

## CHAPTER 6

# Tackling the Emotional Side of CD

*Happiness comes of the capacity to feel deeply, to enjoy simply, to think freely, to risk life, to be needed.*

—Storm Jameson

Celiac disease (CD) is one of the medical mysteries of this century. The obscure symptoms are like a complicated jigsaw puzzle. Only the frame of the puzzle is completed for now but, as research progresses, the complete picture will be seen. The mystery of CD will be solved, and the puzzle completed when all the at-risk groups are diagnosed.

Only another person with CD can comprehend the emotional aspects of CD. Living year after year with a variety of unexplained ailments is extremely frustrating. Those who experience the depression, anxiety, ataxia, or mental foggy understand the significant impact this disease has on the individual and his family. It affects personal relationships, social situations, self esteem, and confidence. The majority of people with CD have been told, "It's all in your head." Family members many times may have developed the habit of "tuning out" their CD family member when they complain.

Eric Cassell describes suffering as: "A state of severe distress caused by events which threaten the integrity of a person." It could easily be said that "suffering" occurs in all CD patients *and* their families.

Because many physicians are still not aware of the prevalence of CD, they are looking for other conditions such as irritable bowel syndrome, chronic fatigue syndrome, fibromyalgia, or Crohn's disease, just to mention a few. This only delays a clear diagnosis of CD and prolongs the suffering.

CD will be recognized as a significant health problem when the pieces of the puzzle are found and the full impact is assessed; some believe that millions of CD patients are undiagnosed. CD may well be the disease of the next decade.

### *Common Emotional Reactions*

Most newly diagnosed CD patients are subject to:

- \* Anxiety
- \* Insecurity
- \* Isolation
- \* Fear of the unknown
- \* Lack of information

Newly diagnosed CD patients need patience and understanding as they educate themselves to a new way of eating. This also applies to the parents of newly diagnosed children, who may feel helpless trying to find the information they need to have a healthy child.

### *Support Groups*

Because doctors may not have the time to educate each individual with CD about the totally new way of life that the disorder demands, celiac support groups know the

importance of support among peers. One support group, the Gluten Free Gang of Central Ohio, uses their group to discuss all new research, recipes, and restaurants in the area and offer support to new CD patients as they enter this new way of life. Here's a transcript of a typical meeting of the Gluten-Free Gang:

"The doctors should address the extreme emotions we experience, but it is rare," Lisa told the group. "After I was diagnosed I was overwhelmed with feelings of guilt and deprivation," Lisa explained. "I felt guilty complaining because many people have a life-threatening illness, such as cancer or multiple sclerosis. I felt guilty because I spent more money on my gluten-free food. I felt deprived because I could not eat exactly what I wanted. Then my feelings jumped back to guilt because people in Third World countries are really deprived of food, not me. The deprived feeling continued for about a year. It was hard to watch everyone dig into my birthday cake, which I couldn't even taste. Then I felt guilty because I was behaving like a child. Restaurant eating was frustrating when I couldn't order what I really wanted," Lisa concluded. "Then I was back to deprivation."

"My wife accused me of turning into a controlling husband because I wanted to become involved in meal planning and what restaurants we went to," Dean said.

"Things have gotten easier for me since I went to an open Alcoholic Anonymous meeting with my friend," Betty Jean said. "My friend explained that he could not drink alcohol because he would end up dead or in jail. He said I would kill myself if I did not eat gluten-free. He showed a lot of empathy for my situation because he just had to stay away from alcohol and I had to watch every drop of food I put in my mouth."

"Do you suggest AA meetings?" a member of the group asked.

"No," Betty Jean said as she laughed, "however, I do think it is a good idea to write down the Serenity Prayer that is said at each AA meeting. Each of us can use it as we adapt to our new way of eating."

#### **The Serenity Prayer**

God grant me the serenity to accept the things I cannot change,  
The courage to change the things I can,  
And the wisdom to know the difference.

"I can use that prayer when I get exasperated repeatedly explaining the disease to friends and relatives," a new member said.

"Think of yourself as a teacher educating the general public," said Maryalice. "You are clearing the path for celiacs in the future."

"What do you do when you are invited to a friend's home for dinner?" the new member asked.

"You can still accept dinner invitations or go to a potluck, just bring your own food. Don't change your social life," Lisa emphasized.

Emotions common to CD patients as they struggle to adapt to a new way of eating include:

- Relief at finally finding out what was wrong.
- Grief over the loss of lifestyle and food.
- Fear of eating something that will make them sick.
- Frustration in finding the right medical help.
- Difficulty in finding appropriate food.
- Difficulty in reading and deciphering labels.
- Difficulty in understanding and overcoming all aspects of depression.

Lucia, a member of the Gluten-Free Gang support group, offers this list of experiences common to all newly diagnosed CD patients:

Looking at a restaurant menu for the first time when trying to order a gluten-free diet (GFD), feeling apprehensive because time is ticking away, silently shedding a few tears, and feeling as if the task is too big to handle.

Trying to decide on a snack or a packed lunch so not to be singled out as different.

Trying to convince family and friends that you cannot go off a GFD “just this once” and “yes, it will hurt me.”

Trying to explain ingredients that indicate gluten in labeling.

Taking two or three additional hours to shop for the family, and that before the trip to the health food store.

Making a daily decision regarding gluten-free ingredients.

Individuals with CD must recognize that they have undertaken a new way of life. These complex feelings are the norm, not the exception, and fortunately, these feelings do not last forever. But because this disease is virtually unknown, you must continually explain it to family, friends, co-workers, teachers, doctors, servers at restaurants, grocers, and many others, almost on a daily basis. When you consider how many contacts are made every day, the challenges are evident.

“Don’t think it is the end of the world,” Mary, another group member said. “It could be worse. Years ago, people did not have support groups or health food stores that now carry numerous gluten-free products. For those celiacs who live in small communities, there are many Internet vendors who also sell gluten-free foods.

“We must remember to mentor newly diagnosed celiacs,” Mary reminded the group. “I can remember coming to my first support group feeling alone, confused, and needing the help of others. I think one of the main

shocks was when I realized how life would be different due to the diagnosis.”

When the mother of a recently diagnosed child walked into the meeting, the consensus of opinion was to ask Barb to share her story. When children are diagnosed with CD the parents have to make the largest adjustment.

“It is interesting to reflect back over the past 2 years since Natalie was diagnosed,” said Barb. “So many emotions come flooding back. In hindsight, I wish we had pushed the celiac testing faster. We are in a minority because Natalie was diagnosed in less than 7 weeks from the first major symptom, though she showed many of the classic symptoms from about 9 months on.

“Dan and I had it pinpointed at about 3 weeks into testing by reading the *Merck Manual*, at our local library, after an upper gastrointestinal series of tests. The numerous tests scared us to death.

“My husband and I reacted very differently after the diagnosis. He was relieved and moved on. I, on the other hand, began to grieve for Natalie. I am getting better, but still have my days.

“I am already a compulsive person and, boy, did her diagnosis set that into overdrive! Nothing like coming home after the diagnosis and gutting your kitchen.

“One time, I remember we were 9 months into our new lifestyle, and I was driving back from my first Celiac Conference at Children’s Hospital. I just burst out into tears and had to pull over. I kept thinking, ‘How am I going to make life somewhat “normal” for Natalie and our family? How am I ever going to learn all of this? It is so overwhelming.’

“I have since thrown out the word ‘normal’ from my vocabulary as much as possible, and my learning curve is beginning to bend a little.

“As parents, Dan and I have to protect Natalie while teaching her to protect herself from food. She has to learn

how to live in a gluten world, and we struggle each day over how to teach her how to do it.

“After our son was born, a dear friend told me, ‘Parenthood is a lifetime of joy and worry.’ Boy, has that phrase taken on even more meaning now. When we have bad days, we always say, ‘This could be a whole lot worse.’ And we know that it could. We thank God for what we have.

“We are all healthier because of Natalie and we know it.

“The Gluten Free Gang has been a blessing. Those of us with kids often struggle, since we are outnumbered by the adults. I have really focused on gathering up parents of children with celiac disease. Several are now coming back to the support group meetings.

“I also have tried to keep us all in contact via e-mail. With young families, it is hard to get to meetings, so we write each other as often as possible with questions, concerns, or just funny stories,” Barb concluded.

### *Support and Education*

Everyone at the meeting gave her a round of applause because, even though they might not have a child with CD, they were able to take courage, hope, and strength from her experience.

Living gluten-free is a choice for health’s sake. When the alternative makes you a high risk for several forms of cancer, plus other catastrophic symptoms, it is understandable that each day you must make a deliberate decision to maintain a gluten-free life. This daily decision takes personal determination, family support, and a physician who is aware of how to treat CD.

The CD community offers an extended helping hand to new CD patients and to anyone who needs guidance in dealing with the disease. Physician’s information is available through the CD community, to provide patient

education and resource materials so that appropriate referrals can be made.

Many people with chronic diseases choose to go into a state of denial. This situation creates a condition in which the family must either “play act” to enable the denial or become confrontational and attempt to expose the denial. In this situation, an integrated health care team can identify the problem “up front.”