

Catatonia in Autism



WHAT FAMILIES AND CARE PARTNERS NEED TO KNOW

What is Catatonia?

Catatonia is a serious but treatable condition that affects movement, speech, behavior, and autonomic functioning (breathing, heart rate, temperature regulation). Often linked to mental health disorders, catatonia can also affect people with autism—and it's more common than you might think.

Up to **10%** of autistic individuals may experience catatonia symptoms at some point across their lives



Features of Catatonia in Autism

- Catatonia in Autism can show up gradually or all at once
- Symptoms may come and go
- There are two forms: Hypokinetic (Shutdown) and Hyperkinetic (Excited)*
**People may alternate between these two states (mild-extreme stillness to mild-extreme agitation)*



Watch for and note the following changes, especially if they present as a loss of previously acquired skills:



HYPOkinetic

- Movement – “freezing”, moving very slowly, or requiring prompting to move
- Trouble crossing thresholds or completing physical movements
- Staring or fixed gaze*
- Mutism or reduced speech/communication*
- Refusal to eat/drink, eating with hands, requiring significant encouragement to eat/drink
- Loss of self-care/daily living skills
- Social withdrawal
- New or worsening urinary incontinence*

HYPERkinetic



- Echolalia, Echopraxia* (echoing others' words or movements) - new onset
- Repetitive/purposeless movements* (increased or new onset)
- Posturing - holding body in unusual positions
- Nudism* (removing clothes)
- Agitation/Restlessness*
- Aggression/Self Injury*
- New or worsening urinary incontinence*

*Autism symptom overlap

In rare cases, catatonia can become life-threatening (called Malignant Catatonia) with high fever, rapid heart rate, and trouble breathing. This is a medical emergency!

Catatonia in Autism

Diagnosis and Treatment - It takes a TEAM effort

Catatonia in autism is often misinterpreted because its symptoms can look like baseline features of autism. The key is to determine whether symptoms are **new** or **different** from the person's **baseline**, or usual, behaviors.

Family/Care Partner Role

- Document symptom triggers and fluctuations
- Provide medical records, developmental history, past standardized test results, therapy notes
- Share home videos that show your family member walking, eating, doing daily activities
- Report changes you've seen - what could they do before the change that they can't do now?

Patient

Clinical Team Role

- Rule out medical causes of symptoms
- Collaborate with family/care partners to estimate patient baseline
- Coordinate with providers across disciplines to ensure best care
- Use standardized catatonia rating scales such as the Bush-Francis Catatonia Rating Scale (BFCRS)

Treatment Options

Treatment usually involves a combination of approaches tailored to the individual:

- **Lorazepam Challenge Test (LCT):** A trial of anti-anxiety meds (like lorazepam). If it helps, that's a clue it may be catatonia.
- **Environmental Supports:** Reduce stress, provide structured routines, offer gentle prompts.
- **Electroconvulsive Therapy (ECT):** Safe, effective, and often life saving for treatment-resistant cases.

Resources and Support

Most people have never heard of Catatonia in Autism, but awareness can make all the difference! These resources may help you talk with your family member's care team:

- The Catatonia Foundation - [Medical Advocacy Tips](#)
- SPACES - [Catatonia in Autism Webinar Series](#)
- Parent Advocacy groups offer information and support. Connecting with people who share similar experiences can help you navigate challenges, find solutions, and feel less alone.

One last thing: YOU know YOUR loved one best. If something seems off, trust your instincts and speak up. Ask your doctor: "Could this be catatonia? Can we try the Lorazepam Challenge Test?"