Aging GLUTEN FREE

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As the population ages, assisted-living facilities and nursing homes have to accommodate more residents with celiac disease. Are they prepared?

BY HEATHER R. JOHNSON

Victoria Gavanza knew it would be hard to find a nursing home for her grandmother, Eleanor, who had both dementia and celiac disease. After a short stint at one facility, the family noticed Eleanor routinely clutching her stomach in pain.

After Eleanor's repeated illnesses from eating gluten-containing foods, her family moved her to Cardigan Nursing and Rehabilitation Center, a small facility in Scituate, Massachusetts. She was the home's first celiac resident. The facility carefully accommodated her needs. When Cardigan staff learned that two family members had celiac disease and gluten sensitivity, they prepared gluten-free meals for the whole family during holidays. "It worked out seamlessly," Gavanza says.

Unfortunately, not every senior with celiac disease has such a positive long-term care experience. Charlie Wilson, of Hixon, Tennessee, ate gluten-free bread and hamburger patties for every lunch and dinner during a two-month stay at an assisted-living facility because those were the only safe options they had available.

While some institutions, such as colleges and universities, have started to put more attention toward providing gluten-free meals, nursing homes and assisted-living facilities—where residents often can't choose for themselves—still fall short.

According to The Big Picture survey from FoodService Director, a publication geared toward the non-commercial foodservice sector, 94 percent of colleges provide gluten-free options for residents compared to only 51 percent of long-term care and senior living facilities. Meanwhile, the rate of celiac diagnosis is increasing, especially among middle-age adults.

A 2009 Mayo Clinic research review reports that one-third of new celiac disease cases are diagnosed after age 65. Another study found that 2 percent of older adults have celiac disease—double the rate of the general population.

Compound those figures with the aging American population, and it's fairly certain that the number of gluten-free individuals placed in long-term care facilities will increase. Much as one would find when dining out, some facilities are well versed in gluten-free best practices and prepared to serve gluten-free meals, while others don't want the responsibility.

Consistency varies by facility and from day to day, says Beckee Moreland, director of the Beyond Celiac GREAT Kitchens program. "One day your entrée may show up covered in gravy, and the next time, it's not," she says. "If facilities don't have consistency in food quality and service with standard menu items, it will be difficult for staff to be consistent with gluten-free meals, even when that lack of consistency may have health consequences."

A few companies are making extra effort to provide consistency. Moreland says that at least 12 facilities have taken part in GREAT Kitchens' optional gluten-free education and awareness training. Skilled nursing and assisted-living company Care One, LLC, recently trained staff in all 70 of its facilities on preparing gluten-free diets. And GenCare Lifestyle, which has four senior and assisted-living facilities in Washington and one in Arizona, acquired a gluten-free food service certification in 2010 through the Gluten Intolerance Group's Gluten-Free Food Service Program (GFFS). That's the good news.

MISTAKES HAPPEN

In an article for Celiac.com, Curtiss Ann Matlock writes about the long struggle of trying to find a nursing home for her 88-year-old mother. Diagnosed with celiac disease at age 75, her mother had suffered a stroke and glaucoma in "rapid succession."

At the chosen facility, Matlock's mother received some gluten-free meals, but also sandwiches and cookies, hot dogs and French fries. Eventually, Matlock moved her mother into her home.

This situation isn't uncommon. Mistakes happen often in health care settings, whether it's a sandwich served to a resident with celiac disease or a slice of cake given to a patient with diabetes.

"Health care settings make mistakes with diet orders of all kinds, not just gluten free," says Janelle Smith, M.S., R.D.N., "Ask the Dietitian" for the Celiac Disease Foundation. "These are failures in the execution of the procedures and policies of that facility."

"There is always potential for tray accuracy errors and for cross-contamination,"

Do your homework

When researching long-term care for yourself or a loved one, ask the food service director or dietitian these questions.

- **Have you accommodated gluten-free residents before? If so, how?** Eleanor fared well as a gluten-free guinea pig. Most do not.
- **What are your food service manager's credentials?** Registered dietitians likely have more knowledge on therapeutic diets than someone who moved through the ranks of food service.
- **May I see your gluten-free meal plan?** If they have one, make sure it provides adequate nutrition. If they don't, ask if they will prepare a gluten-free menu. Ronni Alicea, R.D., MBA, a dietitian in Somerset County, New Jersey, and an expert in gluten-free and geriatric issues, says some facilities will only modify their existing menu, which is not an ideal situation.
- **What steps does your kitchen take to prevent cross-contamination?** "If the facility doesn't have any procedures in place, you will know very quickly," says Smith.
- **Are you able to mark or designate a special tray?** Some facilities mark special meals with a flag or a sticker, which helps staff differentiate between regular and therapeutic meals.
- **Are you able to provide one-on-one staff at meals?** A patient with dementia, for example, may need someone to double-check his or her meal.
- **Are you able to add a standard manager tray-check before staff delivers the meal?** In this case, the manager personally checks the meal before the patient receives it. "Some facilities will allow a tray check for every meal," says Smith.
- **How do you source or prepare food for your residents?** Find out if they prepare food from scratch, use prepared foods or order from a major supplier. Make sure the facility provides gluten-free alternatives for bread, pasta and other standard items.

Not getting the right diet? Advocacy is the best policy.

- **Make unexpected visits.** A surprise visit will allow you to see how staff operates on a given day. Sit with your loved one during mealtime to observe how staff handles the meal.
- **Have a private stash.** Keep gluten-free snacks in the patient's room. "The evening aids may be less knowledgeable about gluten free," says Alicea. Make it easy for them to serve a safe bedtime snack by keeping a box of gluten-free cookies or crackers in the room.
- **Communicate with staff.** If you notice a regime change, make sure the new staff knows about the therapeutic diet.
- **Speak up.** If staff makes a mistake, inform the dietitian. Repeat as necessary. "Make your voice heard," says Hellberg. "Let them know your needs and that you expect them to be met." If proper meals still don't happen, speak with the executive director or another administrator.
- **Contact the Better Business Bureau (BBB).** If communication with directors and executives falls short, contact the BBB and/or state licensing boards. "They need to know if something is not working well," says Smith.
- **Contact your state's long-term care ombudsman program.** The long-term care ombudsman advocates for nursing home, board and care home, and assisted-living residents. The facility should have the address and phone number of the local ombudsman posted. Visit consumervoice.org to locate your ombudsman.

says Kelly Hellberg, M.S., R.D., C.D.N., a consultant with CMS Compliance Group, a regulatory compli ance consulting firm that works with long-term care providers. "These errors aren't necessarily prevalent, but you do find them. The potential is there for a celiac resident to receive a food they are not supposed to have."

Occasionally, residents make mistakes or don't know to say no. A patient may sneak food off another's plate when the staff isn't watching. Residents with dementia, like Eleanor, may eat whatever staff serves them because they no longer know what's safe. Fortunately for Eleanor, Cardigan Nursing knew how to intercept. "They understood what her needs were and worked with us to develop a plan," Gavanza says.

BARRIERS TO CONSISTENCY

It's easy to cook a gluten-free meal at home, where you have complete control over the environment. Preparing a gluten-free meal at a facility presents a set of challenges as the staff must keep these meals free from cross-contamination while simultaneously making meals for dozens of other patients, many with therapeutic diets of their own.

Lack of awareness remains an obstacle among food service managers and staff to providing safe gluten-free meals. "It's a new component in a system that's already used to dealing with allergies," says Hellberg. "The systems are in place to accommodate gluten free, but it's a new facet."

It takes practically a degree's worth of knowledge to understand what gluten is, the damage it does to the body, how to decipher food labels and how to store food. Food service workers don't receive this level of education when they learn how to prepare and serve gluten-free meals. "They don't understand the detriment of including an allergen on a patient's plate," says Smith.

Food service managers and staff are required to complete training such as the ServSafe® Food Handler Program, but it includes only basic information on allergens. According to the company, its in-depth Allergen Training Program covers celiac disease and gluten intolerance; however, the course is only required in Rhode Island and Massachusetts.

Even if food service workers complete a gluten-free or allergen training course, mistakes can occur when a meal gets passed to an untrained employee. "Within an assisted-living facility's food service system, you have many moving parts—the medical prescription of the diet, the care plan, meals ordered by the dietitian, the purchase of appropriate ingredients, meal preparation, and the staff that takes meals to the room or dining hall," says Moreland. "A lot of people touch and control that food. If you have one untrained or unaware person, you risk a mistake. Facilities have to be consistent and set up a strong system of communication to make the process work."

Although glitches in policy and execution remain, changes are afoot, even if slow moving. According to The Big Picture survey, 73 percent of long-term care and senior living facilities cited gluten free as a trend to watch.

"Gluten free is on their radar, but we need to make sure they understand the medical necessity of the gluten-free diet for those with celiac disease and gluten-related disorders," says Moreland.

"Baby boomers are coming to facilities with more allergies and more preferences," adds Hellberg. "The picture is changing." **GF**

Heather Johnson writes about health, health care and other topics from Oakland, California. She has lived gluten free since turning 40. Visit her at heatherraejohnson.com. Follow @HeatherRae71.

Know your rights

The Americans with Disabilities Act (ADA) protects individuals with severe allergies and autoimmune conditions such as celiac disease. That means a nursing home cannot, under most circumstances, refuse to accept or accommodate a patient because he or she has celiac disease. If a facility refuses you or your loved one, reiterate your rights under the ADA. If you have questions, call the ADA information line at 1-800-514-0301.

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