

Just diagnosed with Celiac Disease?

You will be ok! This is going to seem like a lot. After these first big steps, we promise it gets easier. It is OK and normal to grieve as you are changing your lifestyle.

Step 1 - Understand what is happening.

As you make lifestyle changes and announce that you have celiac disease to your family and friends, you will find that most do not understand what celiac disease (CD) is or what is required to improve your health. You'll have to explain often and it's not a straightforward explanation, but you'll find your own way to explain it. Learn as much as you can about the disease.

You will need new processes for cooking at home, going to your family and friends for meals and ordering in restaurants. Not understanding, your friends may challenge you and state it is not THAT BAD to eat gluten occasionally, especially if you have no physical symptoms. It will take time for you to understand this. Unfortunately, almost all the answers are far from black and white. Experiences between people vary greatly, as do answers on healing, symptoms and internal damage levels. It is important to keep it simple.

You'll need to explain this is not an allergy. Reactions vary to ingested gluten:

1. Reaction/symptoms to ingesting gluten can range from annoying to awful. Everyone is different and it can change over time.
2. Whether you feel symptoms or not, damage is occurring in the small intestine and potentially in other systems in the body.

You may or may not start feeling better or different once you are gluten-free (GF). Symptoms (if any), can take weeks, months, or a few years to go away. If after a year you are not seeing improvement, you need to work with your healthcare provider to ensure that there is not another cause to your remaining symptoms. Rule out that you are not inadvertently ingesting gluten. Don't make the mistake of assuming everything is due to CD.

You're going to hear a lot of "everyone is different" and we don't know exactly when you'll heal or feel better. Just do your best and trust that you WILL get the hang of this and get into new routines and feel normal again.

The **tTG blood test**, used to help diagnose CD, measures the tissue transglutaminase antibody (tTG). In BC, if results of the lab test are >12 U/ml (standards can vary depending on the lab and assay used for the test) you still have room for improvement. Anything below 12 is in the "normal" range in BC. The important thing is that whatever your baseline test (the test diagnosing you as potentially having CD), you should see a lower number for each subsequent test. You'll need to be patient. If your numbers are fluctuating, sometimes going up and sometimes going down, you are most likely inadvertently consuming gluten and need to be more vigilant.

Follow the **Celiac Follow Up Care Resource** provided by the Canadian Celiac Association to ensure you are getting the proper follow up care and testing. This document provides information on when you should retest the tTG. If results are not in the "normal range" you still have work to do. On-going exposure to gluten puts you at risk of small intestinal damage, continuation of symptoms and higher risk for the potential of developing other autoimmune diseases.

Once your tTG is normal - take a sigh of relief - then continue what you are doing. We all make mistakes. Just do your best and learn from your mistakes. Your body wants to heal and although accidentally consuming gluten does set you back, you will heal if you continue to be vigilant.

Step 2 - Where is my body at?

You can't plan to improve your health unless you have at least a general picture of where you're at health-wise. The time it will take to heal will vary, depending on many factors including how long you had undiagnosed Celiac Disease. You'll need to monitor your diet and potentially take supplements to ensure healing takes place.

Set up an account on e-Health <https://secure.myehealth.ca/> to monitor your lab tests. You'll never have a 100% clear picture but that's okay. You can see how you are progressing by doing bloodwork and monitoring symptoms (if you have any).

Schedule testing per the Celiac Follow Up Care Resource in conjunction with your physician. It's all about healing your gut - WHICH IS POSSIBLE. Changes may be slow, however if you are showing improvement, this is totally normal. Have your pharmacist check any prescription medications you take for gluten too.

Review test results with your family physician and Dietitian. Determine what foods are important for you to improve your results and what supplements (if any) are needed.

Step 3 - Find a dietician - don't do this part alone. Find one who has or specializes in Celiac Disease.

You may need to try a couple before you find one that you are comfortable with. You can contact the health authority or dial 811 and they can set you up with a dietitian free at a hospital near you.

If you can't wait or want someone who is specialized, search for one in your area at the Canadian Dietitians Website <https://www.dietitians.ca/Find-A-Dietitian.aspx>. Ensure they assist you in learning:

- Learn how to interpret your lab results (ask your family physician this question too)
- Learn how to read labels to ensure you purchase GF products
- Learn what cross contamination means (this can be tricky) and how to avoid it
- Learn diet guidelines so you can go through everything you eat and drink
- Meal ideas to help start you off
- Consider getting the MyHealthyGut application if you have an Apple phone or tablet

Set up a weekly appointment for the first few weeks, questions will build up and you'll want this initially. Over time biweekly/monthly appointments will suffice.

Step 4 - Support the Canadian Celiac Association.

The CCA will provide information to get you started and make it all less overwhelming. If you would like to talk to others that have taken this journey:

- Join a support group
- Join the CCA national and local Facebook groups

Step 5 - Time to go through all your stuff.

You will likely feel pressure to start doing this right away so everything you're eating and using are safe. Eliminate what is obvious, but until you have the information you need, reviewing all your cupboards contents will just need doing again and get even more frustrating. Be patient.

Ok this is the super annoying part but promise it gets easier.

Check all your stuff, review every label, and anything that isn't okay, donate to your local food bank and find a replacement. If you have a mixed kitchen (GF and non-GF), separate GF foods from non-GF foods. Ensure GF foods either have their own cupboard, or place GF products on separate higher shelves.

See the CCA's **Checklist For Food Safety For Newly Diagnosed**, and use the labelling guidelines found either in the front of the CCA Pocket Dictionary or on the Canadian Food Inspection Agency (CFIA) website. Ask your dietitian whenever there are things in question or contact your local chapter of the CCA.

In time, everything will become part of your routine and new lifestyle.