

Coping with Celiac Disease: The Ups and Downs Before, During, and After Diagnosis

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Chronic Medical Conditions

- ▶ “Illness is the night–side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.”
 - Susan Sontag: “Illness as Metaphor”

Before Diagnosis

- ▶ People commonly experience:
 - Diffuse symptoms that come and go over a period of time
 - Attempts to find psychological or circumstantial causes for these symptoms
 - False or partial diagnoses
 - Determination to make the symptoms disappear by changing habits and behavior
 - Strained relationships with family and friends

Before Diagnosis (cont.)

- ▶ Stress that is often not perceived as stress
- ▶ Changes in mood and personality
- ▶ Physical examinations and procedures that may be redundant, unnecessary, or even harmful
- ▶ Different and sometimes incompatible diagnoses and remedies from different specialists consulted
- ▶ Relief at having an answer that seems definitive

Before Diagnosis (cont.)

- ▶ Sick enough to go to the doctor?
- ▶ But which doctor?
- ▶ Frustration and Doubt
- ▶ Going “Crazy”

During Diagnosis

- ▶ I'm not crazy
- ▶ Relief vs Grief
- ▶ Sorrow, Shock, and Fear
- ▶ Negotiating with your Illness

After Diagnosis

- ▶ Grief over lost health
- ▶ After the flowers stop coming
- ▶ A shift in habits
- ▶ Patience as a way of life
- ▶ Acceptance
- ▶ Loss of control
- ▶ Stress
- ▶ Pills and other accoutrements

Common Mental Health Concerns Throughout the Process

- ▶ Depression
- ▶ Anxiety/Fear
- ▶ Self-Pity
- ▶ Pain
- ▶ Anger: Someone or something to blame
- ▶ Repression and “noble” suffering

The Brain–Gut Connection

- ▶ Gut microbiome can influence neural development, brain chemistry, and a wide range of behavioral phenomena including emotional behavior, pain perception, and how the stress system responds
 - Tweaking balance between beneficial and disease-causing bacteria in gut can alter brain chemistry
 - Even mild stress can effect the gut's microbial environment, making individual more vulnerable to infectious disease and affecting central nervous system

The Good Patient

- ▶ The doctor–patient partnership
- ▶ Consistency of care
- ▶ The knowledgeable patient
- ▶ Vigilance
- ▶ Alternative care
- ▶ Saying “The End”

Naming Your Unhealthy Self

- ▶ “I think of myself as a very healthy person...with a problem.”
- ▶ The one-legged marathon runner
- ▶ Who am I now that I’m sick?
- ▶ Misery loves company
- ▶ Me and/or my illness
- ▶ Body Image
- ▶ A body out of control

Naming Your Unhealthy Self (cont.)

- ▶ Sick and physically attractive?
- ▶ Self-love and self-hatred
- ▶ The mind-body split
- ▶ Apostles of imperfection
 - Am I mostly healthy or mostly sick?

The Etiquette of Chronic Illness

- ▶ Acknowledge the Illness
- ▶ Company and Practical Help
- ▶ Useless Advice
- ▶ In Control of Me
- ▶ Public Exposure
- ▶ Excuses

Growing Up Sickly

- ▶ Family Secrets
- ▶ The Indulged Child
- ▶ Everybody's Illness
- ▶ Resentment and Denial
- ▶ Just a Normal Kid
- ▶ Flashbacks

Marriage: For Better and for Worse

- ▶ The Toll Illness Takes
- ▶ Gender Matters
- ▶ Sideways Anger
- ▶ Off Balance

Choices for Chronic Conditions

- ▶ You can tough it out, ignoring symptoms at the risk of getting worse, or you can check out every little quirk, at the risk of hypochondria
- ▶ You can shop for miracle cures, at the risk of harming yourself, or you can trust one doctor's judgment, at the risk of selecting unwisely
- ▶ You can keep your ailment secret, at the risk of deception, or you can talk openly about it, at the risk of self-pity

Choices (cont.)

- ▶ You can ask friends for help, at the risk of becoming a burden, or you can hold fast to your independence, at the risk of isolation
- ▶ You can insist that your family treat you as normal and healthy, at the risk of denying them release for their own worries about you, or you can let them protect you, at the risk of becoming dependent and childlike
- ▶ You can strain your body to its limit, at the risk of harming yourself, or you can play it safe , at the risk of becoming an invalid

Choices (cont.)

- ▶ You can live in terror of degeneration and death, at the risk of becoming immobilized, or you can look upon each good day as a special dispensation, at the risk of smugness
- ▶ You can insist on controlling the course of your life, at the risk of frustration, or you can “go with the flow,” at the risk of passivity
- ▶ You can be angry about your fate, at the risk of bitterness, or you can focus only on your blessings, at the risk of self-delusion

Questions???