

IMPORTANT: Akathisia is a life-threatening medication side effect that the majority of doctors admittedly know little about. It can make anyone instantly suicidal. If a loved one has asked you to read this, they are likely asking you to help them survive it.

What is akathisia?

Akathisia is an extremely distressing neurological disorder characterized by severe agitation, an inability to remain still, and an overwhelming sense of terror. These symptoms are so tortuous that it can lead to violence and suicide. Akathisia is primarily caused by prescribed medications. The most frequent offenders are antipsychotics, antidepressants, anti-nausea medications, and antibiotics, but it can be caused by many other medications as well. It is also common in benzodiazepine withdrawal (e.g., Ativan, Klonopin), especially after long-term use. It most often occurs when starting, stopping, or changing the dose of a medication, but it can occur at any time during treatment and even months after it is discontinued.

[Click here or scan this QR code to watch our short public service announcement:](#)



[Click here or scan this QR code to see a 38-second video illustration of akathisia:](#)



Symptoms

The following common symptoms of akathisia have been reported universally (regardless of whether it was caused by long-term use of a psychiatric medication or by one dose of a non-psychiatric medication):

- Intense physical restlessness with a need for constant movement such as pacing, rocking, foot tapping, hand wringing, and shifting position in a chair
- An overwhelming sense of terror, which has also been described as "chemical terror." This is so pervasive that the person actually feels as if they are experiencing a terrifying event such as being lit on fire or buried alive.
- A feeling often described as wanting to "jump out of my skin"
- Extreme agitation, impatience, and irritability
- Suicidal and/or violent impulses
- Nonsuicidal self-harm impulses (e.g., hitting, cutting)
- Depersonalization-derealization (feeling disconnected from the body, as if observing it from the outside, or a sense that the world is unreal, similar to living in a dream)
- Separation anxiety/monophobia and agoraphobia (a need to be near safe people and places at all times due to the terror)
- Racing thoughts and pressured speech
- Vocal tics (e.g., throat clearing, grunting)
- Hypersensitivity to light and sound
- Subjective physical sensations such as electrical zaps, buzzing, vibrating, burning, bugs crawling under the skin, etc.

Understanding a Loved One with Akathisia

The personality and behavioral changes you have likely noticed in your loved one may be extreme; however, there are thousands of people all over the world today with akathisia who are behaving the same way. They have had a disruption in their brain chemistry that cannot be controlled with psychotherapy, or by "thinking positive." They are likely clingy, pleading for your help, having frequent angry outbursts, neglecting activities of daily living, visiting many doctors, spending a lot of time researching and in support groups, and refusing further medications. These are the stereotypical behaviors of people fighting to survive akathisia.

The following quote from a support group member may help you understand these behaviors, why they are pleading for your help, and why they may seem unable to think or talk about anything else:

It's like someone sets you on fire...now try to have a conversation with someone while you are consumed by the flames. Try watching a movie like that. Check your mail while you are burning. Try taking a nap while the fire burns relentlessly. You can't. It's impossible. The simplest tasks become completely overwhelming because your one and only focus is the fact that you have been set on fire. And, what's worse...no one can see the flames consuming you.

Please keep in mind that akathisia is NOT anxiety. It is caused by a chemical disruption in the brain. Your loved one cannot control it, many people do not survive it, and how you treat them can significantly affect the outcome.

How You Can Help

Do not force them to take a medication. Most people with akathisia are misdiagnosed with a mental illness and prescribed psychiatric medications. Please [click here](#) or scan the QR code to learn how demanding they take these medications or allowing them to be force-drugged could, in effect, be similar to torturing them.



Stay by their side. Due to the terror, many akathisia sufferers need to be near a family member or friend at all times; however, they may be difficult to be around. The severe agitation and terror can cause people to be extremely emotional and have frequent angry outbursts for which they will later apologize ("I hate you – don't leave me"). Treating them as if they can control their symptoms if they want to is a common trigger. Telling them to "think positive" is also a common trigger. This is like telling someone who has been set on fire or thrown out of an airplane without a parachute to "think positive." It is virtually impossible for them to do.

Believe them. Because most doctors know little to nothing about akathisia, most sufferers have to do their own research. Therefore, it is possible that your loved one knows more about their condition than their doctor. They may know they should not take a medication the doctor wants to prescribe or that they should taper off of a medication more slowly than the doctor wants them to. Currently, people whose families simply have blind faith that a doctor knows best are being involuntarily hospitalized, mistreated, force-drugged with medications that make their akathisia much worse, and losing their home, family, and friends – everything they felt they had to live for. Tragically, this scenario has ended in the suicides of many people.

Misdiagnosis

Akathisia has been misdiagnosed for decades. Your loved one may need to see many doctors before finding one who will diagnose them correctly. Although you have likely witnessed a drastic change in their personality and behavior, the inability to be still, angry outbursts, and other stereotypical signs of akathisia, a doctor may not believe this is a drastic change unless you tell them. Additionally, many sufferers spend countless hours researching and then cannot find a doctor who is willing to read the literature and consider their self-diagnosis. Instead, they are misdiagnosed again and warned to stop doing their own research. If your loved one has been misdiagnosed with a mental illness, they have lost some credibility. At this point, they need you to advocate for them by questioning their doctor rather than simply agreeing with a diagnosis other than akathisia and the treatment the doctor suggests.

Common misdiagnoses: Worsening of a mental illness, new mental illness, generalized anxiety disorder, panic disorder, borderline personality disorder, bipolar disorder, attention-deficit/hyperactivity disorder, restless legs syndrome, health anxiety

Functional neurological, somatic symptom, and factitious disorders: In functional neurological and somatic symptom disorders, the symptoms are determined to be anxiety-based (psychosomatic). The vast majority of neurologists today misdiagnose akathisia as a functional neurological disorder. In factitious disorder, a patient is thought to be faking their symptoms for attention. Akathisia is misdiagnosed as these disorders because people who are in so much distress that they are suicidal and have been told it's just anxiety may easily meet the diagnostic criteria. They will do their own research, know the correct medical terms, and have visited many doctors and hospitals. They will also appear to have disproportionate thoughts about the seriousness of their symptoms to a doctor who does not realize they have akathisia.

Drug-seeking: Akathisia is very common in benzodiazepine withdrawal, especially after long-term use. It can also occur with dose tolerance and even between doses. Benzodiazepine-withdrawal akathisia has caused countless suicides. If a loved one who is taking a benzodiazepine complains of akathisia, it is crucial that you advocate for them if their doctor refuses to refill their prescription or insists they taper at a rate faster than suggested in the Ashton Manual (available at benzoinfo.com).

[This short video \(1 min, 51 sec\) illustrates the dangers of cold turkey benzodiazepine withdrawal:](#)



Finally, it is safest to believe a loved one who has told you they have akathisia even if their doctor disagrees. Only someone with symptoms so horrific that they are suicidal would research enough to learn a term many doctors do not know. At this point, you could be their best chance of survival. Already desperate enough to consider ending their life, please do not turn your back on them. As illustrated in the true stories on the next page, this may be the worst thing you could do.

See akathisiaalliance.org for more information:



For additional help, [click here](#) to join "Akathisia - Essential Family and Caregiver Support" on Facebook

TRIGGER WARNING! The following are actual posts from a support group that illustrate the importance of believing a loved one who claims to have akathisia and that the way you treat them can truly be a matter of life or death.

James: I'm done. My girlfriend told me to leave. I've told my mom and brother how bad this is and they just say you need to get your life together. How can you do that when you're frozen in terror every second of every day...over nothing. I'm 35 and feel like a scared child. I don't have anything anymore. No house, no money, no friends, no passions or desires. Lost my partner. No longer with my baby girl who was my only hope, and I'm alone in a house with people who say they're sick of hearing me. My girlfriend is sick of hearing me. Everybody is sick of hearing me. Well, I'm truly sick of reaching out and trying to get them to care. My options are hospital or end it, and I've been to the hospital twice this year and nobody believed me. There's no love, nobody to sit with me and hug me or just say, "I'm here." I can't be alone anymore. I can't do this alone.

Support group administrator (SGA): Christina passed away last week. The doctors told her family it was just anxiety, so they didn't believe her and she was on her own. She tried so hard to make it.

Lisa: Oh my God...my family doesn't believe me either. Why is it so hard for people to believe this neurological damage is from the drugs? I don't get it!

SGA: I don't get it either. The doctors told me Jake was making it up, but I believed him. I don't understand why people can't listen to their loved ones.

Greg: I think it's because they came from the age when people believed that doctors were always right. Plus, there weren't computers or internet back then, so knowledge only came from those they trusted the most, their doctors.

Lisa: This is an unbelievable nightmare. I tell my mom every day that the drugs messed me up and she says I was messed up before that. She refuses to read anything about this. Why does she refuse? I don't understand. Oh my God...when I die nobody will know what happened to me and why. Jesus...this is unbelievably bad. I can't believe this happened to me. I can't. This is so bad.

Greg: Yes, Lisa, somebody will know what happened to you if you die. We will tell them. We are your support. We all know what you're experiencing, so please don't fight this alone. That goes for anyone else on here. By supporting each other, we will all get through this and prove everyone wrong.

SGA (one month later): Our sweet Lisa passed away yesterday, for those of you who didn't know.

Cathy: I have severe agitation, panic, and terror that's getting worse and worse. I'm like a basket case pacing and screaming for hours. I can't sleep because it's complete terror. The mental health team isn't recognizing it as akathisia. They think it's severe anxiety. I don't know what to do. I've been on the phone with the crisis team all morning. They spoke to the consultant and he's not changing my meds. I've taken loads of diazepam and it's not touching it. Seems like it's building in intensity every day. My dad is telling me to shut up and sit down. I can't live like this. I truly can't. I can't get through this hour. It's extreme.

SGA (10 days later): It pains me to announce that Cathy passed away yesterday. Her family continued to not give her the validation she deserved and so desperately needed. I have several screenshots of messages and comments where she said they wouldn't watch any videos, wouldn't research, and told her to just kill herself because she was hurting them with her "delusions."

Marcy: Akathisia made my life torture. The doctor didn't mention anything about side effects. I've had to endure hell due to misdiagnosis. I was tied up, injected and electroshocked against my will. I was thrown into isolation because I screamed in pain and fear and they didn't believe me. Meanwhile, I've lost my home, fiance, work, family, and friends. And, I'm still fighting.

Marcy: I tried to speak to my family today, but they won't listen. They said they can't hear any more about my "invented diseases," that I'm making it up and I need to listen to my doctors. They all just blocked me and won't even pick up the phone. They are very dangerous to me now as they can easily lock me away and tell the psychiatrists I'm making this up. I'm terrified.

Support group member (SGM) #1: Marcy, are you okay? You haven't posted today.

Marcy: No I am not okay. I have to move out of my house tomorrow and can't live alone. I'm too disabled. There is no help.

SGM #1: Marcy hasn't had any activity on her phone for 24 hours. She hasn't answered my messages. This is getting scary. She was in a terrible place. She moved out today...all alone. I'm very worried about her. Please, has anyone heard anything?

SGM #1: Marcy's flatmate just told me she tried to take her life. She's in the hospital, but has been declared brain-dead and her family will let her go soon. I'm so angry at the doctors. She lost her family because of them and couldn't go through the torment alone. There was not a single person to hold her hand. If she'd only had the support and understanding and BELIEF!!!

SGM #2: My family doesn't believe me either. I'm scared I'm going to do this same thing because of a lack of support.

SGM #3: She did not take her life. Big Pharma and her doctors gave her akathisia and her family pushed her over the edge.

SGM #4: Her family, like mine, abandoned her. In this torture, rejection by the people you trusted most is too much to bear.
