Our Digestinve System: Gluten associated allergies - a closer look

Subject Matter Expert Contributor: Michael L. Dougan, MD,PhD

-Gastroenterology Department -Harvard Medical School Complications of cancer immunotherapy Celiac disease Familiar Mediterranean Fever Eosinophilic esophagitis

Massachussets General Hospital

Many, many people suffer through digestive problems that could interfere with every aspect of

their lives. One of these that deserves more attention is celiac disease.

People with celiac disease have an incredible sensitivity to gluten, even for amounts that are not visible with the human eye.

With celiac disease, even if you do not notice symptoms, eating gluten could causing harm.

Getting a proper diagnosis will make people feel better. However, there are also long term consequences, and we want to prevent those.

As a doctor, Dr Dougan wants his patients to feel better. He is committed to help all my patients lead healthier and happier lives.



A CLOSER LOOK AT CELIAC DISEASE

According to statistics provided by the Celiac Disease Foundation (CDF), one in every one hundred people worldwide is affected by celiac disease. The United States has one of the best healthcare systems in the world, yet the CDF states that over 80% of people affected by celiac disease remain undiagnosed and are at risk of long-term health complications. We infer that in developing countries, the means to appropriately diagnose and treat celiac disease are far more limited, and thus, a higher percentage of the population could be undiagnosed. For this reason, our objective is to disseminate information about this topic since gluten-free trends are growing worldwide.

We hope people can familiarize with the setbacks of this allergy and search for a proper diagnosis if they believe they are affected. Furthermore, it is our goal to educate people about celiac disease to increase to increase the quality of life of individuals who are affected by it and to prevent further health complications that could arise if left untreated.

Dr. Michael L. Dougan, a specialist at Massachussetts General Hospital in Boston, MA. has helped us comprehend this phenomena better.

In this article, we will uncover developments, symptoms, and treatments associated with this trending allergen present in some of our favorite everyday foods.

We will also understand why people who are born healthy can fall ill and discuss the importance of controlling the illness with proper lifestyle balance and nutrition before severe consequences appear.

Discovering more about Celiac

By Maria Rada

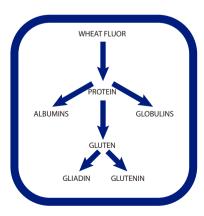
1.- What is celiac disease? Let us rephrase in simple terms

Celiac disease is a kind of inappropriate immune response. Our immune system has evolved to fight off bacteria and viruses that are dangerous to our body, and to ignore things that are not dangerous like the food that we eat. In fact, healthy bacteria live in our colon to help break down food that we eat. But for reasons that we still do not fully understand, the immune system can inappropriately be targeted toward something that is harmless; and in celiac disease, the immune system treats a component of wheat, gluten, well actually, one particular protein within the gluten structure called gliadin.

The immune system treats gliadin as if it were an invading microorganism, such as a virus. It attacks it with the full force it would use to attack a virus. The problem is that it causes collateral damage to the healthy cells that are in contact with the gluten. It is that damage to the healthy cells that causes the symptoms of celiac disease.

When the damage affects the lining of the small intestine, you can lose the little finger-like projections in the small intestine, and then you lose the ability to absorb nutrients from foods properly because the disease turned what should be this very complicated beautiful absorptive surface, with lots of little projections to absorb nutrients, into a flat, barren tube.

Once this happens, the body does not absorb essential nutrients like iron and vitamins. In fact, on certain instances, it does not absorb a lot of anything, and these nutrients all start running out of your body. This can lead to nutritional deficiencies, which most commonly people notice as low redblood cell counts, called anemia.



Does it affect the mental state?

It can, and we do not understand that part so well. One of the vitamins, vitamin B12, definitely has a role in neurons and in sensation, but people can have symptoms even when B12 is not deficient. We do not understand exactly what the connection between celiac disease and cognition is, although every time people are feeling sick and anytime their body is inflamed, there is a certain effect on the brain that comes from immune signals. The immune system signals back to the brain and that is why a lot of feelings of illness happen, for example: many symptoms of the flu or a respiratory tract infection like a cold come from the immune system signaling to the brain that something is wrong, which makes you tired and want to sleep. You can have that feeling all the time, if you have an inappropriate immune r esponse in your small intestine.

Let's talk lifestyle effects. Does it happen because the body is not prepared? Why does this happen?

We do not know many of the causes, but we do know one for sure. There is a molecule that causes our immune system to become activated. We call it HLA or MHC, and this is the molecule that is targeted in a transplant rejection, when you take one person's organ out of the body and put it into another person, and it is part of the code that your body uses to identify you as separate from another person.

Everybody has HLA proteins, they are normal and a normal part of the immune system, but, there are a lot of variations, thousands of different versions of this molecule in the population. Siblings tend to share groups of them. Identical twins share all of them. Unrelated people may share some of them. And they do also fall along ethnicity, so people who are of the same ethnic group are more likely to share some than people who are not of the same ethnic group.

And it turns out that people who are particularly of northern European ancestry, which can be such a small part of their ancestry, have a high risk of having variants of these molecules that in particular increase the risk of celiac disease.

2.- Common symptoms

The most common symptoms are diarrhea, bloating, cramping, and weight loss. There are a lot of other symptoms, but these are the most common.

Most people do know that they are having something wrong with their digestive tract; they do not feel good after eating, and it goes on and on. It usually is not as severe as an infection, so people tend not to be extremely sick. They can be, but they tend not to be so sick that they stay home every day until it gets better. And that is part of why it can ^{go} on so long without getting diagnosed.

f celiac disease came on, so severely that people were so sick that they did not get out of bed, at some point they would go to the emergency room for treatment. Usually they are not in such a bad state, but they do not ask for help because they are not sure that something is wrong or if it is something they ate, and it can go on for a long time that way. They can ask for help, but the doctors who see them are not familiar with this disease and they do not end up getting diagnosed. It rarely gets bad enough that they go into an emergency department and get hospitalized over it.

Another symptom is a rash that is very common with celiac disease which we call dermatitis herpetiformis. It can affect any part of the body but is most commonly found on the elbows and knees. It usually looks either like red bumps or like red fluid-filled bumps, very similar to chicken pox. And that is where the name comes from. It looks like the chickenpox family of infections, but it is not an infectious process. You cannot spread it from one person to another, and you can fix it by becoming gluten-free.

3.- In which foods is gluten commonly found? What are some common sources of gluten?

Gluten is a protein. It is one of the major components of wheat. it is a protein conglomarate and the gliadin is the part of it that usually gets attacked. It is found in wheat, rye and barley and it is what makes those grains so good for creating breads that stick together. The name gluten is because it is a sticky protein. In natural grains, it either does not exist, or it is in a very small quantity. It is cultivated grains that have a lot of it because humans selected for bigger and bigger grains over centuries. People have developed selected versions of wheat, rye, and barley that have really big grains and the reason why they are really big is because they have too much gluten.

It is very hard for everybody to digest gluten. There are people who have symptoms from eating gluten even when they do not have celiac disease, just because it is hard to digest; that is gluten sensitivity.

4.- What is the difference between gluten sensitivity and celiac disease?

Gluten sensitivity is just trouble digesting gluten. If somebody eats a super small amount of it, they will not notice.

On the other hand, celiac disease can cause effects even for small amounts of gluten because much like the fact that your body can fight off a virus that you cannot see with your eye; if you have celiac disease, you can have an attack on your small intestine for an amount of gluten that you cannot see with your eye.

f you have gluten sensitivity, and if you cannot see it, there is not enough of it there to feel sensitivity. If you can see it, you might have symptoms, but if it is a contamination because it was on a plate before you ever started eating off of the plate, you will not have to worry about having symptoms.

So, is it betterto be gluten free since gluten is hard to digest?

Even though it is hard to digest, it does not cause symptoms in most people and it is a good source of nutrition, especially in resource-poor settings. Wheat is very cheap and easy to grow. I do not think there is any reason why people have to avoid it.

The problem is when you go to gluten-substitute foods, like baked goods, that do not have gluten in them, they often have a lot more calories and fat. So, it can be harder to keep a healthy diet if you are eating gluten substituted foods. If you are eating foods that are naturally gluten-free, like fruits and vegetables, that is the best.

f everyone went to a gluten-free diet and were eating more fruits, vegetables, fewer grains, more lean meat; that is a healthier diet than one that has lots of grain, but a diet with lots of grain is a lot easier to grow and feed a population with, so I think, that grain has a very important role in a human diet.

Gluten sensitivity is about symptoms, so if you do not have symptoms, it does not matter; it is not hurting you.

With celiac disease, even if you do not notice the symptoms, it can be hurting you. In the initial state, many of the people who have undiagnosed celiac disease have no symptoms or minimal symptoms, which is why they are undiagnosed.

5.- According to beyondceliac.org - Nation Foundation for Celiac Awareness, 83% of the people with Celiac disease are undiagnosed. Why does this happen? What about underdeveloped countries?

t is hard to say in terms of percentage in underdeveloped countries because we know that the risk is related to ethnicity. Countries that have some degree of European ancestry are going to have a higher risk than countries that do not. Eastern Europe and South America are going to have a higher risk of celiac disease than, say, sub-Saharan Africa.

People of any race can get it, especially when we talk about race as a social construct. That is the reason why I use the word ethnicity. It really is who your ancestors were and really is particular genes, so if you have those genes it does not matter what color your skin is or what country your parents migrated from. It is those genes that are more common in people of Northern European ancestry. I would guess that for example, in South America, there are a lot of people who are undiagnosed compared to other regions of the world.

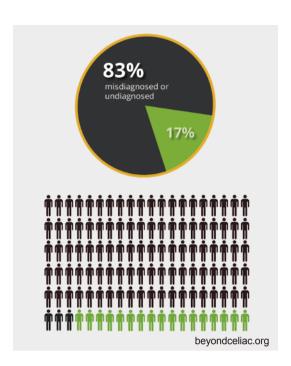
6.- When could be the right moment to look for a specialist?

You eventually need to see a specialist to get a clear diagnosis. The only way to be 100% sure you have celiac disease is through a biopsy, that does require a specialist.

You can always try being gluten-free, and see if it makes you feel better, and it is fine to stay that way. It still does not give you a clear diagnosis. A lot of times people find it hard to be as strictly gluten-free as they need to be to really heal if they do not know they have the disease. If people go entirely based on symptoms, they could be getting low level inflammation and have no one there to tell them.

After the diagnosis any doctor could handle this.
They just have to be familiar with the disease. It is
easy to treat and monitor if they know about it. If a
primary doctor knows that, it is fine, they can do all
the work after the initial diagnosis, but if a primary
doctor does not feel comfortable taking care of the
disease or does not know about celiac disease, that is
a moment to see a specialist.

Certainly, people who have ongoing diarrhea, weight loss, cramping, and bloating, should see somebody who can tell them whether or not this is celiac disease.



7.- In this matter, Nation Foundation for Celiac Awareness indicates that 46% of people with celiac disease have seen, on average, three different doctors before being appropriately diagnosed. Why is this the case?

This is amazing. I do not have a perfect answer for that because a lot of problems with digestion are similar to celiac disease. People who have irritable bowel syndrome (IBS), can present almost the same way. IBS is a collection of disorders related to digestion where people do not move food through their gut as well, or they move food too quickly or they cannot digest certain kinds of food, and they get pain, bloating, cramping, diarrhea, and sometimes constipation; which is different from most people with celiac disease.

Do people that have higher metabolism better off?

t could happen to anybody. Weight does not really change the risk for it; diet does not change the risk. If you are gluten-free, it will not happen. If you are not gluten-free, aside from that, there is no dietary risk that we know about.

Some people prefer to be gluten free because they heard is not healthy

do not think there is any reason to be gluten-free if you do not have symptoms from gluten, and you do not have celiac disease.

8.- What are the steps of the right procedure to get a correct diagnosis?

First, go to see a doctor. Tell them about your symptoms. With those symptoms, the doctor should suspect celiac disease is a possibility.

Anybody who has never been tested for celiac disease with those symptoms should be tested for celiac disease. That's my feeling, even if the doctor thinks that something else is more likely.

Celiac disease looks like a lot of different things. There is a blood test called Tissue Transglutaminase Antibody (tTG-lgA). The test is 95% accurate and 5% uncertain. First, you have to be tested for lgA, a kind of antibody. The reason for that is that a small percentage of the population has deficiency of IgA. If you have a deficiency in IgA, the tTG-lgA will be negative even though you have celiac disease. If tTG-lgA is positive, you probably have celiac disease. And then you do an endoscopy to confirm the diagnosis.

9.- On a similar note, many people tend to be misdiagnosed. Why? How should we address this?

BS (Irritable Bowel Syndrome) is the most common one, and for that one, there is no specific test for it.

fyou have those symptoms, I think the way to address it is to get that blood test to see if you have celiac disease. If the blood test is negative, the possibility of having celiac disease is so low that I do not think you need to pursue it as a diagnosis anymore.

If the symptoms continue, then you need to see a specialist to try to figure out what the other problem is, which could be celiac disease. Part of the steps they will take to figure out what else might be going on would eventually get to celiac disease and in that situation, you are ending up getting a late diagnosis because you have an atypical presentation of it.

Is it worse to have a late diagnosis?

That is not really worse unless you start to get very sick. If you have already lost a lot of weight and you already have nutritional deficiencies, the doctor taking care of you should be trying to get a diagnosis very quickly even if it is not celiac disease.

Another disease that can look like celiac disease is for example lactose intolerance. That is a specific dietary problem that refers to the inability to digest lactose in milk. That is usually best diagnosed by avoiding milk. Something called small intestinal bacterial overgrowth can look like celiac disease. SIBO is the abbreviated version of it, which is bacteria growing in the small intestine that should not be there.

And there are numerous other diseases as well.
Sometimes inflammatory bowel disease can look like celiac disease. Sometimes parasitic infections can look like celiac disease, but all of those would have negative blood testing for celiac.

10.- According to the Celiac Disease Foundation, 34% of the people who are diagnosed with celiac disease are in danger of developing another autoimmune diseases, under what circumstances does this happen?

We do not know why it happens, but it does happen. Common other kinds of auto-immune diseases are thyroid disease and less commonly, type 1 diabetes. We do not know why some people get a cluster of auto-immune diseases and some people do not, except in rare cases where there is a clear genetic predisposition. There are some rare diseases that cluster with multiple autoimmune diseases, but most of the time, we just know that there is an increased risk, and we do not know why.

Microscopic colitis is another one that sometimes goes along with celiac disease. This is something to think about in someone with celiac disease who has diarrhea even though they follow a gluten-free diet.



11.- Could you please explain to us about the importance of a strict gluten-free diet (100% GF) and the impact of crosscontamination? More specifically, what is cross-contamination, what are some misunderstandings about, and the main reason why people are not able to altogether remove gluten from their diets?

Let us start with cross-contamination. As the name implies, it happens when gluten-containing food is on food that should not have gluten (clean food) or is in food that should be gluten-free.

t occurs when people who prepare foods mixed them because they are not aware of the effect of contamination or because the serving ware was used for food containing gluten before and was not properly cleaned or had no washing. It causes cross-contamination. This happens very frequently in restaurants where they have gluten-free food being prepared next to food that contains gluten. It could be someone, like putting croutons on a salad and then taking them off or it could be a fryer that was used for frying breaded something and then used again for something that should not have bread on it, or a deep fryer that is frying French fries that should be gluten-free but also is deep frying chicken which has gluten-containing breading on it.

There are numerous versions of cross contamination, but since it is minuscule quantities that you cannot see that cause contamination, you need to have products that have never touched gluten; you also need to make sure that products that you are eating or eating with have never touched gluten. That is very difficult at restaurants. They have to be incredibly careful to keep these products separate, so if they are not stating that they are remarkably careful about it, they probably are not, and so eating out is the most common way for cross-contamination.

There are some places that have both gluten-containing foods and gluten-free foods and they are very careful. When you are at those restaurants, you have to tell them; usually, it is easier to say you have an allergy. It is not really an allergy; it is a different kind of immune response than an allergy, but people at least know what an allergy is. You also have to ask them how they keep their gluten-free products separate, and if they cannot give you good answers to that, the answer is probably they do not.

Cross-contamination at home can happen usually by serving ware. For example, if you made a sandwich with gluten-containing bread on a plate and then gave it to a person who eats gluten. Then you use that same plate to make a gluten-free sandwich and give it to the next person and the little bit of bread crumb that was left behind carries over to the person who should be gluten-free. Toasters are a very common cause of contamination for this reason.

A lot of prepared foods have gluten contamination at supermarkets. The only way to really be sure that they do not is if they are certified gluten-free. Certified gluten-free should be gluten-free, and most of the time, it is. The FDA does mandate in the United States that all foods contain bolded simple language that identifies ingredients that are the most common allergens which does include gluten. So if you have wheat, barley, or rye in your product, it will have to say that. If it does not say that, it means that the person who is producing it does not think it is there, but that is different than certified gluten-free.

If there is something that is very unlikely to have contamination, like for example beans which are not produced with other kinds of grains, you are probably fine even if it does not say certified gluten-free. But for products that contain grains, you really want it to be certified gluten-free because if it contains a very small amount of gluten, that is not enough to put on the label, it could be enough to make you sick.

12.- Is there a cure, or is this a life-long condition?

am sure there are people who appear to have been cured from celiac disease, but generally, no, there is no cure. We do not think of celiac disease as something that goes away; it is a permanent, lifelong disease.

13.- What are the most significant health risks if one is left undiagnosed or if one does not follow the appropriate treatment?

The most significant, aside from the way you feel (and not everybody feels sick), is anemia, meaning low red blood count. You can also have decreased bone health which can lead to osteoporosis and bone fractures. It is especially a problem in women and mainly in thin women.

There are other nutrient deficiencies that can lead to problems with nerves, and also there is a small risk of lymphoma, which is a kind of cancer of the immune system that is associated with celiac disease. That is very rare, but at the same time a risk that can be more pronounced with untreated celiac disease.

What does happen with products that are not for ingesting or relatives who are not GF at home?

- t is very hard with a super small quantity of gluten in things that you do not ingest to really know if people have to avoid them.
- There are people who are super sensitive, but there are not that many. I do have patients who have to have gluten completely removed; not just worrying about plates and toasters, but actually living in gluten free homes. But to make that kind of a diagnosis, because it is so rare, I re-biopsy people to make sure that the symptoms that they are having are really from ongoing celiac disease. If you thought your hair care product was causing celiac disease, I would have to take a biopsy and see if your celiac disease is active before telling you not to use it.
- If I suspect that a cosmetic product is causing celiac disease, I take a biopsy and see if the celiac disease is still active. Then I ask patients to stop using the product, then re-biopsy and see if their celiac disease is now healed. That is the only way that I will tell someone that a product they are not eating is causing their celiac disease to flare.
- And I think it is a huge negative impact on the quality of life to be worrying about contact with things that you are not eating, and I advise against being too concerned about gluten in products that are not foods, as it is very unlikely that this will cause any problems, even in someone with celiac disease.

14.-Why it is important to raise awareness about celiac disease and why it is important to get a proper diagnosis?

The main reason to get a diagnosis is to alleviate the symptoms that are bothering you.

- Many, many people suffer through digestive problems that can interfere in every aspect of their lives and those could be easily fixed. I think, it is the number one reason. Getting a proper diagnosis will make people feel better, feel happier with their lives and carry on a healthy life.
- However, there are also long-term consequences that we want to prevent too. Particularly issues that you would not notice until they became a problem like a decrease in bone health or the increased risk of lymphoma. It is important to recognize that the alternative, leaving it untreated could bring consequences in 10, 20, or 30 years when suddenly it might be a major problem.

The most important concern is to just stop feeling unwell. If you add up all those days feeling sick, that is a huge burden. Then, I always think that the most important thing is to alleviate symptoms; that is the reason to treat anything. As a doctor, I want patients to feel better, as doctors we also worry about these rare, very bad things that can happen, but most of all I am committed to helping all my patients to lead healthy, happier lives