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Chapter **1**

Finding Out You Have Celiac Disease

When you first find out that you or your loved one has celiac disease, you may be shocked. No one likes to hear bad news, and, as so often happens in this type of situation, you may recall little other than the words *celiac disease* from the conversation you have with your doctor that day.

Over the next few days and weeks, your mind may race nonstop as you mull over your new diagnosis and try to come to grips with it. Or, if the diagnosis is brand new to you, perhaps you are right now in the process of trying to deal with the news.

Celiac Disease For Dummies provides you not just with the facts about celiac disease, but the tools to help you master it. In this chapter, our goal is to help you understand and come to terms with your diagnosis.

Getting to Know Celiac Disease

Celiac disease, also known as celiac sprue, non-tropical sprue, and gluten-sensitive enteropathy, is a condition in which consuming *gluten* — a protein found in wheat, rye, barley, and some other grains — leads, in susceptible people, to damage to the lining of the small intestine, resulting in the inability to properly absorb nutrients into the body. This can lead to many different symptoms, including fatigue, malaise (feeling generally poorly), bloating, and diarrhea. Left untreated or insufficiently treated, celiac disease can lead to damage to other organs. If properly treated, celiac disease typically leads to . . . nothing!



TECHNICAL
STUFF

In your travels, you may see the word *celiac* spelled as *coeliac*. Both terms refer to the same condition. *Celiac* is the spelling far more commonly used in North America and, hence, the spelling we use throughout this book. Incidentally, the term *celiac* (or *coeliac*) comes from the Greek word *Koila*, which refers to the abdomen.

Doctors have known about celiac disease for a long time. Articles describing individuals suffering from diarrhea (most likely due to what we now call celiac disease) first appeared over two thousand years ago. It was, however, Dr. Samuel Gee who, in London, England in 1887, first described the condition in detail and even presciently observed that successful therapy was to be found in changing a patient's diet, although he did not point to gluten as the culprit. That came later (see the “Discovering celiac disease” later in this chapter).

Knowing How Having Celiac Disease Feels

It could well be that you were diagnosed with celiac disease after having been unwell for quite some time. If so, then when you read this section's heading (“Knowing How Having Celiac Disease Feels”), you may have said to yourself, “Hey, I can tell you how it feels. It feels crummy. I had belly pain and I had indigestion and I had . . .” Yup, those things sure can happen. But so too can many other symptoms or, on the other side of the spectrum, few or even no symptoms at all.

In Chapter 2, we look at the whole panoply of symptoms a person with celiac disease can experience. Some of these may lead you to nod your head in recognition (such as the symptoms we just mentioned), and some may take you by surprise (such as discovering the link between celiac disease and conditions as varied as skin rash and infertility).

Dealing with the Diagnosis of Celiac Disease

Some diseases are easy to diagnose. Tell a doctor you have spells where you see flashing lights followed by a throbbing headache, and, dollars to donuts, the doctor will quickly inform you that you may be suffering from migraine headaches.

Diagnosing celiac disease is often not that simple. It involves an interview and examination by a physician and necessitates investigations typically including blood tests and *always* having a fiberoptic scope passed through your mouth, down your esophagus, through your stomach, and into your small intestine where a biopsy is then taken. Okay, we admit, that may not sound particularly pleasant, but as you see in Chapter 3, it ain't so bad at all.

The journey to a diagnosis of celiac disease can take a number of different paths. In Chapter 4, we discuss the different types of celiac disease based on symptoms (or lack thereof). Perhaps you're already aware (and if you're not, you soon will be because it's a recurring theme in this book) of the key role that a nutrient called *gluten* plays in triggering celiac disease. As we discuss in Chapter 5, however, although gluten *triggers* the condition, that's not quite the same as saying it *causes* the condition.

By way of analogy, if ever you were working on your computer and you routinely pressed a key only to suddenly have your computer crash, you could appropriately say that pressing the key *triggered* the crash, but an underlying operating system glitch *caused* the problem in the first place.

What, then, causes celiac disease? The quick answer is we don't know. The more complicated answer is a combination of having a susceptibility to the condition by virtue of your genetic make-up in conjunction with some as yet unknown environmental factor. Chapter 5 contains the full story on the cause, as best we understand it.

Unless people are ill with some sort of gastrointestinal (GI) ailment, they understandably generally think little, if at all, about the incredibly complex processes involved in extracting the good from the food they eat and ridding their bodies of the stuff they don't need. That makes sense. When celiac disease enters your life (either directly or by virtue of a family member now being affected by it), however, having some familiarity with your GI system proves beneficial. Chapter 5 explains how your GI system works when you're healthy and how it malfunctions when you have celiac disease.

DISCOVERING CELIAC DISEASE

The first definitive report of celiac disease was made by Dr. Samuel Gee in London, England in 1887 in his seminal study “On the Coeliac Affection.” Dr. Gee astutely observed that “if the patient can be cured at all, it must be by means of diet.”

He experimented with various diets and noted that “A child, who was fed upon a quart of the best Dutch mussels daily, thrived wonderfully, but relapsed when the season for mussels was over.” It is, perhaps no surprise to any parent that Dr. Gee also reported, “Next season (the child) could not be prevailed upon to take them.”

By 1950, the link between celiac disease and wheat was finally established. In that year, Dr. Willem-Karel Dicke, a Dutch pediatrician, reported that children with symptoms of celiac disease got better when wheat was removed from their diet.

Dicke was suspicious that wheat was the culprit for decades, but this theory only gained traction during World War II. In 1943, wheat products were in short supply in Holland due to a Nazi blockade. During that time, previously unwell children, now deprived of wheat-based products, had relief from their symptoms with them only to return upon the reintroduction of wheat into their diet after the end of the war.

With his theory validated by these tragic circumstances, Dicke went on to publish his findings regarding gluten as the culprit, and the gluten-free diet as the treatment.

Some people have no symptoms, gastrointestinal or otherwise. But even they may end up diagnosed with celiac disease. In Chapter 6, we look at who should be *screened* (tested) for celiac disease and how the screening should be done.

As we mentioned earlier in this chapter, if left untreated or insufficiently treated, celiac disease can not only make you feel unwell, but it can lead to serious damage to your body (including causing complications like osteoporosis, anemia, and more).

In Chapter 7, we take a detailed look at these potential complications and how to avoid them. In Chapter 8, we look at the many ailments that are not directly caused by celiac disease but are *associated* with it. We describe the kinds of symptoms these ailments cause and the symptoms to which you should pay the most heed.

For many people, the most feared complication of celiac disease is cancer. Thankfully, celiac disease seldom leads to this, but it can. In Chapter 9, we make you aware of the types of cancer that are linked to celiac disease and, most important, early warning signs for which you should keep a close watch.

Treating Celiac Disease

Celiac disease can make you feel unwell. It can be a hassle to live with. It can cause complications, including damage to your body. *Oh joy.* So now the good news: You have ultimate power over this condition. Even better, this power is derived not from taking a truckload of pills — or, indeed, any pills at all; no, this power is derived from you modifying your diet to eliminate any and all gluten.

Modifying your diet to eliminate gluten intake, however, isn't simple and requires lots of work and, like they say about the price of freedom, eternal vigilance. In Chapter 10, we look in detail at what constitutes a gluten-free diet and provide all sorts of tips to help you make the necessary changes to the way you eat and how you eat. And, speaking of vigilance, we also look at hidden sources of gluten for which you should be on the lookout.

When it comes to celiac disease, gluten is the most important nutrient that affects the health of your GI system, but it's not the only one. As you see in Chapter 11, celiac disease can lead to low iron levels and difficulty digesting certain milk products (a condition called *lactose intolerance*).

Sometimes, despite carefully following a gluten-free diet, a person continues to feel unwell. Could it be that gluten is sneaking its way into your diet? Or could it be, perhaps, that you don't have celiac disease (doctors do make mistakes, including mistaken diagnoses) or that you have an additional ailment that's causing your symptoms. In Chapter 12 we explore these possibilities.

Living and Thriving with Celiac Disease

Perhaps it's been some time since you were diagnosed with celiac disease and you're nicely on track with your gluten-free existence. What then? Do you need to be monitored for celiac disease-related health issues? If so, how should the monitoring be done? Chapter 13 describes the ongoing care of celiac disease and ways that you can continue to empower yourself.

Although people living with celiac disease share many similar challenges, differences exist for some people based on age, living condition (home or in a college dorm for instance), and special circumstances such as attempting to conceive, or being pregnant. Chapter 14 covers living — and thriving — with celiac disease in these situations.

Better ways of managing celiac disease may emerge in the future. Indeed, there may come a time when you may not need to follow a gluten-free diet. In Chapter 15, we explore these and other possible options for dealing with celiac disease that may come about someday.

Handling the News

From the time you were first told you (or your loved one) had celiac disease until the time you picked up and started reading this book, you probably have experienced many different feelings and conflicting emotions.

If you were feeling poorly — especially if this had been going on for a long time — with typical symptoms of celiac disease (we discuss these in Chapter 2), you likely felt relief that the cause of your troubles was identified and that treatment would make you feel better. At the same time, you may have been understandably upset that you had been saddled with a diagnosis for which there is no cure. All these feelings are perfectly normal.

In this section, we look at a few of the different types of feelings that people experience after being diagnosed with celiac disease.

Experiencing denial

Your first reaction upon being told that you had celiac disease may have been surprise; indeed, you may have been stunned. And it could be that, as the impact of being told you had this life-changing disease sunk in, you doubted it could be the case.

“Me? Celiac disease? No way,” you may have said to yourself or others.

You may have then looked up information online and found that your symptoms didn’t match all of those listed on some sites; this may have provided additional justification to your feelings of denial.

But you still weren’t feeling as well as you should or your lab tests showed you were deficient in certain nutrients, or your bone density was low (as seen with osteoporosis), or you had some other feature of celiac disease which, try as you might, wasn’t going to disappear. Eventually, you likely came — perhaps grudgingly — to accept that you had the condition. Or perhaps as you read this book, you have only recently been diagnosed and you still can’t believe it. Either way, these feelings are perfectly natural.

Being angry

If you felt angry after you were told you had celiac disease, rest assured, this is normal and perfectly understandable. You've got enough going on in your life without being told there is another issue you have to contend with.

Having celiac disease isn't like having a strep throat or bladder infection that will quickly go away after a few days of antibiotics; if you have celiac disease today, you will have it tomorrow and next week and next month and next year, too. And who wants that? Nobody.

It's also perfectly understandable to be angered by the "work" of having celiac disease. All of a sudden, you need to spend far greater effort when shopping and cooking, not to mention the additional expense of buying food that's gluten-free. Also, in addition to the usual considerations regarding fat content, calories, sodium, and so forth, you now also need to scrutinize everything you eat to ensure that it doesn't have gluten.

The diagnosis of celiac disease may not be what led to anger. You may be angry that the diagnosis wasn't made earlier. Many people go months or even years, feeling unwell all the time, before their celiac disease is discovered. During this time, other, incorrect diagnoses may have been made or people may have been told that their problem was "all in your head" or "due to nerves." No wonder a person in this situation feels frustrated or angry.

Another source of anger arises when a person with a delayed diagnosis reflects on the lost opportunity to have prevented complications from celiac disease (such as, for example, osteoporosis).

By the way, we are not casting stones here. Celiac disease is a condition that can both mimic and masquerade as many other diseases and a delayed or missed diagnosis is not uncommon; indeed, many an excellent physician has overlooked this diagnosis.

Regardless of the source of your anger, feeling angry isn't useful. Eventually, anger has to be left behind so that you can get on with your life and get back to and maintain a state of good health.

Feeling sad and taking time to mourn

Feeling sad upon hearing bad news is perfectly understandable and normal. A diagnosis of celiac disease is experienced by some as a loss, who mourn the ending of the "before times" when they didn't have to think about gluten when traveling or eating in restaurants. You may find, however, that if you've been feeling unwell

(especially if it's been for quite some time), your sadness will be mixed with relief now that treatment will get you feeling better in short order. You should realize, however, that even after your celiac disease symptoms are controlled, you may at times feel sad that you have celiac disease. With time, that too will pass.

Taking the next step

Regardless of what feelings you experience after finding out you have celiac disease, none of them have gotten your symptoms to go away or your blood tests to normalize, and now you're ready to take the bull by the horns and deal with your diagnosis. As you learn the ins and outs of living a gluten-free existence, don't get mad at yourself if, from time to time, some of your old angst shows up. That is normal and will pass.

When you're feeling down or frustrated or simply upset at having celiac disease, you may find the following coping strategies helpful:

- » **Be a positive thinker.** Focus on how much better you will feel once you're following a gluten-free diet or, if you're already on treatment, how much better you already feel. Unlike so many other diseases, you have the power to control things without requiring medication.
- » **Know that you're not alone.** Recognize that there are healthcare professionals — most importantly, dietitians — who are there to help you learn what you need to know. You're not on your own!
- » **Involve your family.** As you learn about living gluten-free, you can share your newfound knowledge about nutrition with your partner and your children. You will find that you are — or will shortly become — a true nutrition resource! Also, involving your family allows them to provide you with the support and encouragement you may need and want from time to time.
- » **Seek out a celiac disease community.** Find a support group, either one that meets in your community or online. We discuss online support groups in the next section.

Finding Information and Support on the Internet

We certainly hope that you will find this book a helpful tool to assist you in your quest to find out more about your celiac disease, but we also recognize that a vast amount of additional information is available online.

Some of the information you find online is good, and some is, to put it charitably, not quite as good (or downright awful to be quite frank). In this section, we look at how you can use the web to find more information about celiac disease and how you can seek out Internet support groups to lend you a hand when you need it.

Knowing whether an Internet site is reputable

Okay, sure, sometimes it's obvious when an Internet site is not to be trusted, like if you were to come across a site called www.wesellusedcarsandwealsocureceliacdisease.com. But most of the time, it's not nearly so easy to tell whether you've reached a cutting edge, state-of-the-art site, or one that is far less reputable.

A website that is credible and provides reliable information and advice (recognizing that, of course, none of these criteria guarantees the site will be sound) generally does the following:

- » **Reports facts objectively:** The site provides information in an even-handed way and avoids sensationalism.
- » **Relies on science:** The site doesn't rely on testimonials to the exclusion of science. An unusual or unique treatment that appeared to help a person with celiac disease isn't proof that it worked; perhaps the person got better for an unrelated reason.
- » **Uses ads responsibly:** The site doesn't have advertising or, if it does, the ads, like the site, are not over-the-top declarations encouraging you to buy "instant cure" miracle-type products.
- » **Aims primarily to inform, not to sell:** If the site is run by a scientific organization, hospital, healthcare clinic, or recognized expert on celiac disease, the site is likely very reputable. If the site is owned and run by a company that is marketing a product, question whether the information on the site is appropriately dispassionate and even-handed. Such company-owned sites may be perfectly reasonable and good sources of information; it's just necessary to question it, that's all.
- » **Identifies its author:** The author or authors of the site are identified and, ideally, the site provides background information regarding important details such as their professional qualifications and academic affiliations (if any).



TIP

Google the names of a site's authors. You may discover an author has written hundreds of scientific articles, which is good, or you may discover that they've just lost their medical license because of incompetence — which is, well, bad.

- » **Uses verifiable facts:** Information on the site is referenced or at least supported by verifiable facts rather than just being “stream of consciousness” opinion. Also, if the site quotes scientific studies, check to see whether they were published in obscure-sounding journals; they may be obscure for good reason. (Although, of course, some excellent scientific journals have unusual names.)
- » **Does *not* engage in conspiracy thinking:** If the site talks about conspiracies among the medical community or “big business” or government or some other organization said to be participant in some Machiavellian scheme to “hide the cure” to celiac disease, then you should take a pass on the site.

In Appendix D, we list some helpful and reputable organizations with extensive online resources.

Finding an online celiac disease support group

An Internet-based support group (which, depending on the specific nature of the group, may also be referred to as a discussion group, discussion forum, or chat group) is a place where people affected by a condition, either directly because they have it or indirectly because a loved one has it, can exchange thoughts, ideas, facts, and suggestions. These may be freestanding or may be a group within a social media platform such as Facebook.

Support groups are designed to provide support. That is, however, just the tip of the iceberg. Indeed, support groups provide myriad other functions above and beyond this. They can also have their downsides, however. In the sections that follow, we look at these issues.

Understanding how an online support group can help you

An online support group can help you by providing the following:

- » **Other people’s stories:** If you don’t know other people with celiac disease and as a result are feeling isolated, reading other peoples’ stories about how they have been affected by celiac disease can help you realize that you’re not the only person out there battling the condition.
- » **Patient-provided tips:** You can find many tips that others with celiac disease have posted regarding helpful shopping, cooking, and other “living with celiac disease” topics. For example, a person may have discovered a great place to

buy gluten-free foods (either online or at a bricks-and-mortar store) and may be keen to share this information.

- » **Opportunities to share your story:** You may find it cathartic or stress-relieving to share with others your own trials and tribulations with celiac disease.
- » **Encouragement:** Support groups are designed to provide support! Having a bad day? Feeling fed-up with living gluten-free? Let the group know, and you'll likely find members quickly commiserate and encourage you to keep up your efforts.
- » **Opportunities to help others:** You can gain satisfaction by helping others if you share your own how-to tips with the cybercommunity.
- » **Success stories:** If celiac disease is new to you, you may find it reassuring to read postings from people who have successfully lived with celiac disease for many years.
- » **Substitute for a "real" support group:** Local, "real" (as opposed to online) support groups are less common than they were 20 years ago and may not be available nearby. Online forums allow you to still participate in group discussion and to do so at times that are convenient for you.
- » **Multi-language support:** You may be able to find discussion groups that converse in the language in which you are most comfortable.
- » **Resource to take to your doctor:** If you're having symptoms of one sort or another, you may find postings describing similar issues and what was eventually found to be their cause. You could then ask your healthcare provider if your symptoms, too, might be attributable to this.

Recognizing the downsides of online support groups

Like the web in general, online support groups have both upsides (see the immediately preceding section) and downsides. Here are some of these downsides and what you can do to avoid these pitfalls:

- » **Question your sources.** Anyone can post to a discussion forum. *Anyone.* You could be reading a posting that has been written by a well-informed, knowledgeable, well-meaning individual who has something important to share . . . or you could be reading a posting by someone who is ill-informed and is sharing nothing more than misinformation.
- » **Avoid endless complainers.** Some people participate in a support group for no other reason than because they've got an axe to grind. Although

sometimes reading about someone else's complaints can be helpful in its own way, to read complaint after complaint after complaint can get to be a real downer.

- » **Scrutinize sales pitches.** Online support groups may contain postings by people whose main goal is to try to sell you something, whether or not the product is of proven value or benefit.
- » **Turn away sites dominated by a few individuals.** Online support groups may have posting after posting after posting by a single or small group of individuals who dominate, take over, and hijack discussions.
- » **Leave mean-spirited groups.** Support group postings sometimes degenerate into nothing more than name calling, insults, and other derogatory rants. Not a pretty sight (or site!).



TIP

Look for support groups that are moderated; that is, they have someone (typically a well-meaning, reasonable, and knowledgeable person) who supervises the postings and removes those that fall below or outside an appropriate minimum standard.

Looking at “Real” (Non-Virtual) Support Groups

Regardless of whether you elect to participate in an online support group, we recommend you consider joining a local, non-virtual-world group. By participating in such a group, you can do the following:

- » **Get to know real people.** You get to meet in the flesh other people living with celiac disease. Getting to know snippets of someone's life by reading postings online is one thing; spending time with a “real” person is quite another.
- » **Expand your conversations.** Spending time with others allows you to have expanded conversations not constrained by the limitations of interacting exclusively online. Online postings are, by their very nature, typically a few sentences long and necessarily limited in scope.
- » **Meet people who know your locale.** Local people live locally! The great benefit of meeting local people is that your neighbors likely know the best places in your community to buy gluten-free foods, the most knowledgeable and helpful dietitians and doctors, and so much more.

- » **Mobilize the group to work together.** There is strength in numbers. The group can order food items in bulk to minimize shipping charges and can then divide up the goods among the people that ordered the product; that way, you (and the others) can help avoid storing large amounts of a product that you may use only occasionally. The power of a group can also be helpful in persuading a local health food or specialty food store to stock their shop with gluten-free products that the group identifies as tasty and worth having available locally.
- » **Participate in organized activities.** Participating in such group activities allows you to learn the “gluten-free” ropes of shopping, cooking, and eating out while making new friends and acquaintances. Local support groups often organize helpful events such as
 - Cooking demonstrations
 - Food tastings
 - Restaurant outings
 - Seasonal parties
- » **Attend presentations.** Support groups often invite speakers to talk with the group. A speaker may be a celiac disease specialist, dermatologist (skin specialist), dietitian, or a nurse who specializes in celiac disease.
- » **Join a well-managed support group.** People participating in a real support group are less likely to dominate and take over conversations than what you find on some online forums.
- » **Get real, live human support.** Sometimes, in moments when you’re feeling down, a real hug can feel a heck of a lot better than another hour staring at a screen.



TIP

Here are a few ways you can find a local support group:

- » **Ask your healthcare provider.** Ask your dietitian or celiac disease specialist.
- » **Look up the listings.** If you live in the United States, have a look at the state-by-state listings on the National Celiac Association website: <https://nationalceliac.org/celiac-disease-support-groups>. You can also find a directory of Gluten Intolerance Group local support groups at <https://gluten.org/community/support-groups>. Other suggestions are listed in Appendix D.

