Why it's often hard for people to recognize their own mental illness

Jan. 3, 2022 at 6:00 am Updated Jan. 4, 2022 at 7:27 am

(Jennifer Luxton / The Seattle Times)

By

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If someone was telling you to take insulin but you didn't think you had diabetes, you probably wouldn't take the medication, right?

That's how Bob Krulish explains anosognosia, a tricky condition that accompanies some mental illnesses.

Krulish is a mental health advocate with a local chapter of the National Alliance on Mental Illness based on the Eastside and an author who has made it his life's mission to teach and work with families affected by anosognosia.

Anosognosia (pronounced uh-nah-suh-no-zhuh) is a neurological impairment that affects an estimated 30% of people with schizophrenia and 20% with bipolar disorder, according to the *National Alliance on Mental Illness*, though others believe the percentage may be much higher. Ultimately, anosognosia makes it hard for people with mental illness to have insight into their diagnosis or be aware of it.

This is particularly challenging when it comes to treatment, as people experiencing anosognosia often refuse medication or inpatient care. Family members can be frustrated by their loved ones' response, and the person with mental illness likewise is frustrated — they can't recognize that they're sick and now feel alienated.

"I have no awareness or very little awareness of my illness when I'm in a manic state," said Krulish, who has been diagnosed with bipolar disorder.

Researchers still are untangling why and how exactly anosognosia works. It's believed that the neurological symptom occurs due to damage or malfunction in the brain's frontal lobes. It's not an off-or-on switch, but rather a gradient of awareness (or lack thereof). Anosognosia can also occur in patients with traumatic brain injuries, people who have had strokes, and those with dementia. Family members and even some clinicians can mistake the symptom for denial, but that's not what's happening.

"How does [the brain] understand it's injured, when the organ that is trying to perceive the deficit is actually the one that's injured?" explains Charles Bombardier, a clinical psychologist who heads the

clinical and neuropsychology department at UW Medicine.

“I have a person I saw in hospital just now and I’ve been working with him for a couple of weeks. This person has a brain injury and doesn’t think anything is wrong with him,” Bombardier said.

“There’s no way I’m going to get this guy [to understand] by showing him his CAT scan and saying, ‘Hey, your frontal lobes are really messed up here. You’ve got to believe you got a brain injury,’” Bombardier said. “It just doesn’t get you very far.”

Anosognosia is not just a challenge for people with mental illness and their families. It’s also a crucial factor when it comes to designing laws around treatment and involuntary psychiatric commitment.

“If you are building a system that is based on the idea that anyone can and eventually will recognize that they need treatment … it means the population of people who literally can’t because they have anosognosia are just invisible to the system,” said Lisa Dailey, the executive director of the national organization Treatment Advocacy Center.

Washington state’s laws make it hard to force a person with mental illness into treatment. Only a designated crisis responder (a trained professional with a degree) can petition for an emergency evaluation or for inpatient treatment, and the bar for that is quite high: A person has to be a danger to themselves, others or property; or they must be gravely disabled (meaning they’re forgetting or refusing to eat, sleep or take care of themselves), plus they have to be worsening.

In contrast, 28 states allow any responsible adult (a family member, for example) to petition for involuntary commitment, and 30 states allow any responsible adult to petition for an emergency evaluation.

Family members of people with severe mental illnesses often find themselves caught between trying to help a loved one who cannot recognize they need care, and laws that restrict the ability to force treatment.

Seattle resident Adelia Boyar remembers getting a call around 4 a.m. in 2013 from a judge in New Hampshire calling about Boyar's mother who was being evaluated to determine if she should receive involuntary psychiatric treatment. Boyer's mother has bipolar disorder and was going through a manic episode.

"Basically, they needed me to prove that she was unsafe," she said. "But she's not; she wouldn't ever hurt anybody. She wouldn't hurt herself. She needs help, but because she's not violent or unsafe, then she couldn't be held." Boyar's mom did not meet the bar for involuntary treatment and was released.

Still, some critics worry that a symptom like anosognosia is too subjective and can be used to commit people against their will. Here lies a frequent tension in the mental health field: the rights of people with mental illness to make their own choices contrasted with the right to get care and treatment, even when that person perhaps doesn't know they need it.

After decades of institutionalization that led to warehousing of people at overcrowded state hospitals, many policymakers are reluctant to relax

treatment laws. The antipsychiatry movement in the ‘60s, coupled with the civil rights movement, have pushed more libertarian models of thinking — prioritizing an individual’s right to make decisions about their own medical care — when it comes to involuntary treatment.

Historically, marginalized groups including women, LGBTQ+ members and people of color have been particularly harmed by psychiatry laws and treatment. For example, according to a 2014 article in the World Journal of Psychiatry, Black people in the U.S. are four times more likely to be overdiagnosed with schizophrenia, despite no proof of genetic propensity for the illness.

Krulish, Bombardier and Dailey acknowledge that history and fear. But Dailey adds that if state and federal policies forget about anosognosia, they’ll be harming the very people who need help the most.

“What you’re really doing is saying that you’re OK with some people being completely excluded by the treatment system. And you’re OK with people getting really, really sick,” she said.

Krulish suggests that rather than arguing or reasoning with a person with severe mental illness who’s refusing treatment, that family members and friends instead use a method called **LEAP**: learn, empathize, agree and partner. It’s a program started by Dr. Xavier Amador, a clinical psychologist who researches and writes about anosognosia.

Instead of proving to the person that something is wrong, clinicians and family can focus on goals both parties agree to, such as wanting to be discharged or keeping a steady job. That can build trust, strengthen

relationships, and ultimately improve outcomes for the person with mental illness, Krulish said.

“My whole process is about evoking from the individual what their reasons might be for being on medication, what their reasons might be for behaving differently, what their goals might be,” Krulish said. “I’d much rather see it be internally motivated than externally forced upon them.”

Tips for talking to a loved one about their mental illness:

- Educate yourself. Learn as much about the mental illness your loved one has.
- Listen with empathy and reflectively. Do not try to reason or prove to the person that they have a mental illness or insist they take their medication. Instead, take time to build a trusting relationship. Only give your opinion when asked.
- Focus on goals both you and the other person may want. For example, custody of their children, or a steady job or relationship.
- Consider making a **psychiatric advance directive,** a legal document that explains what kinds of future mental health treatment a person may want. Also consider naming a trusted individual to make those treatment decisions.

Source: Henry Amador Center for Anosognosia, National Alliance on Mental Illness

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