

The Psychological Impact of Celiac Disease

By Kit Kellison

Through some intriguing recent studies, we are learning there exist some worrisome common emotional experiences among celiac patients that will impact their quality of life.

When I queried the ICOR Celiac listserv about how people there coped with celiac disease, I got reflections of many of my own experiences in navigating the illness before and after diagnosis

From the answers sent and the research I've done on the topic, I've found that there are three major types of challenges with which a celiac patient must contend.

The first issue is directly relevant to more than a third of the celiac population. According to a 2009 study published in the journal *Movement Disorders*, 35% of celiac patients report a history of depression, personality changes or even psychosis. As many members mentioned the difficulty in getting doctors and family to take them seriously, the aggravation and demoralization of those who haven't received enough support is particularly problematic for those who have gotten a dose of emotional dysfunction along with disabling somatic symptoms.

Maggie C. of Portland, Maine eloquently spoke of the frustration she felt because of the long delay in her own diagnosis: "I went through a succession of doctors, all of whom had me pegged as a hypochondriac. So I got to thinking of all my symptoms as just symptoms of anxiety, anger, and depression. It didn't help that I was ALSO truly anxious and depressed. Anyway, when I went GF, the anxiety, anger, and depression went away (I like to say: "Buddha ate rice!"). So did the physical symptoms. Now I still have people thinking (and saying) that I'm a hypochondriac because I'm "so picky" about foods, but I care less now about what they think."

Maggie (not her real name) was able to triumph over some serious psychological obstacles in getting a diagnosis; she is almost heroic in summoning the pluck to pull herself together over and over again to face the possibility of yet another esteem battering in the examination room. While

she was able to get the help she had been paying for, I worry about the more average patients in this situation who simply don't have the tools and make-up to do the same. And although she has a valiantly healthy perspective on people in her life who aren't supportive, it is easy to see how taxing it can be to anyone who has to put up a constant defense against insensitive behavior.

Kathy, from California, who was lucky enough to be diagnosed after only 6 months, expresses the emotional toll celiac disease had on her daily life:

“My pre-diagnosis symptoms were primarily emotional. Of, course, I had some gut problems, and some breathing problems, too, but they were nothing compared to how emotionally disturbed I felt--all rather suddenly.

It was ten years ago (!), and my normally upbeat self began experiencing black depressions and bouts of uncontrolled weeping. I just couldn't perk up, and was feeling awful, as though a dark cloud was hovering over me. Because I had no idea what was wrong, I assumed the worst, and my doctor suggested I try an SSRI for mood. Instinctively, I felt that that was not the solution, and that medication would not help.

I was afraid to eat, and lost 15 pounds. This really scared me, and emotionally it compounded the weird experiences I was having...”

I can imagine that it is difficult for the doctor ignorant of advances in celiac disease diagnostic protocol to discern a difference between a very sick patient searching frantically for help and a hypochondriac who researches for reasons to be perceived as ill. Indeed, I doubt there is any difference in how those two types of patients behave. Although we don't know how many people give up looking before they find out why they are sick, the lack of awareness among physicians still appears to be a significant barrier to diagnosis.

The second situation I'd like to talk about begins *at* diagnosis. Once a patient had been lucky enough to find the answer to their deteriorating health, they are told that they must inform their

families that each of them may also be vulnerable to developing celiac disease. I can't count the number of people I've spoken to over my eight years as a celiac patient who have related very tense encounters with immediate family members who have reacted with everything from derision to hostility to their important news. And this at a time when sympathy and support is needed most. Not only does the new patient have a very difficult diet to follow and a sick and damaged body to heal, they have often been scarred just going down an often psychically brutal road to diagnosis.

Colleen of Connecticut wrote: "Communicating the possibility of inherited celiac to my siblings and children was very painful. None of them wanted to hear about it. Denial is real. The best I could do was give them the information and know that they were in charge of their own lives. Most painful of all was my Crohn's diagnosed daughter being unwilling to do a gluten-free trial. After years, she did, and the diet has improved her flares greatly. I don't know whether to be glad she is finally on the wagon, or sad that it took so long, putting her in greater long term danger."

Students of mythology will remember that Cassandra was given a gift by Apollo who was quite taken with her beauty. He gifted her the ability to see the future. But when she didn't return his affections, he added the curse that nobody would believe her predictions. When Cassandra foretold of a great impending tragedy, everyone ignored her tearful pleading.

Just like Cassandra, often celiac patients feel an enormous responsibility to convince immediate family of the importance of this disease. They are told to convey the information to our children, siblings and parents so that they will know what to look out for. They then feel badly on multiple levels when their good intentions are rejected. Not only do they feel unsupported and abandoned in the face of efforts to treat an often devastating illness, they are thwarted in their quest to prevent loved ones from facing the same fate. In addition, there is often additional demoralization when their character or credibility is called into question by loved ones who don't understand that the new restrictive diet is not a personal lifestyle choice, it is the only known treatment for a serious disease.

Sometimes the resulting rifts in the family are never healed, which brings me to the third aspect, the social complications that arise because of the diet. I've heard from many celiac patients over the years who have felt forced into making the choice to cut ties from family and friends over what they perceive as an environment that has proven hostile to their very health.

Some patients do everything they can, however to see the bright side of the situation. I heard from one woman that separation from such family members actually raised her quality of life. Indeed, one respondent who related that although the men who would date her in spite of her difficult diet belonged to a shrinking pool, she felt that it was a good litmus test for mate suitability.

Unfortunately, the social pressures put on the celiac patient can decrease the commitment to dietary compliance. A CD patient who consumes gluten is a much higher risk for certain cancers, heart disease, and of course, psychological illness, letting alone the potential devastation to his intestinal tract and the many other autoimmune consequences.

A study done of 70 Indian school children showed that 18% were non-compliant to the gluten-free diet. From the study: "Dietary restrictions have impact on child's social activities and thus psychosocial parameters (PSC score) are better in the dietary compliant group." In other words, kids who have better support for their diet are more compliant than those who are lacking in social support. It's easy to see how this might apply to adults as well, especially those in care facilities where they little to say about their food choices.

Maggie, who is able to dine out, offered an excellent strategy for dealing with restaurant staff: "The key in restaurants to maintain control of the Q and A. That requires a pro-active state of mind.

My shorthand: 'X and X are probably absolutely fine, but anything, *anything* at all, that comes in a bottle, can or packet is suspect.' Any half-way decent chef is happy to cooperate. When the server comes back and recites said list, I am very positive and cheerful as we check off each okay item. If something's not okay, I just say "oops! oh well. Thanks so much for checking." and on to the next possibility. The goal is to convey a sense that this gf stuff is really really easy,

given just the littlest bit of help. Freak 'em out with worry, and you'll wind up with nothing but a plate of steamed vegetables.”

Maggie also sets a great example when invited to a friend’s home: “When people invite me to dinner, I accept with pleasure, then say they may want to rethink it when they hear how much trouble I am. This gives me a chance to assess their kitchen expertise and make my own decision about whether to push hard for meeting in a restaurant or to insist (ever so nicely) upon bringing my own food.”

Others, including me, feel they are too sensitive to risk restaurant food and just order a drink or bring bottled water. Invariably, tension arises when people who are eating express discomfort when you can’t dine with them. Often, invitations decrease over time and the entire burden of social interaction must fall on the patient. Either the patient entertains, or invites others to outside events, or becomes more and more excluded.

Answering my question about social invitations, one woman noted that when she wants company, it is necessary for her to do all the entertaining, and that invitations are rarely reciprocated.

There is real a need to address issues of social support in celiac disease patients. We know that celiac disease is an autoimmune disorder that, because of its psychological manifestations, leaves patients especially vulnerable to social stress. And stress, of course, has a very negative impact on autoimmune patients in general.

One last think I’d like to touch on before putting this article to bed, is some recent findings concerning cognitive decline in celiac patients. A study in October of 2006 published in the Archives of Neurology shows a link between dementia onset and celiac disease. Says Joseph Murray, M.D., a Mayo Clinic gastroenterologist investigator of the study, "There has been a fair amount written before about celiac disease and neurological issues like peripheral neuropathy (nerve problems causing numbness or pain) or balance problems, but this degree of brain problem -- the cognitive decline we've found here -- has not been recognized before. I was not expecting there would be so many celiac disease patients with cognitive decline.”

Again, the unsinkable Maggie relates a story that is much like my own:

“I was quite sick, though I didn't know it, when I was diagnosed (biopsy, 1996). The cognitive changes were the most consequential and scary. I simply could not hold thoughts together, couldn't reason my way through work-related problems. Had I forgotten how to do what I do? It couldn't be...but it seemed to be.

In a matter of months, I went from being a model of success in the office where I was then working to a failure. Having no idea why I simply couldn't pull it together, I figured my problem was psychological: I had no respect for the executive. I stalled and covered and tried to buy time. No luck. I spent more time in the bathroom than normal, but not so much that I thought anything serious was going on. In fact I was pretty happy to have a few moments to myself and away from the pressure to do something I seemed unable to do. Ultimately and justifiably, they fired me. That was the last big project, in a free-lance business, for which I was hired...but (a big) consequence was the damage to my reputation.”

Those of us who have experienced dementia in our parents and other close relatives know that the slow destruction of the brain can create paranoia, severe anxiety, depression and aggressive behavior. Dr. Murray suspects that in CD, a direct antibody attack on the brain is responsible for the dementia and other neurological manifestations of celiac patients, although it is likely a complex etiology. If the disease can cause numbness, balance disorders, migraines and problems walking, it shouldn't surprise anyone that psychology could be similarly impacted.

ICOR Listserv:

<http://www.lsoft.com/scripts/wl.exe?SL1=CELIAC&H=LISTSERV.ICORS.ORG>

Celiac Disease Increases Risk of Neurological and Psychiatric Disorders: . *Mov Disord*. 2009;24:2358-2362.<http://www.medscape.com/viewarticle/714823>

Assessment of dietary compliance to Gluten Free Diet and psychosocial problems in Indian children with celiac disease [Indian Journal of Pediatrics Volume 77, Number 6](#), 649-654, DOI: 10.1007/s12098-010-0092-3 <http://www.springerlink.com/content/883211r030875r39/>

Cognitive impairment and celiac disease. [Hu WT](#), [Murray JA](#), [Greenaway MC](#), [Parisi JE](#), [Josephs KA](#). *Arch Neurol*. 2006 Oct;63(10):1440-6
<http://www.ncbi.nlm.nih.gov/pubmed/17030661>