



erc

epilepsy RESOURCE CONNECTION

arc-sedgwickcounty.org/erc.html

hotline

Does the ADA Cover Epilepsy?

Until 1999, there was little fanfare about whether a person with epilepsy is covered by the Americans with Disabilities Act, or its model counterpart, the Rehabilitation Act of 1973. Most cases presumed that epilepsy was a covered disability. Since 1999, though, courts have been struggling with figuring out exactly who should benefit from the ADA.

"I had to try harder than anyone at my job. I knew that if my employer found out I had epilepsy I would be history. They would force me out by cutting my hours to nothing or harassing me. Paramedics would point and make fun of me after a seizure. I stay at home and avoid public places when I can. I've been laughed at, stared at, and completely stripped of any dignity for many years, and a lot of those times it was by teachers, employers, store employees and even doctors."
- Kelly Jo W., Brooklyn, Ind.

In 1999 the Supreme Court handed down its now landmark decision in *Sutton v. United Airlines*, requiring that the effect of mitigating measures (such as the use of medication to control epilepsy or diabetes) be considered in determining if someone has a disability under the ADA. Since then, courts have recognized that epilepsy is a disability in only a few instances. As a result, people with epilepsy are questioning whether they are even entitled to the protections of the law. Even more troubling is that employers, public accommodations, schools and state agencies have also begun to ask the same question.

"I was a subcontractor under NASA. After I was diagnosed with epilepsy I was told that I was a liability and should go home. I feel I am treated differently by the on-site clinic due to my seizures. It seems I have to follow a different set of rules than my coworkers. I feel sorry for a place the size of my employer that can help send a man to the moon but will not take the time to educate themselves about such a common condition as epilepsy." - Marietta F., Picayune, MS

Seizures can cause exhaustion for up to 36 hours after an episode. Memory losses, disorientation and cognitive delay are also common. Only 75 percent of those with epilepsy will be able to control their condition with medicine, and even some of those individuals run the risk of a breakthrough seizure. The medications themselves can have negative side effects such as drowsiness, slurred speech and impaired memory.

People with epilepsy also too often suffer from low self-esteem. The stigma associated with the disease and the inability to drive if one's seizures are not controlled can lead to social isolation. Economically, people with epilepsy are far worse off, as well. The unemployment rate is five times higher than that for the general population, and this is in part attributable to the discriminatory attitudes of employers.

"I had a seizure. I was still post-ictal when the cops and ambulance arrived. I was restrained, which caused me to panic and bite a police officer. I was forced to go to the hospital against my will. I was handcuffed to the stretcher in the ambulance, and I was handcuffed for 3-4 hours in the hospital. I was placed in a room where only my family members were allowed in. My fiancé was not allowed into the room. The hospital staff knew I had seizures, but nobody seemed to think the handcuffs were wrong. I also have a photo of the bruises on my arm." - Terri M., Chelmsford, Mass.

People with epilepsy need a strong anti-discrimination law that actually covers them – as Congress originally intended. Now, however, the Supreme Court's decision has created an absurd Catch-22 by allowing employers to say a person is "too disabled" to do the job but not "disabled enough" to be protected by the law. The case is thrown out of court and the individual is never given the chance to do the job. This is wrong!

CONTINUED ON BACK

Spring

GLIMMER GROUP

a support group for parents & caregivers

(This group meets quarterly at 2919 West Second Street)

"Mother's Day Art"

Saturday, APRIL 14, 2007

10:00 AM - Noon

Bring the kids to work on an art project supervised by City Arts, while parents get a chance to share on their common experience of raising children living with seizure disorders.

PLEASE RSVP so we have an accurate count of kids attending.

RSVP: (316) 943-1191

Research Links

Tooth-brushing to Seizures

Tooth-brushing may trigger seizures in certain people with epilepsy, and researchers say lesions in a specific part of the brain may be a cause in some people, according to an article published in the March 6, 2007, issue of *Neurology*[®], the scientific journal of the American Academy of Neurology.

The article reviewed the cases of three adults with epilepsy who experienced seizures while brushing their teeth. Two of the adults reported some of their seizures occurred when they brushed certain areas of their mouth. The seizures varied from jerking and twitching of the face to salivating vigorously. One patient was unable to let go of the toothbrush during the seizure.

The seizures were confirmed by video monitoring.

Using an MRI, researchers found all three patients had lesions in the somatosensory area of the brain, which is close to the hand and speech motor areas.

"The rhythmic act of brushing teeth may excite an already overly excitable area of the brain," said study author Wendy D'Souza, MBChB, MPH, with the Department of Neurology and Neurological Research at St. Vincent's Hospital, the University of Melbourne in Melbourne, Australia, and a member of the American Academy of Neurology. "

"This is similar to photosensitive epilepsy, which involves seizures triggered by flashing lights and moving patterns. Since tooth-brushing involves persistent rhythmic action, this may explain why this trigger is more likely to induce seizures in the somatosensory area of the brain compared to other oral stimuli, such as eating," said D'Souza. ✚ EPILEPSY FOUNDATION

Adult Epilepsy Support Group

Meets Second Tuesday of Month, 6:30 PM @ 2919 W. 2nd Street, Wichita

April 10th: "Positive Mental Health and Epilepsy"

May 8th: "Discussing Epilepsy With Others"

People with conditions like epilepsy who manage their disabilities with medication or other measures are viewed as "too functional" to have a disability and are denied the ADA's protection from employment discrimination. People denied a job or fired because an employer mistakenly believes they cannot perform the job – or because the employer does not want "people like that" in the workplace – are also denied the ADA's protection from employment discrimination.

The ADA needs to be restored to Congress' original intent – to make clear that epilepsy is a disability. The ADA should be interpreted in a manner similar to other federal civil rights laws to ensure that people with medical conditions like epilepsy are not unfairly denied employment opportunities based on irrelevant characteristics, but are instead employed based on ability to do the job.

"I was removed from service at the Post Office and fighting for my job back has taken so many twists and turns that I have found out how incredible it is how ignorant people are about epilepsy. You try to explain and they don't believe you. Like I really like to put myself and my future in jeopardy with this condition, yet someone else comes along with alcohol problems or other ailments and the response is positive. Why? Epilepsy is a condition that is real, but people look at me like I'm from some planet or a circus freak. For this reason, I have lost my job and I want to work. I can work! I just have this problem called epilepsy that disables me sometimes. But I'm OK. I don't want SSDI or Medicaid! I WANT TO WORK!" -Edwin O., Hollywood, Fla.

✿ HOW YOU CAN HELP ✿

Contact your representatives and tell your story of discrimination. Urge them to support full restoration of the protections intended with the Americans with Disabilities Act. ✧ EPILEPSY FOUNDATION

New Uses For Drug Keppra®

New research has revealed that taking the drug levetiracetam (Keppra®) on its own rather than as an add-on therapy may help treat epilepsy patients whose seizures aren't controlled by their current medication.

Researchers compared the drug to carbamazepine (Tegretol®), studying around 600 adults who had had two or more seizures in the previous year. Results revealed that 73 % of the people taking levetiracetam had no seizures for at least six months, compared to 72.8 % of those on controlled-release carbamazepine.

Both drugs produced equivalent seizure freedom rates in newly diagnosed epilepsy," said study author Professor Martin Brodie, from the Western Infirmary Epilepsy Unit in Glasgow, Scotland.

"Levetiracetam helps fill a need for safe and well-tolerated, easy-to-use epilepsy drugs, particularly because more than 30 % of patients do not achieve seizure control with existing treatments."

The authors say this research confirms the belief that most patients will respond to their first epilepsy drug at a low dosage.

✧ EPILEPSY ACTION

Epilepsy 101: Getting a Job

If your seizure control is not yet good enough for you to get a driver's license, avoid jobs that would require you to drive as part of the job, or that would place you in hazardous situations. Think about jobs that allow you to work at home, at your own pace. Keep in mind that the growth of the Internet economy has created many non-traditional job opportunities for people with computer skills.

If your seizure control is completely reliable, almost all jobs should be open to you. In fact, the only thing you may want to do that other job applicants don't is to learn how to talk comfortably about epilepsy with other people so that, if you discuss your epilepsy with an employer, you can explain how much or how little impact it has on your ability to perform your job well.



It is not always necessary to discuss epilepsy with a potential employer, however. Whether you do or not is up to you. If you have excellent seizure control and the employer does not ask any health-related questions, there's no reason to start talking about epilepsy unless you want to. Under the Americans with Disabilities Act, employers with more than 15 employees may not ask any health-related questions until after they have offered you the job. The important thing is whether you are able to do the job as described. Employers are also required to make reasonable accommodation for a disability.

If you decide to talk about your epilepsy, or if you have to because of a legal question from the employer (after a job has been offered), remember that the more confident, well-informed, and relaxed you can be, the more reassured the employer is likely to be. Explain how long you've had epilepsy and how well it's controlled. If you drive, say so. Say how long you've been seizure-free. Explain that research studies show the longer people are free of seizures, the greater the likelihood they will stay that way.

If you've never had a convulsive seizure in your life, mention that as well. Remember, the average person thinks everyone with epilepsy has convulsions all the time. If you have only occasional seizures, point that out, too. Explain that if one should occur it will only last a very short time. And always explain how this condition actually affects your ability to perform in a job. Remember, too, that studies show people who have acquired good job skills have a better chance of getting a job, whether or not they have epilepsy.

An excellent resource in helping you is Vocational Rehabilitation. By contacting your local vocational rehabilitation office, you will tap into a wealth of resources related to employment options for people with disabilities. Vocational Rehabilitation, a state-supported division of services, assists individuals with disabilities who are pursuing meaningful careers. VR assists those individuals to secure gainful employment commensurate with their abilities and capabilities through local job searches and awareness of self-employment and telecommuting opportunities. To find a VR office near you, goto: www.srskansas.org/locations.htm ✧ EPILEPSY FOUNDATION

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Cyberonics®



Via Christi
Comprehensive Epilepsy Center

host a monthly luncheon
presentation on
VNS Therapy®

11:30 - 12:30

Third Wednesday of the month

RSVP is required to attend. (316) 268-8562

Via Christi St. Francis Hospital in Wichita

