



Celiac Sprue Association®

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THE NURSING HOME CHALLENGE

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A few of our members have voiced concerns about the care of someone on the gluten free diet in the nursing home setting. This article is dedicated to my mother, Olive S. Wilkins (1905-1993) a person who lived with celiac disease and lactose intolerance from 1958 to 1993.

My mother was diagnosed with celiac disease in 1958 and developed lactose intolerance later in life. After a hospitalization in September 1989, it became necessary to find her a nursing home placement. As her advocate, I visited five nursing homes. She was refused admission to two of them because the staff believed they could not monitor a gluten-free (GF) diet. Perhaps I could have chosen to protest this refusal, as all nursing homes must have registered dietitians on their staffs. However, I believed it would be more beneficial for my mother's care to choose one that was receptive to dealing with the GF diet.

I learned that the registered dietitian (RD) is often only on the premises 2-3 days a week. He/she sets up the dietary plan with the proper nutrition requirements. Fortunately the RD was receptive to my suggestions and tailored the necessary nutritional needs to my mother's individual tastes and dietary requirements. The majority of the day-by-day dietary care fell on the staff and manager of the kitchen, the dining room monitor and dietary aides. The manager of the kitchen went through the storeroom and checked all the labels. She conferred with me about the two-week menu plan and any questionable ingredients. As dinner was served at the noon meal, the evening meal became the most difficult to manage. Often mother's only choice would be a GF sandwich. We agreed that I would supply the GF bread and they would store it in their freezer. In checking out their mayonnaise, it became necessary for me to supply large jars of a GF brand. They allowed me to bring in GF muffins, cakes and cookies in sealed containers. These were stored in the freezer and were served on her tray with the appropriate meal. We kept GF cookies, rice cakes, GF peanut butter, GF brown rice cereal and her favorite GF candy in sealed tins in her room. This way she could supplement her meals and have something for the afternoon socials. I also provided bananas, as the kitchen's supply often ran out by the end of the week. As you will note, this required much time and effort as well as many compromises along the way. Eventually, a cost analysis of mother's dietary intake was done and the manager began to order the bread directly from the supplier.

When Mother was first admitted, she ate in the dining room and was able to monitor her own meals. As time passed, she became less able to do this and started to eat in her room. At this time we had to begin depending on the dietary staff to monitor her meals.

Thankfully, a foundation of education and trust had been laid. Even though there was still an occasional error at my mother's expense, the staff remained open to my perusal of the menu and receptive to suggestions concerning what needed to be substituted or eliminated.

Another area of concern was with her medications. After having the physician specifically order GF and lactose-free medications, I spent some time with the charge nurse voicing the need for Mother to have her own supply of certain medications and to not use the generic supply. Gradually, all shifts realized the importance of these choices.

I cannot emphasize enough the necessity of establishing a good rapport with the staff at all levels of the client's care. Take advantage of the client's rights and have your family or advocate attend the Patient Care Plan Meetings that a nursing home is required to hold on a quarterly basis. This is the place to voice concerns and have them implemented into the plan of care. Find a means for you, your family, or an advocate to become involved in the nursing home routine. Attend the family and resident meetings. Make your presence seen and your voice heard. Volunteer! I served as a waitperson at the spring and fall dinner dances, helped shelve library books, sang hymns at the worship services, and served refreshments at the afternoon socials. These activities can coincide with the days of your visits. All of the above will promote increased awareness and will strengthen the bond of trust and mutual respect with the staff at all levels of nursing home care.

My recommendation is to begin to train an advocate before your aging process becomes critical. Familiarize yourself, your family, and your advocate with the resources that are available (see below). As a team, develop an assertive attitude. Balance a blend of constant commitment to quality care with the necessary compromises to integrate the GF diet into the desired standard of care. Educate yourself, your family members, your advocate, and the nursing home personnel. A well-informed family, client, and/or advocate with a commitment to caring can ensure optimal care for the nursing home resident.

No nursing home should refuse to address the needs of a resident with celiac disease. The federal Nursing Home Reform Law requires that a nursing home provide care to maintain the highest possible level of functioning of residents and must make reasonable accommodation to the needs of its residents. State public health and consumer protection laws also protect the rights of nursing home residents.

Assistance is available for help in resolving nursing home problems. (Thank you to Liane Zeitz, Esq. for her valuable contribution of resources.)

Age Info Center (Telephone; 1-800-243-4636, website: www.800ageinfo.com) can refer you to the local nursing home Ombudsman Program for your area.

Legal services. Free legal services may be available to those sixty years of age and over by contacting your local legal services program (in Massachusetts: www.maslegalservices.org) For referrals to private elder law attorneys, see the website for the Massachusetts Chapter of the National Academy of Elder Law Attorneys (www.manaela.org) or the national website www.naela.org.

The National Citizen's Coalition for Nursing Home Reform (Telephone: 202-332-2275, website: www.nccnhr.org), a national advocacy organization, is an excellent source of information on nursing home issues and has published *Nursing Homes, Getting Good Care There* by Sarah Greene Burger, Virginia Fraser, Sara Hunt, and Barbara Frank. This book is an invaluable resource for families, friends, and caregivers of nursing home residents.