Katelyn Creech
photo by Chris Fritchie

Coping with Chronic Illness

By Jennifer Nelson

HAVE YOU EVER seen someone who appeared healthy park his or her car in a space reserved for the disabled? Did you wonder why the person was allowed to park in that space? If so, you're definitely not alone.

Katelyn Creech, a 19-year-old college student living in Frisco, said she used to question people in those situations. She'd think that because they looked healthy, they must be healthy. However, her diagnosis with an invisible chronic illness has changed her point of view. "I don't think I'll ever look at anyone who gets out of a car parked in a space reserved for the disabled the same, even if they don't have a wheelchair. I've learned that there are invisible chronic illnesses that I can't see but affect people every day. I'm learning not to make snap judgments."

CHRONIC ILLNESS

The term "chronic illness" has begun to appear more often in the media. An Internet search comes up with more than three million hits. What's even more astonishing though, is that more than 90 million people in the U.S. are dealing with a chronic illness, according to the 2004 U.S. Census. That amounts to approximately one out of every three Americans.

A general definition of chronic illness is a health condition or conditions that last for more than a few months. Some chronic illnesses eventually go away, perhaps as a child out grows it. Other illnesses require management for the person's entire life. These conditions can be anything from asthma and diabetes to chronic fatigue syndrome and cardiovascular disease.

POTS is a disorder in which the body can't make the necessary adjustments to counteract gravity when standing.

Many times we think of chronic illness as only affecting adults. However, Forbes.com reported in June "chronic conditions now affect 15 to 18 percent of children and teens." Katelyn Creech and Nikki Darwin are two of those young people who live with chronic illnesses. Both of their illnesses are lesser known than those mentioned above and are also "invisible," meaning Katelyn and Nikki appear healthy to someone who doesn't know them.

KATELYN AND POTS

Katelyn's perspective about people who look healthy changed after she was

diagnosed with postural orthostatic tachycardia syndrome, also called POTS. The diagnosis was made in April 2007 after six months of being bounced around from doctor to doctor when she began to feel dizzy and exhausted. While her condition baffled some and caused others to mislabel it, one doctor noticed that her heart rate was too high for the average teenager simply walking around a room. He sent her to an electro-physiologist who did a tilt-table test, during which Katelyn had to lay on a table that tilted her to an almost-standing position. The results from this test led the doctors to diagnose her with POTS.

POTS is a disorder in which the body can't make the necessary adjustments to counteract gravity when standing. Each person's body reacts differently, but this can cause fainting, fatigue, lightheadedness, a rapid heartbeat, anxiety, generalized weakness, nausea, shortness of breath and more. According to www.POTSPlace.com, people with POTS "use about three times more energy to stand than a healthy person. It is as if these patients are running in place all the time. Research shows that POTS patients' quality of life is similar to those with congestive heart failure and chronic obstructive pulmonary disease." POTS can show up at any time in a person's life and is often triggered by a virus, giving birth or being exposed to stressors such as surgery, trauma or chemotherapy. In Katelyn's case, a previous heart condition is thought to be linked to her developing POTS.

When Katelyn was first diagnosed, she said it felt like she was going through a grieving process. "My life as I knew it before was changing completely. I had different times of anger and confusion. It took a while to realize this was something I was going to have to live with."

While there is no cure for POTS, there are a variety of techniques that can lessen its effects. In August, Katelyn met with Dr. Benjamin Levine, a cardiovascular disease physician in Dallas. He said her heart was basically like the Grinch's heart – it was three sizes too small. Dr. Levine thought that if Katelyn worked to enlarge her heart by strengthening her legs and performing cardio activities, it was possible that she would feel much better after five to six months.

Nikki Darwin

photo by Chris Fritchie

Katelyn says having POTS has affected her in a lot of ways. Any physical activity is extremely tiring. This limits activities like walking around the mall and going to her classes at Collin College. Katelyn enjoys singing and musical theater, so she was quite devastated at first to learn that she might not be able to do those things anymore. She is also more prone to being anxious and stressed because POTS makes her heart beat faster than normal.

Most of Katelyn's friends have been very helpful. She has, however, encountered people who just don't understand. "There've been people I've talked to who don't understand it at all because I don't look sick. That's one of the things about having an invisible chronic illness. One lady came up to me and said, 'You look so good.' And I just thought, 'Thank you! I don't feel very good, but I'm glad I look good!'"

Overall, Katelyn has a positive attitude, a lot of which has to do with her faith. "I'm a Christian, so I believe that all of this happened for a purpose. I can question that purpose all I want to, but I need to learn how to live with it and cope with it." She says her realization that so few people really understand POTS and other chronic illnesses has motivated her to help educate others.

NIKKI AND EDS

Nikki Darwin, a freshman at Creighton University School of Nursing, loves basketball. She's played since she was in the seventh grade. In high school, her 6' 1" frame along with her natural ability allowed her to excel in the game. During her sophomore year, Nikki began to have excruciating back pain. She spent months in doctors' offices having x-rays taken and blood drawn until a doctor on the board of the Ehlers-Danlos Foundation reviewed her case. He determined that she had Ehlers-Danlos Syndrome (EDS).

People with EDS do not produce collagen correctly. Collagen is the "glue" that adds strength and elasticity to connective tissue. This tissue should be

providing support to many body parts, including the skin, muscles and ligaments. Depending on the severity and type, EDS can lead to extremely serious and even life-threatening conditions. While EDS is genetic, many children often don't develop the condition until after puberty, just like Nikki.

People with EDS can have a wide variety of symptoms. Nikki had always been sensitive to light and extremely flexible. After she was diagnosed, Nikki also began to have neurological problems, occasionally forgetting what she had done during the previous day or week. After a game of basketball, Nikki was barely able to move for the next few days. In addition, Nikki developed POTS because her blood vessels are more elastic than normal, creating problems circulating blood to her heart. Other symptoms can include an extra high palate, a small mouth and easy bruising. These are just a few of the possible signs.

As with POTS, there is no cure for EDS – just ways to manage it. Nikki has had to discontinue basketball. After she began to have neurological problems, the doctors realized that the connective tissue around her brain stem isn't holding it in place like it should. If she were hit or jolted in a certain way, it could lead to serious brain injuries. She's also been told to exercise regularly to keep her muscles strong, using techniques that will work her muscles without overextending her joints.

"It was really hard being unable to play basketball, especially last year – my senior year," said Nikki. "I was still on the team. I just wasn't playing. I was more like a coach. But it was hard to sit on the bench while wanting to play."

While EDS is genetic, many children often don't develop the condition until after puberty, just like Nikki.

Nikki says it has been easier to deal with since she is no longer involved in organized basketball, but she does still go shoot around at the gym. "I just have to take things as they come. I'll have a couple of days where I won't really remember what's going on. I just have to take it as it comes."

EDS often runs in families and Nikki's two brothers have now been diagnosed with the chronic illness. Together they are involved in a study at the National Institutes of Health in Baltimore, Maryland, in the hope that they can help find a cure. She has also raised more than $6,000 for the Ehlers-Danlos National Foundation with "Nikki's JPII Charm Project." Nikki and her classmates at John Paul II High School in Plano, along with Peer Assistance and Leadership (PAL) and the National Honor Society, hired a Texas artist and jeweler to create sterling silver charms and lapel pins of the high school crest. These continue to be sold, with all proceeds going to the EDNF.

CHRONIC ILLNESS AND YOU

Both Katelyn and Nikki learned a few things through their experiences. First, chronic illnesses can be difficult to diagnose. If you think you have a chronic illness, don't give up, even if it takes a little while to determine a diagnosis. Search for doctors who deal with chronic illnesses or the specific illness you think you have. Do your own research, but of course always see a doctor. Next, Katelyn and Nikki also learned that because they look healthy, others often forget they do have difficult days. Don't judge others by how they appear on the outside. You never know what might be going on inside.

Jennifer Nelson is a freelance writer living in Frisco.

More Information on Chronic Illnesses

www.potsplace.com
www.chronicbabe.com
www.dynakids.org
www.restministries.org
www.invisibleillness.com
www.ednf.org
www.firstgiving.com/nikkidarwin