



# EPILEPSY YORK REGION

## Coming Out of the Shadows: The Stigma of Epilepsy

This article was contributed by Aliza Panjwani, September 2009

For most of the general public, it may come as a surprise that epilepsy is one of the oldest conditions known to man. In fact, the earliest mention of epilepsy dates back to fifth millennium B.C. Mesopotamia (even more ancient than your grandmother's knitted blue scarf!). Given epilepsy's perpetual existence, one would imagine that the stigma surrounding it decreased through the ages. Unfortunately, it seems as if the reverse has happened. Many people that can serve as advocates and supporters of epilepsy are not open about having it because they are wary of negative treatment.

Celebrities and other public figures are often in the position to serve as role models. I can think of many an affliction represented by well-known media personalities. Take Michael J. Fox as an example, he is an active role model for the people that suffer from Parkinson's disease. We know of many public figures that have served as spokespersons of breast cancer (Sheryl Crowe, Nancy Reagan, and Christina Applegate). Diabetes has been well-represented by famous media figures such as Larry King, Halle Berry, and Mary Tyler Moore. There are countless such examples. Now, try thinking of current public figures that serve as ambassadors of epilepsy. How many come to mind? One or two? Perhaps none?

Fortunately, we can find our inspiration from shining personalities in history (blasts from the past, if you will) that not only lived with epilepsy, but accomplished unforgettable things during the course of their lives. Consider Aristotle, the gifted philosopher you grew up hearing about. His metaphysical treatises and deductive logic may have escaped some of us. But, we can at least give him our vote as a highly intelligent man who contributed immense knowledge to the fields of science and philosophy. What you may have not learned in philosophy class is that Aristotle had epilepsy. What did having epilepsy take away from his intelligence? Nothing.

If you enjoy reading, but intricate philosophical writings are not really your preference, well...you are not the only soul in that imaginary room. You may, however, have heard of Charles Dickens or Lord Byron. The name Edgar Allan Poe may result in a resounding head nod, but I'll even accept a noncommittal mutter. Who remembers the young and adventurous storybook character Alice? You know, the one that explored wonderland (now, I'm getting lots of nods, I'm sure). Lewis Carroll, the author, is known to have had epilepsy. In fact, several examples of epilepsy symptoms can be found in his writings. For example, Alice begins her wondrous journey in wonderland when she falls into a hole. Interestingly, many people experience a similar "falling into a hole" feeling during their seizures. These literary 'prophets' were exceptional poets and storytellers, and guess what? They also had epilepsy.

Brilliant world leaders are also known to have had epilepsy. We are all familiar with Napoleon Bonaparte, Alexander the Great, and Julius Caesar. They are extraordinary exemplars of generals that led armies to victory, built empires, and innovated change even in the most tumultuous times. Though they had epilepsy, it did not prevent them from accomplishing remarkable feats that are still discussed today. Can you honestly imagine coming out the victor in a chess game with any one of these guys? However, the accomplishments of these infamous personalities are not really most relevant here. It is the fact that these historical figures embraced their ability to be great.

Given that epilepsy dates back to the time of such thinkers and doers, the amount of myths surrounding it are especially surprising. Although some people may think otherwise, epilepsy does not affect intelligence. Having epilepsy does not mean that one cannot work or handle responsibility. Most people with epilepsy are not physically limited. Although research is still ongoing, current treatment options are beneficial to many. However, most of the general public is either unaware of epilepsy, is only aware of its misconceptions, or thinks that epilepsy is extremely rare and affects few and far in between.

That may be the biggest misconception of all. In fact, as I sit here in the York region Epilepsy office, my eyes are privy to a poster that reads the following: 300,000 Canadians have epilepsy and are coming out of the shadows. That number is an estimate, and is probably even larger than we think. Contrary to the poster, it is evident that the stigma surrounding epilepsy is so great that people are reluctant to emerge out of its shadows. As a result, currently there are not many public role models that have epilepsy, which is why looking to a few historical personalities as a source of inspiration seemed fitting. While we wait for the future public role models of epilepsy to take a stand (and they will), we should remind ourselves that by being active in our own communities, we can help reduce the stigma, making their journey easier. Begin today. If you do not know a lot about epilepsy, you should start learning. And, if you already know about it, then you should start sharing. Educate yourself, and then *Pass It On*.

If you would like to help increase the awareness of others or further your own, we encourage you to contact us at 1-866-EPILEPSY (1-866-374-5377).



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