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ADVOCACY BULLETIN

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HOW LEARNING ABOUT ANOSOGNOSIA MIGHT JUST CHANGE YOUR LIFE

WRITTEN BY BONITA SAUDER

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Have you heard of the term “anosognosia”? If so, you are one of a small minority. However, it is more likely that you are not familiar with this word and are trying to figure out how to pronounce it! If you are reading this as part of our Advocacy section of The Notepad, you likely support a loved one who lives with a serious mental illness. You may already know the importance

of acknowledging anosognosia and how it has helped you to be a better advocate for people living with mental illness. As for the rest of you, please keep reading. Once you learn about anosognosia and how understanding it can change your life, the word will be rolling off your tongue.

People do not usually join an organization like ours unless they have been personally affected by mental illness, and often, after floundering alone for a while. And that is why we exist – to be here to help support you while you pick up the pieces. We have all worn your shoes and made it out the other side. Many of us became involved with Pathways (SMIS) because we want to share what we have learned. Apart from offering courses, workshops, support groups and lectures, we also share resources and information with other local agencies and pay close attention to the developments with our neighbours to the south, through the National Alliance on Mental Illness (NAMI), the largest grass roots mental illness organization in the United States.

As the BC affiliate of NAMI, our volunteer Family-to-Family course leaders are trained to share a wide variety of science based, peer-reviewed information as part of a curriculum developed and updated over the last few decades. In addition to the evolution of psychiatric care, neuroscience, medication, therapy and other treatments, we have become increasingly better educated as to how people with various kinds of mental illness feel. And how do we know? Well, plenty of researchers are doing excellent work, but most importantly, people who were once debilitated with mental illness

recover – and they tell us.

Anosognosia, however, is not actually one of those aspects of mental illness that people in recovery will tell you that they experienced. This is because the word itself, which has been used for more than 2,000 years, means “lack of insight into one’s own illness”. People who experience this symptom simply do not realize they are sick and in need of treatment – be it medication, hospitalization or even just a trip to the doctor. This is because they do not perceive or experience reality in the same way as someone without anosognosia. This symptom of their mental illness is often the reason some physicians, family members and other caregivers think the ill person is being difficult or is in denial. However, that would mean we could eventually convince that person they are ill and in need of treatment. Anosognosia does not allow a seriously mental ill person to be coaxed into accepting their prognosis.

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The caregiver of a person with a serious mental illness AND anosognosia is soon at wits end, trying to convince their loved one they are sick. If the ill person manages to get medical attention (and it may be without consent), they will continue to disbelieve everyone. Even when they are stable, days or weeks later, a person with anosognosia will still not accept they are, or ever were sick. They might feel much better. In fact, they likely do. However, anosognosia does not just disappear. It sticks around – and

convinces whoever has it, that they do not need help, or medication or therapy.

For people who live with a serious mental illness, such as schizophrenia and other psychotic illnesses, it makes sense for their supporters, loved ones and health professionals to determine if anosognosia is a symptom of their illness. As Dr. Xavier Amador states in his seminal book, "I Am Not Sick. I Don't Need Help", "nearly 60% of people living with schizophrenia, about 25% of those with schizoaffective disorder, and nearly 50% of subjects with bi-polar disorder were unaware of being ill." So, once again, these people are not "in denial" and their inability to see themselves as having a brain disorder is not their fault or anyone else's.

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If you need a dose of empathy and some help with how to deal with someone close to you who may have this symptom CAUSED by their psychotic illness, we suggest [visiting this page](#) from NAMI.

We also think you might be interested in watching [this Ted Talk](#) by Dr. Xavier Amador "I'm Not Sick, I Don't Need Help!"

If you have any questions about this article or the topic of anosognosia, please get in touch: info@pathwayssmi.org.

