

## Providing Gluten-Free Services Can Make a Difference

by Susan Lockhart, PhD and Maria Rivera-Trudeau, MBA<sup>3</sup>



Susan Lockhart, PhD



Maria Rivera-Trudeau, MBA

The Gluten Intolerance Group (GIG)<sup>1</sup> estimates that 30% of people newly diagnosed with celiac disease are age 60 years or older. In 2003 it was reported that more than 2 million people in the United States had celiac disease, or about 1 in 133 people.<sup>2</sup> Numbers are now estimated to be 3 million for people with celiac disease and an additional 18 million for people with gluten intolerance. When gluten-free individuals seek healthcare services, they need to consider a facility's ability to meet their gluten-free needs.

A major teaching hospital in the Southeastern United States recently received low satisfaction scores from Maria<sup>3</sup>, an over age 60 gluten-free patient. Even though her medical care was excellent, her hospital experience was not. She thought she had prepared the facility for her gluten-free needs. She filled out and made copies of GIG's hospitalization forms and took them with her to her pre-admission appointment. The admissions nurse sent the forms to the hospital Food Services and Pharmacy Departments and put them in her chart.

Alas, when her hospital meals began to arrive, they contained foods like wheat biscuits, liquid commercial egg mixtures and malt vinegar, none of which are gluten free. It took her three days, and multiple conversations with Food Services staff and supervisors, to get gluten-free meals. She was told that the main problem was only three members of the Food Services staff knew how to input gluten-free menu codes into the computer correctly and they were off duty. Her dissatisfaction with the facility illustrates the importance of training all staff and of establishing policies and procedures for caring for and for monitoring services for gluten-free patients.

With her medications, Maria had better luck. As she was being prepared for surgery, the staff checked to make sure the IV form of the antibiotic her surgeon ordered was gluten-free because the pill form was not. The pharmacist verified that the IV form was gluten free. The pharmacist later gave her a list of the gluten-free medications on formulary so she could confirm that all her medications were gluten free.

Based on Maria's experience, the authors have these recommendations for facilities seeking business from the growing gluten-free community:

- Educate all staff about specific needs of celiac and gluten-intolerant patients and reinforce staff training with reminder messages.
- Make sure patients have identified an advocate to help them with their gluten-free needs if they are unable to speak for themselves.
- Ask gluten-free patients to fill out forms in advance for their chart and key hospital departments, including Food Services and Pharmacy. These forms can be found on the GIG and live2bglutenfree websites.

<sup>1</sup>The Gluten Intolerance Group is a national organization that provides support to persons with gluten intolerances, including celiac disease and dermatitis herpetiformis.

<sup>2</sup>Fasano A, Berti I, Gerarduzzi T, et al. Prevalence of celiac disease in at-risk and not-at-risk groups in the United States. *Archives of Internal Medicine*. 2003;163(3):268-292.

<sup>3</sup>Co-author Maria Rivera-Trudeau, MBA.

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(continued)

- Label the front of the gluten-free patient's hospital chart with "Allergy: Gluten" and give them a hospital bracelet with the same label.
- Provide patients with a list of gluten-free medications on the hospital's formulary.
- Add a specific question to patient evaluation forms to monitor the facility's capacity to care for gluten-free patients. Ask every gluten-free patient to summarize and to share their gluten-free experience to benefit other gluten-free patients and to provide feedback to staff.
- Make staff training modifications as necessary.
- Work with the local GIG chapter to obtain training resources and to communicate the facility's gluten-free awareness and capacity to provide gluten-free services.

With the internet, social media and active gluten-free support groups, it is easy for gluten-free patients to share their healthcare encounters; good or bad. Taking steps to make your facility safe for gluten-free patients can lead to good public relations with the growing number of gluten-free community members. If these community members know a hospital or assisted living facility can provide gluten-free services, they will be more likely to select it.

*For more information on living gluten free, recipes and resources visit [www.live2bglutenfree.com](http://www.live2bglutenfree.com).*

*The authors are health professionals who are now retired from careers in Federal service. They were both diagnosed with gluten intolerance as adults. They started their website and blog to help other adults who are newly diagnosed with gluten intolerance or celiac disease adopt and maintain gluten-free lifestyles.*