

Carpe Diem – Seize the Day Blog

Editor's Note: Content presented in the Carpe Diem – Seize the Day Blog is for awareness and informational purposes only, and it is not meant to be a diagnostic tool.

On March 26th we celebrate World-Wide Epilepsy Awareness Day. People in countries around the world are invited to wear purple and host events in support of epilepsy awareness. Last year, people in more than 85 countries on all continents participated in Purple Day! We need to increase the public's knowledge of a neurological condition affecting nearly 65 million people worldwide.

March 26th is also known as Purple Day. Epilepsy Alliance Ohio encourages you to wear your purple in support of epilepsy awareness. Another important goal for the day is removing the stigma associated with epilepsy. Those with epilepsy can lead normal lives, especially when their epilepsy is controlled.



Those with epilepsy are reluctant to go out. Because having a seizure can be so unpredictable and embarrassing. They think: “What if I have a seizure? What will people do? What will they think of me?”

Those and many other self-doubting questions run through the mind of a person with epilepsy. Even if they have only had a few seizures, there is always the fear that silent (or not so silent) enemy may strike again. So why chance it?

Social Stigma

The history of epilepsy is in a sense the history of stigma, which is deeply discrediting and can reduce a person with epilepsy from a whole and unique person to a tainted, discounted one. Stigma carries a sense of shame associated with being “epileptic” and the fear of discrimination. Fear, misunderstanding and the resulting social stigma surrounding epilepsy can result in social, and sometimes even legal discrimination.

All over the world, the social consequences of epilepsy are often the cause of more suffering than the seizures themselves. Problems are especially felt in the fields of education and employment, personal relationships and sometimes, even law. These attitudes undermine the treatment of the condition globally.

A fundamental part of ridding the world of the stigma, which has cost people with epilepsy so dearly for so long, is to raise public and professional awareness and to change the legislation which reinforces this fear and discrimination.

Stress

Just the stress of dealing with society's often hostile attitudes toward disability in general and epilepsy, can cause you to hide your condition so you will not be stigmatized. And there is the possibility of being "found out." So, isolation becomes preferable to social interaction. Confidence and self-esteem plummet replaced by feelings of helplessness and depression.

Then there is the added emotional baggage of fearing recurring seizures. It is like a cloud hanging over your head, or impending doom. The loss of control, embarrassment, and humiliation strike again.

Contemporary western culture has glorified the image of the controlled and independent adult. The unpredictability of having a seizure, as well as the obvious loss of control during seizures, does not exactly fit this image. And by "failing" to meet these standards, a person's sense of self-worth is affected.

In one study, participants anticipated that their self-perceptions and self-esteem would be more positive if they did not have epilepsy. Self-perception turned out to be one of the most important predictors of successful social relationships in people with epilepsy — even more important than seizure frequency, severity, or other medical factors!

Limitations

Lots of people with epilepsy have physical disabilities which also limit independence. Like not having a driver's license and being stuck — except for rides from others or public transportation, which is not available everywhere. So, the ability to do simple things like grocery shopping, errands, getting to a doctor's appointment and just socializing in general are stymied.

Plus, with many there is the stress of not being able to commute to a job. Or not having a job at all. Which means no insurance, the agony of social security and whatever other financial assistance is available. More than 50% of people with seizures are either underemployed or unemployed. That is a staggering statistic. So, there is the economic strain of sustaining a household, not to mention the added expenses of anti-seizure meds.

Adjustment

The impact of epilepsy can be devastating and debilitating if you choose it to be. But it is also very manageable with the love, support, acceptance, openness and understanding of family, friends, peers, and the community. With education, shared information, more self-knowledge, and acceptance, you can gain a greater sense of mastery over both your fears and your seizures.

That way, YOU take control. Remember: Knowledge is power. And epilepsy is just a condition. Ultimately, you are in charge of your life!

Please know that Epilepsy Alliance Ohio is ready to provide epilepsy awareness training, seizure recognition and seizure first aid training. If you know of any schools, organizations, first responders, or businesses that need any of our training program, please be sure to contact Karen Brown (Karen.Brown@epilepsy-ohio.org) or me, Steve Hutton, at Steve.Hutton@epilepsy-ohio.org.

Resources:

<http://psychcentral.com/lib/2006/embracing-the-challenge-of-life-with-epilepsy/>
http://www.ucb.com/_up/ucb_com_news/documents/Epilepsy_and_Quality_of_Life.pdf
http://neurologyasia.org/articles/20073_010.pdf
http://www.charge.org.uk/htmlsite/about_txt.shtml
<http://ninascourage.org/psycho-social-aspects/>
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3200035/>

Editor's Note: The Carpe Diem – Seize the Day Blog will be distributed and posted weekly.
Always remember – CARPE DIEM – SEIZE THE DAY!

Steve.Hutton@epilepsy-ohio.org