The Catatonia Foundation

No one's life should be lost to catatonia

The Catatonia Foundation: Insights and Impact

Advancing understanding, changing outcomes.

Harry's Journey: As Told by His Mother

I'm Rebecca Sparrell, the most recent member of The Catatonia Foundation's Board of Directors. I joined because this organization's mission is personal to me.

My son Harry began experiencing catatonia in April 2025 at six years old. We brought him to a Boston-based children's hospital, and for the next several months there were more questions than answers.

In the video below, Rebecca shares what her family observed, experienced, and struggled to understand as Harry's condition unfolded.

After watching, please return to the newsletter to read the lessons that helped Harry's family advocate for him—and that may help other families navigating catatonia.

These are some of the lessons I learned throughout this process.

Speak up

I disagreed with the medical team when things didn't sound right, even if it felt uncomfortable. I didn't always do it perfectly, but each time it brought us somewhere better. One of the pediatricians told us matter-of-factly that we needed to consider schizophrenia, despite Harry not having any history of psychiatric issues as well as the fact that six years old is unthinkably young for such a diagnosis. I spoke up, and this led to us being assigned a complex care team which helped us focus our efforts with a consistent team instead of different doctors every day.

Thankfully, there were doctors at the hospital who have experience with catatonia and were quick to refute the dramatic diagnosis casually thrown out by the pediatrician, but this experience speaks to a lack of understanding of catatonia among many doctors, even in one of most respected children's hospitals in the country. We need to increase awareness for medical practitioners so that catatonia is better recognized, quicker to be treated, and not dismissed as mental illness. Without awareness, some people remain catatonic for far too long.

Build a compelling backstory about your loved one

Harry's catatonia resembled profound autism, and it was like he had lost his many skills overnight. It was important for us to make sure that the doctors understood his baseline skills, and we wanted something more objective and compelling than our words. We happened to have a video taken with my phone a few days before Harry became catatonic, and we also pulled up older videos that showed his extensive language and vibrant personality. These videos were extremely helpful in helping doctors understand who Harry had been before becoming catatonic. Consider what you could use to help build a case for who your loved one really is to show how impacted they are by catatonia. If there isn't something readily available in your phone, perhaps there is a video in your loved one's phone or on their social media page.

Ask for help

Now I can look back and see that, despite it being such a challenging time, we essentially had everything going for us. We were in Boston, arguably one of the best places in the world for medical care. We were able to shift our jobs temporarily to support our son: my husband worked remotely, and I took a leave from my position. We both speak English, which meant there was no language barrier with the medical team. We were local, which meant that our friends and family were able to visit and support us, and we were also able to take breaks to go home, do laundry, and sleep in our own bed. We are educated and not intimidated to communicate with doctors. We could ask for clarity when we didn't understand and make suggestions to discuss with them. Despite having everything going for us, it was the hardest thing I've ever been through, mainly because navigating under such emotional weight was incredibly hard. Consider what you need to wage this battle for your loved one, and ask for what you don't have and need.

Reach out

I started an Instagram page to capture Harry's journey as a way to keep everyone in our lives updated on how he was doing, since there were so many people worried about him. I continued the page as a means to get feedback from and connect with others whose loved ones experienced catatonia, and ultimately this led to me being connected with The Catatonia Foundation.

Be open to possible solutions

In our case, the only treatment that helped Harry recover was electroconvulsive therapy (ECT). Initially, we were shocked at this being considered, but we just didn't know what we didn't know. Despite being misunderstood and having poor

representation in the media, ECT is a safe and effective treatment for catatonia. In Massachusetts it is only legal for children aged 13 and up, so we needed to secure permission from the state for this treatment, and Harry became the youngest person in the state to receive ECT. Everyone involved in Harry's care wrote letters on behalf of him, including us. Happily, ECT brought Harry back to us, and now he is his chatty, silly, precocious self again. It is important that medical professionals have an updated understanding of ECT and aren't letting its previous misconceptions and misuses cloud their judgment. Without ECT, Harry would likely still be trapped in catatonia.

Give yourself grace

When a loved one is struggling with a disease, it is incredibly hard. You are doing the hardest work of your life. Lean on the people who love you, accept their offers for help, take breaks whenever you can, and let go of anything that doesn't serve you during times of stress.

You can continue following Harry's journey on Instagram.

Last summer, Harry was practically non-verbal from catatonia. This photo shows Harry now, participating in a remote visit with his doctor, asking questions and sharing information

“Catatonia Doesn’t Happen in Children”
…Except It Does.

A persistent—and harmful—myth in psychiatry is that catatonia is an adult condition, or something seen only in severe adult psychosis. That belief alone can delay recognition and treatment in children and adolescents when they begin to show clear signs of catatonia.

The 2022 *CNS Spectrums* case series by Reinfeld and Gill* describes three adolescents whose catatonia was initially overlooked for different reasons.

The first case involves a 12-year-old girl initially thought to have depression or bipolar disorder. Further evaluation later revealed significant psychological bullying at school and sexual abuse by an unknown perpetrator. Despite an extensive neurological work-up, catatonia was not considered until clinicians observed a marked improvement in her symptoms following a dose of lorazepam—without the sedation that would typically be expected.

The second case describes a 15-year-old boy with a history of bipolar disorder, psychosis, and cannabis use. His unusual behaviors were attributed to psychosis, and prominent catatonic features were missed. As his condition worsened and progressed to malignant catatonia, antipsychotic medication was discontinued and oral lorazepam was initiated, leading to gradual clinical improvement.

The third case involves an 18-year-old young man with autism spectrum disorder who experienced a clear change from his baseline functioning during the COVID-19 pandemic. Although he exhibited multiple signs consistent with catatonia, treatment focused on managing hyperactivity. When lorazepam was eventually initiated, several of his symptoms resolved rapidly.

Across all three cases, catatonia was obscured by co-occurring diagnoses, trauma history, or neurodevelopmental differences—until changes from baseline and response to lorazepam revealed a unifying, treatable condition.

When clinicians assume catatonia does not occur in children or adolescents, they tend to explain new or worsening symptoms as part of something the patient already has—autism, trauma, mood disorder, psychosis, or “behavioral” change.

In these situations, the original diagnosis becomes the explanation for everything that follows. Changes in movement, speech, behavior, or functioning are not

recognized as signs of a new condition, even when those changes are severe or progressive. As a result, catatonia can remain hidden in plain sight.

This pattern—when a serious condition is missed because its symptoms are attributed to an existing diagnosis—is called diagnostic overshadowing. Reinfeld and Gill show how this process can delay recognition and treatment, allowing catatonia to worsen over time despite being treatable

There are several reasons why children/adolescents are especially vulnerable to diagnostic overshadowing:

1. Catatonia is under-recognized and under-taught in child and adolescent psychiatry.
Many clinicians receive little to no formal training in identifying catatonia in children and adolescents, including how it presents differently across developmental stages or how to treat it safely and effectively.

2. Children and adolescents—especially those that are neurodivergent—often cannot describe their internal experience.
Without self-report, recognition depends on careful observation of changes in movement, initiation, speech, and functioning. When those changes overlap with baseline diagnoses—they are easily misattributed.

3. Developmental and psychiatric diagnoses are often already present.
Autism, intellectual disability, trauma-related conditions, and early-onset mood or psychotic disorders increase vulnerability to catatonia. Yet these same diagnoses are frequently used to explain away its symptoms.

4. Systems are fragmented.
Treatment is often fragmented between schools, outpatient providers, emergency departments, inpatient units, and specialists. Without a unifying lens, no one may see the full pattern of decline.

Together, these factors create the perfect conditions for diagnostic overshadowing—where catatonia is present or worsening, but not recognized. This matters because when catatonia is recognized, there are effective treatments.

Reinfeld and Gill conclude that better education and training are urgently needed to improve how catatonia is recognized and treated—especially in children and adolescents.

Harry's story reminds us why this matters. Acute changes in functioning are not "just part of the diagnosis." They are signals. And when we assume catatonia doesn't happen in children or adolescents, we stop looking for it—often at great cost.

At The Catatonia Foundation, raising awareness means challenging outdated assumptions. Catatonia *does* occur in children/adolescents. And recognizing it can change outcomes.

*Reinfeld S, and Gill P (2022). Diagnostic overshadowing clouding the efficient recognition of pediatric catatonia: a case series. CNS Spectrums https://doi.org/10.1017/S1092852922001158

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Awareness grows person by person, share by share. You can make a meaningful difference by helping amplify this campaign:

- Share this email
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- Like and comment on our posts (this dramatically increases reach)
- Share our posts and/or add them to your Stories
- Invite friends, family, and colleagues to follow and engage as well

Every interaction helps extend accurate information to someone who may desperately need it—today or in the future.

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