



It's Not Just In Your Head: The Psychological Impacts of Celiac Disease

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Welcome!

Marie-Nathalie Beaudoin, PhD

- *Training Director at Bay Area Family Therapy & Training Associates*
- *Instructor of Child Development, & Family Therapy at John F. Kennedy University*
 - *She and her son are diagnosed with celiac*
- *Currently co-authoring “A Medical Issue Affecting the Diagnosis of Mood, Attention and Autistic Disorders: A Closer Look at Celiac Disease and Gluten Intolerance”*
- *Author of “The SKiLL-ionaire in every child”*



On Tonight's Plate...

1. Understanding the Link Between Celiac and Psychological Disorders:

- *How can a problem in the gut impact psychological functioning?*

2. Overview of Psychological Issues Associated with Celiac Disease and Gluten Intolerance:

- *Which areas of psychological functioning are most affected?*

3. The Post Gluten-Free Recovery from Psychological Issues:

- *What else can you do to feel better?*

4. What Concerns You?

- *Dr. Beaudoin answers your questions!*



I. Understanding the Link Between Celiac and Psychological Disorders

- ***Malnutrition & Vitamin Deficiency***
- ***Toxins***
- ***Immune response***
- ***Secondary diseases, i.e. thyroid malfunctioning***



Understanding the Link: *Malnutrition & Deficiencies*

- Damaged gut is unable to assimilate certain nutrients essential to proper functioning of a number of organs
- Damaged villi cannot properly process and assimilate a number of nutrients, particularly:
 - *Vitamin B, such as B6, B12, & Folate*
 - *Iron*
 - *Vitamin D, K*
 - *Calcium*



Hallert, C., Grant, C., Grehn, S., Granno, C., Hultén, S., Midhagen, G., Ström, M., Svensson, H. & Valdimarsson, T. (2002). Evidence of poor vitamin status in celiac patients on a gluten-free diet for 10 years. *Alimentary Pharmacology & Therapeutics*, 16, 1333-1339.

Bhadada, S., Bhansali, A., Kochhar, R., Menon, A.S., Kant Sinha, S., Dutta, P., Kanwal Nain, C. (2008). Does every short stature child need screening for celiac disease? *Journal of Gastroenterology and Hepatology*, 23, 253-256.

Mora, Barera, Beccio, Proverbio, Weber, Bianchi, Chiumello (1999). Bone density and bone metabolism are normal after long-term gluten free diet in young celiac patients. *The American Journal of Gastroenterology*, 94(2), 398-403.



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Implications of *Malnutrition & Deficiencies*

- The body becomes unable to produce enough tryptophan and other monoamine precursors needed for the production of key neurotransmitters in the brain such as serotonin, dopamine and norepinephrine.
- ***This biochemical imbalance in the brain is associated with emotional problems.***



Hernanz, A., & Polanco, I. (1991). Plasma precursor amino acids of central nervous system monoamines in children with coeliac disease. *Gut*, 32, 1478-1481.



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Understanding the Link: *Toxins*

- Celiac disease is also called “leaky gut”
- Poorly digested food overtax filtering organs such as the liver
- Some toxins affect opioid receptors of the brain. For example, byproducts of milk entering the blood stream.

Stevens, F.M. & Mc Loughlin, R.M. (2005). Is celiac disease a potentially treatable cause of liver failure? *European Journal of Gastroenterology & Hepatology*, 17, 1015-1017.

Whiteley, P., Haracopos, D., Knivsberg, A.M., Ludvig Reichelt, K., Parlar, S., Jacobsen, J., Seim, A., Pedersen, L., Schondel, M., Shattock, P. (2010). The ScanBrit randomized, controlled, single-blind study of a gluten- and casein-free dietary intervention for children with autism spectrum disorders. *Nutritional Neuroscience*, 13(2), 87-100.



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Understanding the Link: *Immune Response*

- Inflammation: The body's natural response to assault
- Production of antibodies against own tissue
- Swelling, i.e. abdominal, joint pain, headaches, hypoperfusion in brain
- Production of stress hormones
- Byproducts of digestion end up in the blood stream and affect different parts of the body such as joints

Toscano, Conti, Anastasi, Mariani, Tiberti, Poggi, et al. (2000). Importance of gluten in the induction of endocrine autoantibodies and organ dysfunction in adolescent celiac patients. *The American Journal of Gastroenterology*, 95(7), pp1742-1748.

Addolorato, G., Di Giuda, D., De Rossi, G., Valenza, V., Domenicali, M., Caputo, F. Gasbarrini, A, Capristo, E., Gasbarrini, G. (2004). Regional cerebral hypoperfusion in patients with celiac disease. *American Journal of Medicine*, 116, 312-117.



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Understanding the Link: *Secondary Disease*

- After many years of this regimen, organs can become chronically affected and develop primary diseases.
- Common example is thyroid disease:
 - *Studies show that in people who have celiac AND depression, up to 80% of them have a comorbid thyroid disease.*

• Carta, M.G., Hardoy, M.C., Boy, M.F., Mariotti, S., Carpiniello, B., Usai, P. (2002). Association between panic disorder, major depressive disorder and celiac disease: A possible role of thyroid autoimmunity. *Journal of Psychosomatic Research*, 53, 789-793.

• Velluzzi, F., Caradonna, A., Boy, M.F., Pinna, M.A., Cabula, R., Lai, M.A., Liras, E. Corda, G., et al. (1998). Thyroid and Celiac Disease: Clinical, serological and echographic study. *American Journal of Gastroenterology*, 93, 976-9.



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2. Review of Associated Psychological Issues

New research shows that celiac can manifest itself through psychological problems impacting:

- **Cognitions (thinking)**
- **Affect (emotions)**
- **Behaviors**
- **Social Interactions**

Hadjivassiliou, M., et al. (1996). Is cryptic gluten sensitivity an important cause of neurological illness? *Lancet*, 347, 369-71.

Hadjivassiliou, M., et al. (2002) Gluten sensitivity as a neurological illness. *Journal of Neurology, Neurosurgery & Psychiatry*, 72, 560-563.



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Associated Issue:

Cognitions

- Brain fog
- Memory lapse
- Headaches in up to 50% of people with celiac disease
- Attention difficulty

Bushara, K. (2005). Neurologic presentation of celiac disease. *Gastroenterology*, 128, S92-S97.

Hu, W., Murray, J., Greenaway, M., Parisi, J., Josephs, K. (2006). Cognitive Impairment and celiac disease. *Archives of Neurology*, 63, pp1440-1446.

Hadjivassiliou, M., Grünewald, R.A., Lawden, M., Davies-Jones, G.A.B., Powell, T., Smith, C.M.L. (2001). Headache and CNS white matter abnormalities associated with gluten sensitivity. *Neurology*, 56, 385-388.

Peterson, V. & Peterson, R. (2009). The gluten effect: How innocent wheat is ruining your health. True Health Publishing.



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Example:

Cognition

- *Sarah, 43, didn't understand what was happening to her. She had been a bright, creative, and productive manager all her life. Since being a mother of two children she felt her brain was failing her. She experienced memory losses, language distortions, unpredictable brain fog, and intense headaches she called "brain swelling."*



Associated Issue:

Affect

- Most common affective disorders reported include:
 - **Depression**
 - *Moodiness, discouragement, overwhelmed, non-restful sleep*
 - **Anxiety**
 - *Phobias, separation anxiety, obsessive compulsive, social phobia, panic attacks*
 - **Irritability**
 - *Impatience and grumpiness in adults; Anger outbursts in children*

Addolorato, G., Leggio, L., D'Angelo, C., Mirijello, A., Ferrulli, A., Cardone, S., Vonghia, L., Abenavoli, L., Leso, V., Nesci, A., Piano, S., Capristo, E., Gasbarrini, G. (2008). Affective and psychiatric disorders in celiac disease. *Digestive Diseases*, 26, 140-148.

Ludvigsson, J.F., Reutfors, J., Ösby, U., Ekblom, A., Montgomery, S.M. (2007). Coeliac disease and risk of mood disorders - a general population-based cohort study. *Journal of Affective Disorders*, 99, 117-126.

Addolorato, G., Mirijello, A., D'Angelo, C., Leggio, L., Ferrulli, A., Vonghia, L., Cardone, S., Leso, V., Micelli, A., Gasbarrini, G. (2008). Social phobia in coeliac disease. *Scandinavian Journal of Gastroenterology*, 43, pp.410-415.

Pynnönen, P.A., Isometsä, E.T., Verkasalo, M.A., Savilahti, E., Aalberg, V.A. (2002). Untreated celiac disease and development of mental disorders in children and adolescents. *Psychosomatics*, 43(4), 331-335.



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Example:

Affect

- *Mia, 5 years old, suffered from intense separation anxiety. She also had regular nightmares, a blood phobia and was scared on swings and bicycles.*
- *Lucy, 41 years old, was diagnosed with depression and prescribed medication. She had lost interest for activities she previously loved, and accomplished the minimum possible in her daily life. This led her to be impatient and grumpy with her family.*



Research example:

Affect

- A review of the computerized medical files of 13,776 CD patients in Sweden reported that a significant percentage of them had been diagnosed with depression or bipolar disorder before being finally tested for celiac.
- In adult populations, studies show that between 30% and 71% of untreated CD score as having a depressive disorder.

Addolorato, G., et al. (1996). Anxiety and depression in adult untreated celiac subjects and in patients affected by inflammatory bowel disease: A personality "trait" or a reactive illness? *Hepatogastroenterology*, 43, 1513-1517.
Corvaglia, L., Catamo, R., Pepe, G., Lazzari, R., & Corvaglia, E. (1999). Depression in adult untreated celiac subjects: Diagnosis by the pediatrician. *American Journal of Gastroenterology*, 94(3), 839-843. Ludvigsson, J.F., Reutfors, J., Ösby, U., Ekblom, A., Montgomery, S.M. (2007). Coeliac disease and risk of mood disorders - a general population-based cohort study. *Journal of Affective Disorders*, 99, 117-126.



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Associated Issue:

Behaviors

- **Hyperactive:** ADD,ADHD
- **Hypoactive:** Lethargy, fatigue
- **Ataxia:** Clumsiness, poor coordination, imbalance
- **Eating and weight issues:** Under and over

Niederhofer, H., & Pittschieler, K., (2006). A Preliminary investigation of ADHD symptoms in persons with celiac disease. *Journal of Attention Disorders*, 10(2), 200-204.

Siniscalchi, M., Iovino, P., Tortora, R., Forestiero, S., Somma, A., Capuano, L., Franzese, M.D., Sabbatini, F. Ciacci, C. (2005). Fatigue in adult celiac disease. *Alimentary Pharmacology & Therapeutics*, 22, 489-494.

Empson, M. (1998). Celiac and chronic fatigue. *American Journal of Medicine*, 105, 79-80.

Schmahmann, J. (2004). Disorders of the cerebellum: Ataxia, dysmetria of thoughts, and the cerebellar cognitive affective syndrome. *Journal of Neuropsychiatry & Clinical Neuroscience*, 16, 367-378.

Erkasalo, M.A., Raitakari, O.T., Viikari, J., Marniemi, J., Savilahti, E. (2005). Undiagnosed silent coeliac disease: A risk for underachievement? *Scandinavian Journal of Gastroenterology*, 40, 1407-1412.



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Example:

Behaviors

- *Fernando, 9, just can't sit still, except when he's playing video-games. He needs to fidget all the time and inappropriately blurts out comments in class. His reduced attention span gets in the way of his academic performance at school. His parents are discouraged and seek consultation for ADD/ADHD evaluation.*
- *Lucy and Sarah both experienced tremendous fatigue and napped in the afternoon.*



Research Example:

Behaviors

- In a recent study of randomly selected 2,427 healthy adults, undiagnosed silent celiac disease was significantly associated with underachievement as measured by education, unemployment, and socio-economic status. These subjects were 4 times less likely to enter college.

Verkasalo, M.A., Raitakari, O.T., Viikari, J., Marniemi, J., Savilahti, E. (2005). Undiagnosed silent coeliac disease: A risk for underachievement? *Scandinavian Journal of Gastroenterology*, 40, 1407-1412.



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Associated Issues:

Social

- Avoidance of social situations
- Withdrawn
- Uncomfortable
- Fear of people
- Asperger's Syndrome and autism in children

Addolorato, G., Mirijello, A., D'Angelo, C., Leggio, L., Ferrulli, A., Vonghia, L., Cardone, S., Leso, V., Micelli, A., Gasbarrini, G. (2008). Social phobia in coeliac disease. *Scandinavian Journal of Gastroenterology*, 43, pp.410-415

Whiteley, P., Haracopos, D., Knivsberg, A.M., Ludvig Reichelt, K., Parlar, S., Jacobsen, J., Seim, A., Pedersen, L., Schondel, M., Shattock, P. (2010). The ScanBrit randomized, controlled, single-blind study of a gluten- and casein-free dietary intervention for children with autism spectrum disorders. *Nutritional Neuroscience*, 13(2), 87-100.

Genius, S.J., & Bouchard, T. (2010). Celiac disease presenting as autism. *Journal of Child Neurology*, 25(1), 114-119.



Example:

Social Issue

- *Alexander, 11, was referred to me because he had bullying problems at school. He was both the recipient and perpetrator in a number of incidents at recess. He was described as having very little empathy, not being able to put himself in others' shoes, being very poor communicator, having no social skills and living in his own bubble. For a number of reasons, his pediatrician was leaning towards a diagnosis of Asperger but his parents wanted a second opinion.*



Research Example:

Social

- *Interestingly, the first description of Asperger syndrome was made by Hans Asperger, in 1961, and he was actually describing the behaviors of a group of 12 celiac children who he perceived as being excessively introverted, fearful of people, moody and unable to enjoy human interaction. These same children became friendly, flexible and independent thinkers after 2 years gluten-free.*

Asperger, H. (1961). Psychopathology of children with celiac disease. *Annal Paediatrica*, 197, 346-351.



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Research Example:

Social

- A recent study followed 26 children with an autism spectrum disorder for 12 months on a GF and CF diet and showed significant improvements on all measures of communication, social interactions, inattention and hyperactivity.

Whiteley, P., Haracopos, D., Knivsberg, A.M., Ludvig Reichelt, K., Parlar, S., Jacobsen, J., Seim, A., Pedersen, L., Schondel, M., Shattock, P. (2010). The ScanBrit randomized, controlled, single-blind study of a gluten- and casein-free dietary intervention for children with autism spectrum disorders. *Nutritional Neuroscience*, 13(2), 87-100.



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3. Post Gluten-Free Recovery from Psychological Issues

- **Biological factors:**
 - *Your body may need help*
- **Cognitive factors:**
 - *Lessons from neuroscience and how we think*
- **Affective factors:**
 - *Rebalancing your experience*
- **Social factors:**
 - *Connecting with others*



Post Recovery:

Biological Factors

- Exercise daily about 30 minutes
- Be vigilant with regards to contamination
- Consult with a knowledgeable dietitian or specialized doctor
- Supplements often recommended such as Vitamin B and digestive enzymes
- Other organs may be damaged and require care such as the thyroid

Hallert, C., Grant, C., Grehn, S., Granno, C., Hultén, S., Midhagen, G., Ström, M., Svensson, H. & Valdimarsson, T. (2002). Evidence of poor vitamin status in celiac patients on a gluten-free diet for 10 years. *Alimentary Pharmacology & Therapeutics*, 16, 1333-1339.



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Example:

Biological Factor

- Sarah experienced a dramatic shift in mental abilities within a couple of weeks of the gluten-free diet. Brain fog, memory problems and language issues all vanished. For some time, however, she needed to take Vitamin B and melatonin to normalize her sleep cycles. While her digestive system healed, she also had to be on a grain and dairy-free diet for two months, with extra servings of proteins to rebuild her tissues.



Example:

Biological Factor

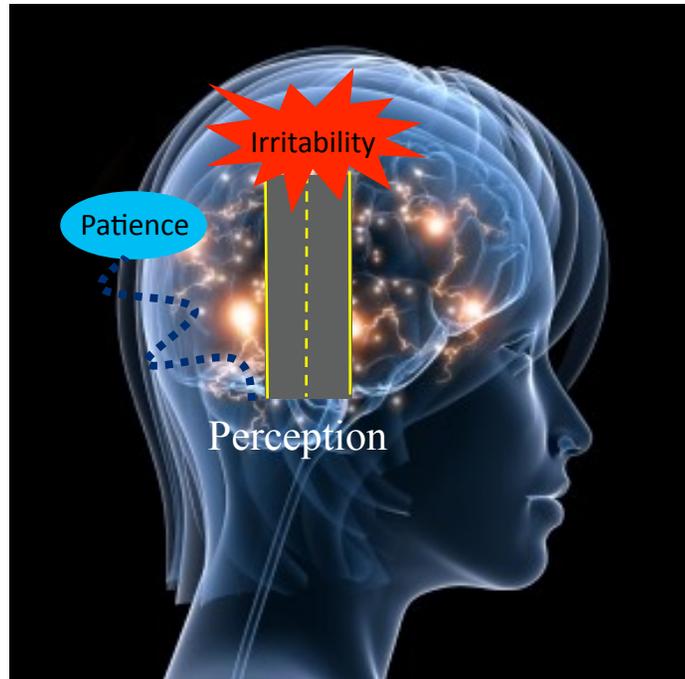
- *Half of the subjects in a study of 30 adults between the ages of 45-64 years old, with a biopsy proven remission, showed signs of poor vitamin status 10 years after being GF. This was particularly the case with vitamin B's.*

Hallert, et. al. (2002). Evidence of poor vitamin status in coeliac patients on a gluten-free diet for 10 years. *Alimentary Pharmacology & Therapeutics*, 16, 1333-1339.



Post Recovery: *Cognitive Factors*

How we think actually shapes the neural connections in our brain!



Beaudoin, M.N. (2010). The Skill-ionaire in every child: Boosting children's socio-emotional skills using the latest in brain research. SF, CA: Goshawk Publications.



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Implications:

Cognitive Factors

- People develop habitual ways of interpreting the world and their lives.
- If someone recovering from depression finds themselves feeling crummy one day, they are more likely to think “I’m having another episode of depression” rather than “I’m tired” or “coming down with a cold”. This interpretation of their bodily experience leads to a search for reasons to be depressed.

Zimbardo, P.G. (1999). Discontinuity theory: Cognitive and social searches for rationality and normality--may lead to madness. In M. P. Zanna (Ed.), *Advances in Experimental Social Psychology*, (Vol. 31, pp. 345-86). San Diego, CA: Academic Press.



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Example:

Cognitive Factors

- *Lucy experienced a lot more energy to deal with parenting. However, she still would easily fall into grumpiness with any slight inconvenience mainly because she would think her daughter was not making an effort or because a problem could have been prevented.*



Example:

Conversations with Lucy

- *“The old habit of grumpiness gets you to react and think this is a big deal, how would you prefer to look at this situation?”*
- *“Was there a time this week when you could have responded with grumpiness but managed to hold on to your preference for patience?”*



Post Recovery: *Affective Factors*

- Some studies reveal complete remission of depression, anxiety and irritability with GF diet, especially with younger populations.
- Other studies, especially on depression, are associated with mixed results.

Pynnönen, P.A., Isometsä, E.T., Verkasalo, M.A., Kahkonen, S.A., Sipila, I., Savilahti, E., Aalberg, V.A. (2005). Gluten-free diet may alleviate depressive and behavioral symptoms in adolescents with coeliac disease: A prospective follow-up case-series study. *BMC Psychiatry*, 5 (14), 1471-1476.

Addolorato, G., Capristo, E., Ghittoni, G., Valeri, C., Masciana, R., Ancona, C., Gasbarrini, G. (2001). Anxiety but not depression decreases in coeliac patients after one-year gluten-free diet: A longitudinal study. *Scandinavian Journal of Gastroenterology*, 36, 502-506.



Example:

Affective Factors

- Possible explanations:
 - *Non adherence to the GF diet*
 - *Other intolerances*
 - *Thyroid problems*
 - *Nutritional deficiencies*
 - *Lengthy recovery period*
 - *Difficulties accepting dietary change and its social implications*
 - *Habitual ways of experiencing life*



Example:

Affective Factors

- *Mia became visibly less anxious within a few weeks of a gluten & casein-free diet. She remained, however, “scared of being scared.”*



Example:

Conversations with Mia

- *“The old habit of Fear makes you anticipate having a nightmare. How many nightmares did you have since going gluten-free?”*
- *“The old habit of Fear makes you think you will be terribly anxious if your parents leave you at this birthday party. Have you noticed how different you are now? Can you list the ways in which you might feel different?”*



Example:

Affective Factors

After many years of living in a bubble of discomfort, many forget to really live moments of well-being, satisfaction or joy.



Example:

Affective Factors

- Some people reconnect with well-being through mindfulness exercises where they learn to “inhabit” moments of well-being.
 - *Example: Think of a time during the week where you could experience satisfaction. Do you tend to actually notice, live and experience satisfaction as much as you could? What is the maximum amount of positive feelings you can experience in your favorite activity?*
- Meditation has been found to increase cortical thickness.

Lazar, S., Kerr, C., et al. (Nov. 2005). Meditation experience is associated with increased cortical thickness. *NeuroReport*, 16(17), 1893-1897.



Social Factors:

Connecting with Others

- Studies show that connecting with others enhances people's ability to handle the gluten-free diet.
- There are different ways to connect with others:
 - *A confidant*
 - *Celiac support group*
 - *Counseling*
 - *Increasing comfort level with disclosure of dietary restrictions*

Leffler, Edwards-George, Dennis, Schuppan,, Cook et al. (2007). Factors that influence adherence to a gluten free diet in adults with celiac disease. *Digestive Disease & Science*, 53 (6), pp. 1573-81.



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Social Factors:

Connecting with Others

- Celiac support groups are widely available
- Advantages include:
 - *Access to emotional support and sharing of experience*
 - *Valuable information on latest gluten-free products*
 - *Tips on how to improve health related concerns*
 - *A sense of not being alone in dealing with this issue*
 - *Fun social interactions*



Social Factors:

Connecting with Others

- Some forms of counseling or brief therapy can provide personalized education and support with regards to integrating the gluten-free diet in the particularities of your life.

For example, what happened with Alexander?



Social Factor:

Growing Awareness!

- **15-25% of U.S. consumers report looking for gluten-free products.** *US News and World Report*
- **Growth in this segment is expected to reach \$2.6 billion by 2012.** *Packaged Facts*
- **Since 2008, one New York-based Wegmans store store-brand gluten-free products have grown to 800.** *Post-journal.com*



Social Factors:

Eating Out

Due to increased awareness, it has become much easier to mention a dietary restriction and be understood!

1. Restaurants:

- *Talk to them before, during and after.*

2. Responding to social situations with friends:

- *Everyone has or will have a health condition at some point or another.*

3. Traveling:

- *It may be easier than you think! A letter, a cooler and kitchenette can help you along the way.*



Answers to your questions!

1. *A GF diet makes me feel so much better but I have not been diagnosed with CD. What if I get tested and the results are negative? Would that be all in my head?*



Answers to your questions!

- 2. My daughter, 5 years old, and I both have CD. What impact will it have as she grows older and faces bullying, birthday parties or dating?*



Answers to your questions!

3. *Does social isolation play a role in the worsening of depression?*



Answers to your questions!

4. *How can a person with celiac tell friends and family members that they are not willing to eat at their house, including the use of their dishes?*



Answers to your questions!

5. *Since I was diagnosed with celiac, in May 2009, it seems like I have a never ending tumbling of illnesses. How can I help my doctors see that I don't make this up? I now take photos of my rashes, mouth sores, etc.*



Helpful Readings on Celiac

- Ford, R. (2006). *Full of it: The shocking truth about gluten*. Auckland, NZ: RRS Global Limited.
- Peterson, V. & Peterson, R. (2009). *The gluten effect: How innocent wheat is ruining your health*. New York: True Health Publishing.
- Korn, D. (2001). *Kids with celiac*. Bethesda, MD: Woodbine.
- Dennis, M. & Leffler, D. (2010). *Real Life with Celiac Disease: Troubleshooting and Thriving Gluten Free*. Bethesda, MD: AGA Press.



Helpful readings on Psychology & Mental Health

- Beaudoin, M.N. (2010). *The SKiLL-ionaire in every child: Boosting children's socio-emotional skills using the latest in brain research*. SF: Goshawk Publications. (www.skillionaire.org)
- Begley, S. (2007). *Train your mind, change your brain*. New York: Ballantine Books.
- Byron, K. (2007). *A thousand names for joy*. New York: Harmony Books.
- Kabat-Zinn, J. (1990). *Full catastrophe living: Using the wisdom of your body and mind to face stress, pain and illness*. New York: Dell.
- Siegel, D. (2007). *The mindful brain*. New York: W.W. Norton.



Final Thoughts

It's not all in your head!
You can take many actions to improve your
mental well-being.

www.CeliacCentral.org/Resources

- *Hospitals & Labs*
- *Support Groups, i.e. gluten.net, CSAceliacs.org*
- *International Groups*
- *Books and Magazines*
- *Government Resources, i.e. CDC.gov, who.int/mental_health*



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Thank You!!

Thank you!

Questions? Comments? Feedback?

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