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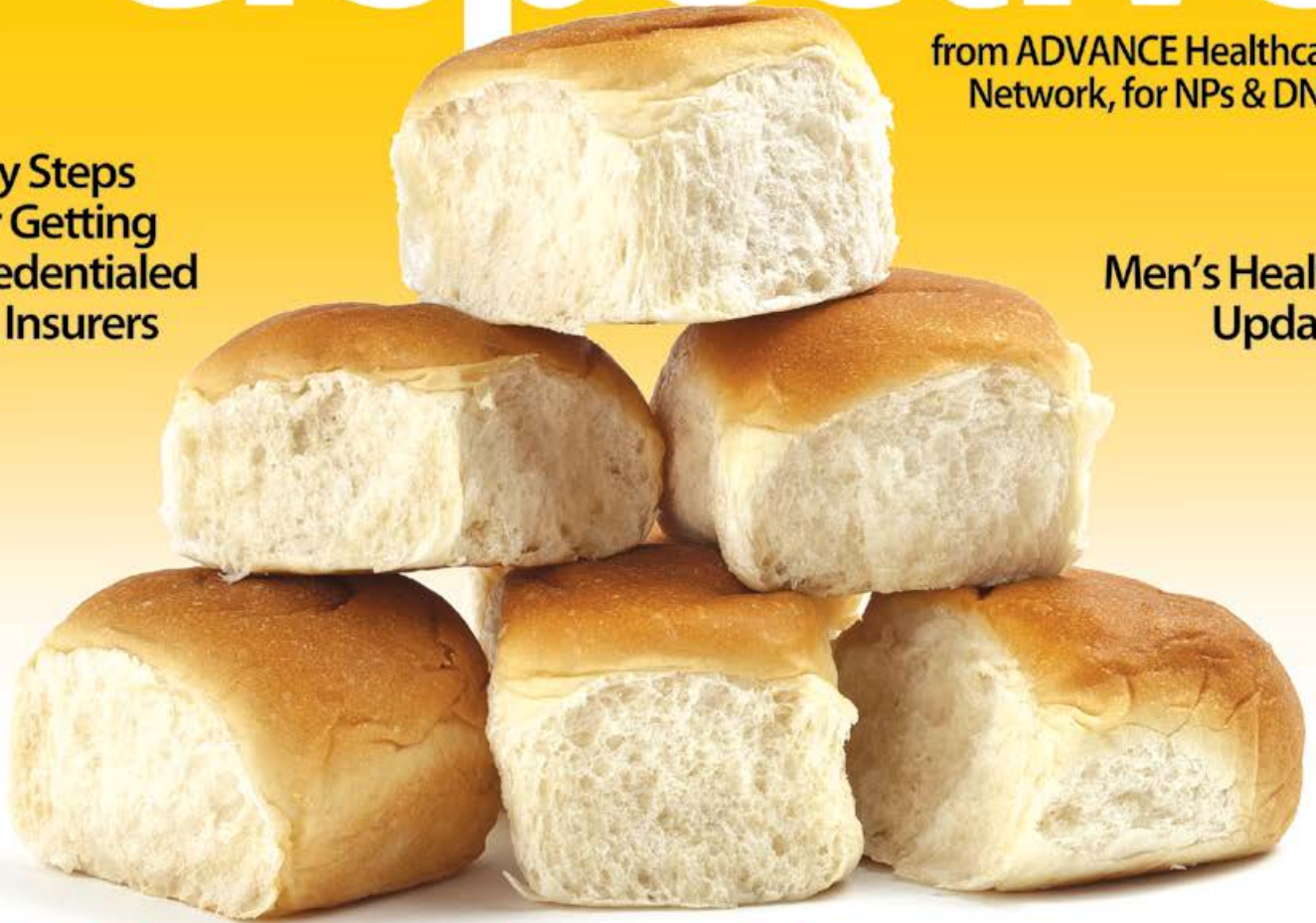
Nurse Practitioner Perspective

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Celiac Disease Update

**A majority of patients go undiagnosed
due to a lack of understanding**

By Catlin Nalley



May is Celiac Disease Awareness Month, however, because the majority of cases are undiagnosed, efforts to educate the healthcare community and public are necessary year round.

Celiac disease is an autoimmune disorder that occurs in genetically predisposed people. The ingestion of gluten by people with celiac disease results in damage to the small intestine. An estimated 3 million Americans have celiac disease, but 2.5 million of them have not been diagnosed, reports the Celiac Disease Foundation (CDF; celiac.org). Without treatment, celiac disease can lead to health problems including type 1 diabetes, anemia, osteoporosis and intestinal cancers, according to CDF.

Given these effects, why do the majority of people with celiac disease go undiagnosed and untreated? The condition's widely varying symptoms, as well as a lack of understanding among healthcare professionals, are key contributors.

Signs & Symptoms

To accurately diagnosis celiac disease, providers must first have the expertise to recognize its numerous symptoms. More than 300 signs and symptoms have been associated with the condition, explained Marilyn Geller, chief executive officer of CDF. These symptoms include anemia, fatigue, vitamin deficiency, abdominal pain, bone or joint pain, and seizures.

"Unfortunately, the symptoms of celiac disease can be very nonspecific, meaning they can mimic a lot of other conditions as well," explained Christine Salem, MS, APRN, FNP-C, a nurse practitioner in the Division of Gastroenterology, Hepatology & Nutrition at Ohio State University Wexner Medical Center in Columbus. "Given the array of symptoms, it is important that providers remain vigilant.

"Celiac disease is a disorder of malabsorption, therefore, providers should watch for signs of weight loss, abdominal distress, bloating, fatigue, and loss of appetite, to name a few," Salem continued. "All of these are red flags that should trigger a celiac disease diagnostic."

Jody Morris, MSN, RN, APRN-BC,

a member of CDF's board of directors, learned firsthand the challenges of diagnosing celiac disease. "My daughter wasn't diagnosed by her pediatrician, but rather by one of my nurse practitioner friends," she explained. "It was failure to thrive for my daughter, not the normal gastrointestinal issues that made it more difficult to recognize."

As a nurse practitioner, Morris recognizes the important role her profession can play in accurate and timely diagnosis. "In healthcare, you must consider every possibility," she said. "And nurse practitioners are in the perfect position to recognize celiac disease early and help patients get the specialized care they need."

Education Efforts

In an effort to increase the number of diagnoses made, CDF and organizations such as the National Foundation for Celiac Awareness (www.celiaccentral.org) and the Celiac Support Association (www.csaceliacs.org) provide education to providers as well as patients.

Healthcare professionals interested in enhancing their understanding of the disease can do so through continuing education courses and conferences. CDF conducts grand rounds at various hospitals every year. "Our top priority is filling in the gaps when it comes to diagnosing celiac disease," said Talia Hassid, communications coordinator

for CDF. "And that is done by educating both practitioners and patients.

"More often than not, the responsibility falls on the patient to request the diagnostic tests," she said. "One of the primary tools that we have on our website is a Celiac Disease Symptoms and Conditions Checklist that allows people to compare their symptoms to those of the condition."

The printable document is a useful tool to share with a provider and prompt the necessary testing. If a patient needs to find a practitioner who has experience with celiac disease, CDF's Healthcare Practitioner Directory is a useful free tool and is available at celiac.org/directory.

Confirming the Diagnosis

Once patient and provider determine that celiac disease could be a possibility, diagnostic testing is necessary.

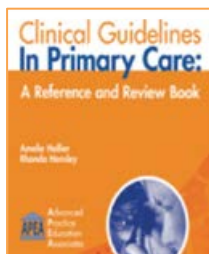
"The first thing we do is order a celiac serology, a blood panel that tests for specific markers," Salem said. "At this time we would also check for any vitamin deficiencies."

Markers for celiac disease include elevated levels of anti-tissue transglutaminase antibodies (tTG) and immunoglobulin A (IgA), Salem explained. However, these results do not produce a definitive diagnosis.

"Following the serology, patients with elevated levels of tTG and IgA will undergo esophagogastroduodenoscopy [EGD], an



Dr. Amelie Hollier,
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endoscopic procedure that involves biopsy of the small bowel to look for damage to its lining,” Salem said. “The EGD has long been considered the diagnostic gold standard for celiac disease.”

People who have a first-degree relative with celiac disease have a 1 in 10 chance of also developing the disease; therefore, when someone is diagnosed, family members are encouraged to be tested as well, noted CDF’s Geller.

“Celiac disease can develop over time, so this testing is recommended every 2 years for the rest of their lives,” Geller explained. “Family members can utilize antibody testing, but there is also genetic testing, which will identify whether someone has the genetic marker for the disease.

“If results reveal that someone has the genetic marker for celiac disease, there is a possibility that they will one day develop celiac disease and therefore require continued testing,” Geller said. “This can be very useful, especially for large families.”

Some people may not be diagnosed with celiac disease but exhibit sensitivity to gluten. Gluten sensitivity presents with some symptoms associated with celiac disease, but it does not result in damage to the small intestine. As with celiac disease, the only treatment for gluten sensitivity is to follow a gluten-free diet.

“While gluten sensitivity is still a gray area, it is a common disorder that should be addressed,” Salem said. “It follows the same diagnostic procedure as celiac disease; however, the patient’s EGD will not show the same damage to the small bowel.”

When a patient shows signs of gluten sensitivity, Salem puts them on a gluten-free diet for 2 weeks and then slowly integrates gluten back into their diet to determine their level of intolerance. “Oftentimes, patients will come to me and question the validity of their symptoms,” Salem said. “It is our job as providers to reassure them. Gluten sensitivity is a very real disease that requires equal attention.”

Going Gluten-Free

Adopting a gluten-free lifestyle can be daunting. “When faced with the consequences of not going gluten-free, most

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people are committed to changing their lifestyle, but it can be an overwhelming process," Morris said. "I would refer to a dietitian who has experience working with celiac disease. There is a steep learning curve when it comes to a gluten-free diet. However, with the right support a patient committed to health will be successful."

Raised awareness and increased diligence has made the process easier. In 2014, the FDA instituted its "Gluten-Free Labeling Rule," which permits manufacturers to label a product gluten-free only if it contains less than 20 parts per million (ppm) of gluten.

"Adopting a healthy, gluten-free diet requires constant consideration," Hassid said. "Simply switching one food item for its gluten-free equivalent does not guarantee better health.

"With higher fat and sugar levels in some gluten substitutes, patients may find themselves gaining weight and wondering what they are doing wrong," she continued. "The

healthiest plan of action is to adopt a diet that is as naturally gluten-free as possible; otherwise patients will find they aren't much healthier than they were before."

Lifelong Diligence

Celiac disease requires lifelong diligence. Adhering to a gluten-free diet does not eliminate every risk. Patients should undergo antibody testing again 6 months after diagnosis and continue with yearly follow-ups afterward, Morris said.

"The risks associated with celiac disease do not disappear after a patient begins to live gluten-free," Geller noted. "And with a correlation to a number of other autoimmune diseases, such as type 1 diabetes and multiple sclerosis, continued monitoring and follow-up is needed.

"This myth has been created that going on a gluten-free diet cures all, but that is sending the wrong message to people who have celiac disease and the public as a whole," she said. "Misconceptions

like this and a continued lack of understanding make the role of healthcare providers all the more important. It is their responsibility to have the knowledge and expertise to not only treat patients with this condition, but also to provide education to the community at large."

"The most important thing to remember is to listen to a patient's symptoms and what they are feeling," Salem emphasized. "As a nurse practitioner I have learned that patients know their bodies very well and when they come to us in distress, we have to pay attention.

"Patients with a true celiac intolerance are missing important nutrients that they need daily to survive," she concluded. "We are witnessing a global epidemic, which is why it is important that healthcare providers remain diligent and always listen to their patients concerns." ■

Catlin Nalley is the associate editor. Contact: cnalley@advanceweb.com

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North American Congress of Clinical Toxicology	San Francisco, CA	October 8-12
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