

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. Akathisia is far more common than has been reported in the past and remains dangerously under-diagnosed and under-reported today.

Click here or scan this QR code to watch a 38-second video illustration of akathisia:



In this short video, Joseph Glenmullen, MD, explains akathisia and why it causes suicide:



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)
- Subjective physical sensations such as electrical zaps, buzzing, vibrating, burning, bugs crawling under the skin, etc.
- Hypersensitivity to light and sound
- Executive dysfunction (impulsivity, disorganization, inattention, emotional dysregulation)

Recognizing Akathisia (ICD-10-CM Code G25.71)

Key Points

- Akathisia is a neurological disorder composed of both neurological and psychological symptoms.
- Motor symptoms can be variable, briefly suppressed, increase with attention, and decrease with distraction.
- Motor symptoms may increase with physical and/or psychological distress.
- Excessive movements are not always evident.
- Due to the above-noted motor characteristics, akathisia can easily be misdiagnosed as a functional neurological disorder.

Clinical Assessment (By Perminder Sachdev, MD, PhD, FRANCZP)

There is no consensus regarding which movements, if any, are characteristic of akathisia. In our study, the features that best discriminated akathisia from non-akathisia were i) shifting weight from foot to foot, or walking on the spot, ii) inability to keep legs still (subjectively), iii) feelings of inner restlessness, and iv) shifting of body position in the chair. However, these features are not present in every patient, and in the milder cases, only the subjective report may be present, at least on brief examination, and only prolonged observation will reveal any motor disorder. Voluntary movements and effortful tasks tend to reduce the movements. The majority of the patients report that akathisic movements are voluntary and in response to subjective distress. Except for the most severe cases, patients are able to voluntarily suppress the movements at least for short periods. Another feature of the movements is their marked variability over time, and their usual disappearance during sleep. Tremor of the extremities is not uncommonly associated, and this may be regarded as the co-occurrence of drug-induced parkinsonism.

Misdiagnosis and Suicidality

Akathisia is not subtle. Its symptoms are so severe, in fact, that there are many reports of people with no history of mental illness or depression who took their lives within days of its onset. The importance of an accurate and swift diagnosis cannot be stressed enough. As the suicidality is primarily due to its subjective symptoms, it is crucial to consider a self-diagnosis even when a patient exhibits no objective signs. Failure to do so and an alternate misdiagnosis are currently resulting in unnecessary involuntary hospitalizations, forced drugging with medications that worsen the akathisia, loss of family support, abandonment, homelessness, and a much greater risk of suicide (see page 3).

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

Functional neurological, somatic symptom, and factitious disorders: Patients with symptoms severe enough to cause suicidality may easily meet the criteria for these disorders until they find a doctor who recognizes their akathisia. They will appear to have disproportionate and persistent thoughts about the seriousness of their symptoms, have a persistently high level of anxiety about their symptoms, and spend excessive time devoted to these symptoms. They will do their own research, know the correct medical terms, be eager to have numerous tests performed, and have a history of visiting many doctors and hospitals.

Drug-Seeking: Akathisia is very common in benzodiazepine withdrawal, especially if prescribed long term. It can also occur with tolerance and between doses. To these patients, even one missed dose can cause significant worsening. Due to the increased suicidality, they know they may not survive a cold-turkey withdrawal. They are not drug-seeking to get high. They simply need their prescription renewed so they can taper at a rate slow enough to prevent a return of the akathisia.

This video (1 min, 51 sec) illustrates the harm currently being caused by abrupt cessation of benzodiazepines:



Treating Akathisia

Pharmacological treatment of akathisia is extremely difficult because a medication that helps one patient may harm another. Please consult the literature for suggested treatment options. If a patient is tapering off a psychotropic medication, it is crucial to continue their tapering schedule. A faster taper can result in a return, or severe worsening, of their akathisia.

Note: Threatening to restrain and/or force drug patients exhibiting signs of akathisia, including self-harm, could significantly worsen their condition. Using a calm tone to assure them they are safe may be much more effective.

The following dopamine-depleting medications can cause or significantly worsen akathisia:

aripiprazole (Abilify) asenapine (Saphris) cariprazine (Vraylar) chlorpromazine (Thorazine) ciprofloxacin (Cipro) citalopram (Celexa) clozapine (Clozaril) delafloxacin (Baxdela) desvenlafaxine (Pristiq)

domperidone (Motilium) doxycycline droperidol (Inapsine) duloxetine (Cymbalta) escitalopram (Lexapro) fluoxetine (Prozac) fluphenazine (Modecate) flupentixol (Fluanxol) gemifloxacin (Factive)

haloperidol (Haldol) iloperidone (Fanapt) levofloxacin (Levaquin) levomilnacipran (Fetzima) loxapine (Loxitane) Iurasidone (Latuda) metoclopramide (Reglan) milnacipran (Savella) moxifloxacin (Avelox)

ofloxacin (Floxin) olanzapine (Zyprexa) paliperidone (Invega) paroxetine (Paxil) perphenazine (Trilafon) pimozide (Orap) prochlorperazine (Compazine) promethazine (Phenergan) quetiapine (Seroquel)

risperidone (Risperdal) sertraline (Zoloft) thiothixene (Navane) tiapride (Tiapridal) trifluoperazine (Stelazine) trimethobenzamide (Tigan) venlafaxine (Effexor) ziprasidone (Geodon) zuclopenthixol (Clopixol)

Visit akathisiaalliance.org for more information.

Website





TRIGGER WARNING: The following are actual posts from an akathisia support group.

Support group administrator (SGA): Christina passed away last week. The doctors told her family she just had 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 next hour. It's extreme.

SGA (10 days later): It pains me to announce that Cathy passed 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."

Jason had akathisia due to SSRI withdrawal that was misdiagnosed as psychosis, and he was prescribed an antipsychotic. Knowing this would likely make his akathisia worse, he refused to take it. He was then force-medicated.

Jason: Being force-medicated with Abilify for four weeks and sectioned if I don't follow through. They say burning and pain is psychotic. If anything bad happens to me, can you please explain how bad this is on my Facebook wall?

Mike: Antipsychotics are the worst possible class of drugs to give to a person with this condition! It's like giving peanut butter to treat somebody with a peanut allergy!

David: I am so upset for you — I am shaking so bad I can hardly type this — I wish you were closer man, you could come stay with my parents and I. The mental health system is completely broken — how can it allow this kind of treatment to iatrogenic patients?! Abilify is the drug that caused my akathisia and tardive dyskinesia. Why can't they understand it will cause you further harm, both mentally and physically? How close will they watch you... can you pretend to take the drug and dispose of it somehow? You're a warrior — sending lots of positive energy, strength and love your way!

Jason: I tried spitting them out, but the mental health nurse sat with me in a condescending way and said take it now.

Jason was force-medicated with the antipsychotic for two weeks. His akathisia became much worse — and he took his life.

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.