

A Proactive Approach To Holidays For People With Chronic Diseases

(NAPSA)—A house full of guests. Cooking for a crowd. Financial pressures and end-of-year deadlines. For many, the holidays can evoke feelings of stress rather than cheer. For people living with chronic rare diseases like Michelle Hardy, stress may have an even greater impact.

Michelle experienced her first attack of a rare disease called hereditary angioedema (HAE) when she was 17. After having her wisdom teeth removed, the swelling she experienced was far from normal: Her eyes swelled shut and her lips were so swollen she was unrecognizable. Michelle's doctor didn't know how to treat the attack, but within a few days, she was back to normal.

At the time, neither Michelle nor her physician knew that she was living with HAE, a rare genetic disorder that causes painful and potentially life-threatening swelling attacks through the body, including arms, legs, face, abdomen and upper airway.

Michelle spent nearly 20 years coping with HAE attacks before she was diagnosed. During this time, she did her best to battle through her symptoms and not let HAE interfere with her life. She also became aware of the importance of stress management and wellness when living with chronic diseases.

"For HAE patients, and for everyone, living a healthy lifestyle means not just treating the symptoms of your disease, but taking a proactive approach to wellness and being an informed patient. For people with genetic disorders, being informed means that they know their family's history with the disease and have shared that information with their physicians. We can then use that information to develop an effective treatment plan," said Dr. Mark D. Scarupa of the Institute for Asthma & Allergy, who has been treating HAE patients for over 10 years.

Michelle sometimes felt as though stress management was just another item on an extensive to-do list at a busy time of the year. She found that by living mindfully, she was able to enjoy the holidays and make the most of time with her family. If you have experiences similar to Michelle's, stress management coach Pamela Cappelletta, Ed. D., NCC, recommends the following tactics to manage stress:

- Adjust your perspective: Set your intention daily to be positive and hopeful.



- Identify and understand your personal stressors.

- When you feel yourself getting stressed, stop and take deep breaths.

- Adopt a healthy lifestyle through diet, exercise and good sleeping habits.

- Talk to your doctor if you find yourself overwhelmed by stress.

For families like Michelle's, the holidays can also provide an opportunity to discuss rare genetic disorders such as HAE. In Michelle's case, she was able to get diagnosed, after 20 years of mystery, because her sister heard about HAE from a physician friend. By sharing that knowledge, others in Michelle's family have been able to get an HAE diagnosis sooner. As the case of Michelle and her family demonstrates, discussing rare genetic disorders can bring previously unknown information to light and help family members in understanding their disease.

"Once I received my diagnosis, I took control of my life," Michelle said. "I became an expert in my hereditary angioedema tailored treatment, understanding its genetic origins in my family, and how to apply stress management and wellness tactics to provide myself the opportunity to lead a healthy lifestyle even with this disorder."

Today, Michelle knows that stress management is an important part of maintaining her general well-being. She considers herself lucky that in addition to her supportive family and friends, she was able to find an organization dedicated to advocating for people living with HAE, the US Hereditary Angioedema Association (US HAEA, www.haea.org). Her challenging path to diagnosis also inspired her to become a Patient Ambassador for Shire (www.shire.com), a pharmaceutical company focused on rare diseases like HAE, to help raise awareness about HAE and the support available.