

ADVANCE FOR NURSES

Walking With Nathaniel

Family advocates for research into illness that claimed their son's and brother's life

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By Kay Bensing, MA, RN

It's a sunny, tranquil September day in Cheyney, PA. Judy and Denis Asselin have lived in this bucolic community for more than 30 years. In this idyllic setting, where life is less frenetic than nearby Philadelphia, they raised two children.

Judy, a middle school teacher, and Denis, a high school French teacher, wanted to provide the best cultural, educational and social experiences for their children. Nathaniel was two years older than his sister, Carrie. The siblings were close, played together and with their friends. Looking back to the children's pre-teen years, the couple noted, "Life was good then - no, it was great!"

Frightening Thoughts

However, when Nathaniel was 11, in fifth grade, his parents noticed their exceptionally bright son, who loved life, who could make others laugh and was admired by younger children, became consumed with anxiety and perceived his body to be grossly imperfect.

For 13 years, Nathaniel struggled with body dysmorphic disorder (BDD), although he wasn't definitively diagnosed with the disorder until he was 17. The disorder "severely constricted his life," according to his mother. The hopelessness and depression he lived with were relentless.

Despite receiving the best treatment for his illness from the leading experts in the country, the periods when the young man's mood lifted were rare. He didn't believe his life was ever going to get any better, according to his parents.

On April 15, 2011, at age 24, Nathaniel took his life. His friend found him in the woods near his home. He had written a note to his parents that said, "In the weeks, months and years that follow, I am sure you will wonder what you might have done differently. Please don't. We all did the absolute best we could and there is no regret in that."

BDD - Not a Rare Disease

In an article published July 30 in the Philadelphia Inquirer, Judy Asselin wrote: "Nathaniel suffered from body dysmorphic disorder, a severe brain disease that affects an astonishing three million to five million Americans, striking most in adolescence. The BDD suicide rate is 45 times the rate found in the general population, according to one study, and twice the rate of those with severe depression or eating disorders. Yet this disease is largely unknown to the public."

Today, the Asselin family is committed to educating healthcare professionals and the public about BDD. Their hope is that others diagnosed



NATHANIEL'S LIFE: Above, Nathaniel running cross country in high school. Above right, Nathaniel as a small child. At right, the last photo of Nathaniel. *courtesy Judy and Denis Asselin*

with this debilitating disorder can benefit from the latest research and treatments.

Body Preoccupation

Judy talked to *ADVANCE* about Nathaniel's illness. She hopes nurses can develop awareness about BDD and intervene appropriately when caring for patients like her son. She emphasized those with BDD can be very secretive about their symptoms. They feel ashamed of their appearance.



A FAMILY STILL FIGHTING: Judy (left), Carrie and Denis Asselin during the pilgrimage on the Camino de Santiago in Spain. Carrie Asselin (below) greets her father, Denis, as he crossed the finish line in June 2012 after walking 525 miles in 45 days, beginning at the Asselin home and finishing in Boston.

"The first thing we noticed about Nathaniel was his routine pleasure in running and physical exercise had become an obsession," said Judy. "He would go out for a 2-mile run, come home and an hour later run again." His parents also noticed he became preoccupied with what he thought was increased fat on his belly, even though his weight was normal. He also believed he had dark circles under his eyes. These perceived body flaws then triggered obsessions and compulsions that caused Nathaniel to stop eating.

It didn't take long for Nathaniel's weight loss to precipitate physical problems. He was admitted to a pediatric psychiatric hospital where he was evaluated and treated for the eating disorder. Judy and Denis explained the primary focus of their son's treatment at this time was for him to gain weight to prevent life-threatening complications.

Response to Treatment

Once Nathaniel was medically stable during this hospital admission, he was diagnosed with obsessive-compulsive disorder (OCD) by psychiatrists who compared his signs and symptoms to the standardized criteria of the Diagnostic and Statistical Manual of Mental Disorders (DSM IV).

Nathaniel was prescribed Luvox (fluvoxamine maleate), one of the first selective serotonin reuptake inhibitors (SSRIs) to be successfully used in the treatment of children with OCD. He responded well to Luvox after being discharged from the hospital. He returned to school and was doing well with his classes.

During middle school, Nathaniel's anxiety decreased, Judy and Denis noted, and there was less body preoccupation, which is the norm for boys at this pre-puberty age. However, their son

still had a need to be super-vigilant about his hair - putting gel on it several times a day - and doing quick checks of how he looked in the mirror. These behaviors are typical of children with BDD, his parents reported. Nathaniel was doing well in school. In ninth grade, he competed with senior students and won a physics prize.

OCD Diagnosis

Even though Nathaniel seemed to be more at peace with himself after his initial hospitalization, Judy and Denis searched for information about OCD from experts. What caused this dramatic change in their son, who had been healthy and outgoing before pre-adolescence?

Most of the information about OCD was vague and not conclusive. "The most definitive information we received was that it was probably genetic and could have had a viral or bacterial trigger," explained Denis. Judy recalled learning from an expert at Duke University Medical School that there were a number of patients with OCD who had Streptococcal

infections right before they developed OCD symptoms. In 2012, there still is no documented cause for OCD, although it is more common than once thought and most patients are diagnosed before age 30. The treatments remain the same as Nathaniel received - SSRIs and cognitive-behavioral therapy (CBT).

Breakthrough at 17

When Nathaniel began his sophomore year of high school, his obsession/compulsion with his body, specifically his skin, increased dramatically. This is normally a time when male teens grapple with body anxiety due to puberty.

"He thought his skin was grotesque, when he had a beautiful complexion," Judy shared. He would use all kinds of preparations on his skin, picked at minor blemishes and begged to go to a dermatologist, but never had any cosmetic surgeries, as many with BDD do, she added. Different SSRIs were tried and therapists encouraged CBT, although Nathaniel didn't think this therapy worked for him.

At this point, Nathaniel dropped out of high school and was home schooled. During an appointment with one of the many therapists Nathaniel had seen, he described how he shaved himself with the bathroom light off, trying to avoid looking at his face. Judy and Denis said with this description, the therapist recognized this behavior as a symptom of BDD. Familiar with the disorder, the therapist introduced the Asselins to the work of Katharine Phillips, MD, professor of psychiatry at Brown University, Providence RI, and director of the body image program at Rhode Island Hospital.

Phillips was finishing her psychiatric residency at Harvard, in the late 1980s, when a troubled woman reported her misery was completely related to her hair. Phillips did research and found references to an obscure disease, BDD. She learned these patients described some part of their body - usually nose, skin, hair and hips - as "ugly, abnormal or deformed."

Today, Phillips is the leading expert and researcher on BDD in the U.S. Her research has led clinicians to become more aware of the disorder and how to treat it. Phillips is hopeful further brain and neurological imaging will result in more findings about BDD that will aid in diagnosis and treatment. Wrote Phillips, "If you haven't known someone with BDD, it's easy to trivialize; but if you see how devastating this disorder can be, you take it seriously."

Final Months

Nathaniel had seen Phillips twice for diagnosis and treatment. He felt relieved that she completely understood his symptoms, especially his decreased quality of life. He was also reassured when the expert told him he was getting the best treatment available. Judy and Denis remember Nathaniel's last few months before he died. He was helping to coach the local middle school's cross-country team in the fall of 2010. "He enjoyed this so much and was less anxious. As always, the younger students enjoyed working with him."

When this activity ended, Nathaniel was very sad. He relapsed quickly and his parents believe he just couldn't bear the return of his torment.

Shortly after Nathaniel died, his sister Carrie was scheduled to graduate from college. Her last course was a pilgrimage on the Camino de Santiago in Spain. This pilgrimage route attracts people around the world who are facing a life transition. Carrie asked her parents to join her on the 2-week trek "so that we could begin together to grapple with the injustice and enormity of our loss," Judy wrote in her article.

One year after Nathaniel's death, Denis began another pilgrimage to honor his son and build awareness about BDD. He walked 525 miles in 45 days, beginning at the Asselin home and finishing in Boston. He visited every treatment center, clinic and hospital where his son had been treated, met many who knew or had BDD. Denis raised \$25,685 from the pilgrimage that was donated to the International OCD Foundation in Boston. It is being used to support BDD awareness and research. The Asselin family is dedicated to actively working to help others with BDD improve the quality of their lives.

For more information about BDD, e-mail Judy and Denis Asselin at walkingwithnathaniel@gmail.com.

Kay Bensing is a frequent contributor to ADVANCE.

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