



Five Things Everyone Should Know about Celiac Disease and Quality of Life

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For many people, being diagnosed with celiac disease (CD) brings a feeling of relief and the end to a long, frustrating road of unknowns. However, along with the relief, the diagnosis can also bring more questions including, "What kind of life am I going to have now?"

The answer to that question is "It depends." The official recommendation of the American Gastroenterological Association Institute (2006) regarding the treatment of CD is strict compliance to a gluten-free diet (GFD). While being diagnosed with CD may be out of your hands, the quality of life you experience after diagnosis may be within your control largely based on your adherence to a GFD.

Based on research, following are five things you should know about CD and quality of life.

1) You will probably feel better after implementing a GFD...at least for awhile.

Two studies (Mustalahti, 2002; Nachman et al., in press) examined quality of life, gastrointestinal symptoms, and dietary adherence in participants diagnosed with CD. Their quality of life and gastrointestinal symptoms were compared to those of healthy non-celiac participants.

At the time of diagnosis. Mustalahti et al. (2002) reported the healthy non-celiac group and the group with screen-detected CD had similar quality of life assessments, which were significantly higher than those of the symptom-detected group¹. For gastrointestinal symptoms, researchers reported the same trend. Gastrointestinal symptoms at diagnosis were significantly worse in the symptom-detected CD group than in the screen-detected CD or the healthy non-celiac group. However, these symptoms were similar in the screen-detected CD and healthy non-celiac group. Nachman et al. (in press) reported similar findings. At diagnosis, participants with CD reported significantly lower quality of life and significantly more gastrointestinal symptoms and depression than the healthy non-celiac group.

One year later. Mustalahti et al. (2002) found that after one year of being on a GFD, quality of life increased for participants in both the screen-detected and symptom-detected groups. In fact, quality of life for the symptom-detected group matched the quality of life of the healthy non-celiac participants and the quality of life in the screen-detected group was higher than the healthy non-celiac participants. For both groups diagnosed with CD, gastrointestinal symptoms decreased at the one year follow-up. Gastrointestinal symptoms for the screen-detected CD group were lower than the symptoms of the healthy non-celiac group. Nachman et al. (in press) again reported similar findings. At the one year follow-up, participants with CD reported a significantly higher quality of life and a significant decrease in gastrointestinal symptoms and depression compared to diagnosis. Their quality of life, gastrointestinal symptoms, and depression were not significantly different from the healthy nonceliac group.

No surprises here, right? At diagnosis, you typically feel lousy but once you start making dietary changes, you typically feel better. You may even feel as well as people without CD.

2) To keep feeling better, you need to stay on a GFD for the long-term and be strictly compliant.

Four years later. Nachman et al. (in press) reported many of the gains identified at the one year follow-up for participants diagnosed with CD were **not** sustained at the four year time point. Compared to their assessments at the one year time point in five dimensions of their quality of life—social function, general health perception, role limitation due to physical problems, role limitations due to emotional problems, and vitality—participants reported a significant decrease. Depression was significantly worse and significantly more participants had depression scores that categorized them as experiencing moderate to severe depression.



When compared to the healthy group, participants with CD reported a significantly lower quality of life, more gastrointestinal symptoms (with the exception of constipation), and increased depression at the four year time point. Also, when compared to the healthy group, participants with classical CD² reported significantly lower quality of life for the five domains and significantly more symptoms for the diarrhea and constipation syndromes.

One note of good news was that participants with CD still reported feeling significantly better at the four year time point than at diagnosis.

With a few exceptions, participants with CD who were strictly compliant with a GFD reported significantly higher quality of life than partially compliant participants. Also, across all dimensions, strictly compliant participants had similar outcomes compared to the healthy group with the exception of general health perception in the quality of life assessment, which was still higher than that of partially compliant participants.

With strict compliance to a GFD over the long-term, you can experience a level of quality of life that is similar to the quality of life experienced by people without CD. If you are only partially compliant, you will likely feel only partially healthy.

3) Your perception of how compliant you are may be skewed.

In a study conducted by Leffler et al. (2008), compliance with a GFD was self-reported by participants with CD, evaluated by a dietitian with expertise in CD and GFD, and analyzed by a tTG test. The dietitian rated 44.2% of the participants as having "excellent" adherence and 34.4% as having "good" adherence. However, when self-reported, adherence to a GFD was overestimated. Seventy percent (70.1%) of participants rated themselves as strictly adherent when in fact their tTG was elevated.

These findings point to important questions: Are you aware when you are being less than diligent with your GFD? Do you really know how compliant you are being with your GFD?

While you may think you are being strictly compliant with your GFD, outside confirmation of adherence by a tTG test or nutritional evaluation from a physician and dietitian with expertise in CD may be helpful to keep you on track (AGA Institute, 2006).

4) Some people may have an easier time adhering to a GFD, others may be at risk for non-adherence.

Married? Have other food intolerances? People with CD who answered "yes" to either questions were more adherent to their GFD than those who answered "no" to either question according to research conducted by Leffler et al. (2008). Other factors associated with better GFD adherence included:

- believing that accidental and purposeful gluten exposure has important health ramifications
- reporting a good understanding of GFD
- scoring higher on a GFD knowledge quiz
- ability to follow a GFD when traveling, dining out, or during social events
- ability to follow a GFD despite changes in mood and stress level

Edwards George et al. (2009) also identified several factors associated with GFD adherence. The authors reported that higher levels of non-adherence as evaluated by a dietitian were associated with:

- higher depression
- higher levels of anxiety
- lower levels of conscientiousness, order, self-discipline, deliberation, and readiness to re-examine values



Additionally, Ciacci, Lavarone, Siniscalchi, Romano, and De Rosa (2002) identified anger as the main emotion associated with non-adherence.

None of the findings above establish a cause and effect relationship. However, the findings can help educate people diagnosed with CD and those who treat them who may be at risk for poor quality of life and increased symptoms due to non-adherence.

5) To keep feeling better and increase the likelihood of compliance over the long-term, it is important to seek support, education, and follow-up.

What, where, and who? In response to the difficulties in altering long-standing dietary habits and maintaining compliance with a GFD, the AGA Institute (2006) recommends that people with CD join a CD support group and have regular follow-up evaluations. Over half of the participants in a study conducted by Leffler et al. (2008) belonged to a CD support group and a high percentage of these participants (86.5%) reported the membership was helpful. Two people identified by the most participants as being helpful in providing information and support for the GFD included their dietitian (63.0%) and gastroenterologist (57.1%). Their primary care physician (35.7%) and pharmacist (22.7%) were identified by fewer participants as being helpful. The Internet was cited by the most participants (85.1%) as being most helpful in learning about GFD followed by dietitian (64.9%), gastroenterologist (50.6%), friends with CD (48.7%), friends without CD (44.8%), other media (43.5%), and primary care physician (24.7%).

Isolation, lack of knowledge, and inconsistent follow-up can negatively impact your ability to feel better.

Finally, although alternative treatments for CD are being investigated for the future, keeping these five points in mind will help you have a better quality of life today.



About Ursula Saqui, Ph.D

Combining expertise in human behavior and research, Ursula Saqui, Ph.D., LMFT provides individuals, businesses, and non-profits the information and strategies they need to be successful. One of her favorite things to do as President of [Saqui Research](#) is translate academic research into practical, understandable information.



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Notes

¹ In this particular study, screen-detected CD was diagnosed by serologically testing first-degree relatives of celiac patients.

² Classical CD is characterized by mainly gastrointestinal symptoms, atypical CD by a lack of gastrointestinal symptoms but the presence of other conditions such as autoimmune diseases, and silent CD by a lack of symptoms but positive serologic test and villous atrophy on biopsy.