

Note: This example, drawn from real conversations with a Celiac patient, is intended to give a sense of the targeted health literacy information we can offer.

I've been diagnosed with Celiac disease. I know it means I'm allergic to gluten and I can't eat it any more. My doctor says it'll take me a while to feel better. I'm kind of confused about it all, and I just want to understand my situation!

I'm glad you have a diagnosis and hope you will feel better very soon! Celiac disease is definitely "trouble with gluten" but it's not quite an allergy. Usually when we talk about food allergies, we mean a specific type of immune response involving a molecule called IgE that floats around in your blood. The food allergy happens when the IgE sticks abnormally to food proteins you absorbed and sets off a big allergic response including swelling, itching, vomiting, or trouble breathing. It's an emergency. Celiac disease is similar to a food allergy because it involves abnormal actions of your immune system: it is a chronic auto-immune disease. But IgE is not involved, and the symptoms that a person with Celiac disease gets after eating gluten are not the same as those of a food allergy.

Instead, with Celiac disease, something goes wrong with bits of gluten proteins in the intestine. Anything in our intestines is normally "checked out" by our immune system to make sure that it's not an invading germ. If you have Celiac, gluten bits you've eaten get incorrectly identified as invaders while they are in your small intestine, and your immune system swarms in to attack. In the process, your own immune system damages and eventually destroys the lining of your small intestine. This damage causes your small intestine to be unable to do its main job, which is absorb nutrients. Without enough nutrients, you might have weak bones (not enough calcium), or anemia (not enough iron). The damage also causes the classic symptoms of Celiac disease: diarrhea and abdominal pain.

Will I ever recover from Celiac?

If you maintain a strictly gluten-free diet, the research suggests that you will feel somewhat better within a few days. Your damaged intestines will fully heal in 3-24 months (the older you are, the longer it takes, generally). During this time, any other symptoms of Celiac disease should get less and less until they are completely gone. As far as we know, none of the damage caused by Celiac disease is permanent. However, at this time, medical science has not figured out how to make it safe for you to eat gluten again. Therefore, to stay healthy, you will have to eat gluten-free for your whole life.

I thought Celiac was about being allergic to gluten and wheat. Why am I supposed to avoid barley?

Gluten is a protein, which is a type of biomolecule – a molecule made by a living thing. It is made inside quite a few different kinds of plants, most famously wheat. However, gluten is not a synonym for wheat, nor is it exclusive to wheat. Other types of grains (grasses with seeds we eat) that are closely related to wheat also make gluten, including barley, rye, and some types of

oats. And of course, humanity has developed many different kinds of wheat over the millennia. Some of those kinds of wheat are durum (of pasta fame), semolina (noodles and couscous), farro (often eaten whole), graham (of cracker fame), and spelt (used in breads). All of them have gluten.

Although no other plants make gluten, there are plenty of sneaky ways that gluten from these grains get into other food products, which is why the list of foods you'll need to avoid includes things other than just strictly grains.

Can I pass Celiac to my spouse or kids?

Celiac disease is not contagious like a cold or flu, and it is impossible to pass it to your spouse. It does, however, have a strong genetic component. About 95% of people who have Celiac disease have one of the two biggest genetic risk factors for the disease. It is very rare to develop Celiac disease WITHOUT these risk factors. Therefore, unless you are one of the rare people who has Celiac disease without carrying the common risk genes, you have a chance of passing those risk genes along to your children. However, this does not guarantee that they will have Celiac disease. In fact, it is more likely that they will not. Their risk is about 1 in 10. (I'm a living example! I actually have BOTH genetic risk factor for Celiac disease, and a first-degree relative who is diagnosed. That means I have about a 1 in 7 chance of developing Celiac, but so far, I haven't.)