The Catatonia Foundation

What would you like patients who are struggling to get a diagnosis to know?

Dr. McCall:
I hate to put any obligation upon the families, but truth be told, you have to advocate for yourself sometimes. And this means that the families, loving families of a person with severe mental disorder that seems to have odd physical signs, they need to be educated too — not just the providers — to ask the hard questions: “Could my loved one in fact have catatonia?”

This is a large task because there's so much mental illness in this country and so many loving people taking care of these folks. But it's a task that's, I think, worth undertaking to increase awareness so that family members can advocate for their loved ones. The second problem is then finding a provider who's even ever heard of catatonia. A lot of times this is a term completely unfamiliar to them — not even mentioning what the specific signs are of the illness or its treatment. And then finally, of course, having access to the treatments themselves.

We could argue about how many things that are relevant, but I think at a minimum would be oral intramuscular intravenous sedatives like the benzodiazepine lorazepam, and that should be uniformly available. I can't imagine the setting in the United States where you couldn't get that. That's often very helpful. And sometimes that's enough, but we also need, if necessary, access to electroconvulsive therapy.

Providers around the country, psychiatrists that conduct electroconvulsive therapy, need to be on guard, ready and willing to receive cases which are not proceeding well. Ideally, every psychiatric unit in the United States should have local access to ECT. If not in their own hospital, but somebody I would say within 30 miles. So we need to have greater access to ECT as well.

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