdrawal
- ***Excited:*** restlessness, agitation, or impulsive movements, sometimes echoing words or gestures
- ***Mixed:*** alternating between excited and stuporous states
- ***Malignant:*** fever and autonomic instability—this is a life-threatening emergency requiring immediate medical care

In autism and in youth:

- In autism and other neurodevelopmental conditions, catatonia may appear as regression, loss of skills, self-injury, or aggression, and is often mistaken for the underlying condition.
- It can also occur in children and adolescents without autism but remains frequently underrecognized.

HOW PHYSICIANS DIAGNOSE CATATONIA

Diagnosis requires a careful systematic assessment, which typically includes:

- ***Medical and psychiatric history —*** medications, substance use, recent illness
- ***Family and caregiver input —*** observed changes from baseline and symptom patterns over time often provide important information
- ***Neurological and physical examination —*** to assess motor signs and rule out other medical or neurological causes
- ***Laboratory or imaging studies —*** when needed to rule out medical causes

Structured screening tools can help support the diagnosis:

- ***Catatonia Quick Screen (CQS):*** A brief tool assessing four features—excitement, mutism, staring, and posturing. A positive finding on any one of these suggests possible catatonia and warrants a full assessment.
- ***Bush-Francis Catatonia Rating Scale (BFCRS):*** A checklist of 23 signs. The first 14 are used for screening; the presence of two or more signs is generally considered a positive screen. From there, all 23 signs can be rated to measure severity and track changes over time (The rating scale and resources to help you understand it are on The Catatonia Foundation's website).
- ***Lorazepam Challenge:*** A small test dose of lorazepam is given. Rapid improvement strongly suggests catatonia, though a lack of response does not rule it out. The test is generally safe, inexpensive, and easy to perform.

TREATMENT

- ***Benzodiazepines:*** This class of medication is often the first treatment tried, and many patients experience improvement. Lorazepam is most commonly used, though other benzodiazepines are also prescribed.
- ***Electroconvulsive therapy (ECT):*** Highly effective, generally safe, and often life-saving.
- ***Other options:*** Certain medications—such as amantadine, memantine, or zolpidem—have been reported to help in some cases.
- ***Antipsychotics:*** These medications have been reported to worsen catatonia, though they are sometimes given (with caution) when another psychiatric condition is present.
- ***Ongoing care:*** Some patients need continued treatment, either with benzodiazepines or maintenance ECT, to prevent relapse.

WHAT FAMILIES AND CAREGIVERS CAN DO

Families are often the first to notice changes. Recognizing catatonia early and speaking up can make a real difference in getting timely, effective treatment.

1. Notice and record changes

- Watch for sudden shifts in movement, speech, affect, or behavior (e.g., uncharacteristic, stupor, withdrawn, agitated).
- Record brief notes or short videos capturing observations.
- Familiarize yourself with the BFCRS to help recognize signs so you can share clear observations.

2. Communicate with clinicians

- Share your notes and videos with the treating physician.
- Bring this brochure or direct them to The Catatonia Foundation website for resources.
- Tell the clinician if symptoms fluctuate with stress, illness, or medication changes—these factors may influence symptoms.
- If relevant, mention any history of trauma, which can sometimes play a role in the onset or worsening of catatonia.

3. Advocacy

- Advocacy can be difficult, but it often makes the difference in getting the right care.
- Speak up if your concerns are dismissed, if catatonia isn't being considered, or if treatment is delayed.
- Ask (if relevant) whether a catatonia expert can be consulted.

4. Know when it's urgent

Catatonia can become a medical emergency. Seek immediate help if your loved one:

- Refuses food or fluids
- Has sudden or unexplained changes in vital signs
- Becomes severely agitated, aggressive, or self-injurious
- Rapidly alternates between stupor and excitement

5. Understand barriers

Recognizing the barriers to diagnosis and treatment will help families understand why catatonia may be missed, share accurate information, and be informed and strong advocates.

- Catatonia remains underrecognized in medical education and practice.
- Limited expertise and overlapping symptoms can delay diagnosis.
- Stigma and misconceptions about catatonia and the use of lorazepam and ECT can further delay appropriate care.

OUR COMMITMENT

The Catatonia Foundation is a 501(c)(3) nonprofit dedicated to ending needless suffering and death from catatonia through:

- **Awareness and education** for medical professionals and the public
- **Advocacy and support** for patients, families, and caregivers
- **Research collaboration** to improve diagnosis and treatment

We update our materials as new knowledge emerges and collaborate globally with clinicians, researchers, and advocates to advance care and understanding (More resources for families, caregivers, and clinicians are available on our website).

The Catatonia Foundation has a clear and urgent vision—No one's life should be lost to catatonia.

WAYS TO SUPPORT THE FOUNDATION

Many families tell us, *"I don't want anyone else to go through what we went through."* That's why The Catatonia Foundation exists—and why your support matters.

Here's how you can help:

- ***Share your story —*** whether it's recovery or struggle, your experience highlights the need for better awareness, education, research, and care
- ***Spread the word —*** tell others about catatonia and our resources
- ***Volunteer your skills —*** outreach, design, peer support, fundraising, leadership, nonprofit
- ***Donate or fundraise —*** your contribution helps advance our goals (awareness, education, support, advocacy, research) so families and clinicians have the tools they need to improve understanding and outcomes

Together, we can make sure no family faces catatonia alone.

The Catatonia Foundation
thecatatoniafoundation.org
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