

Parent Resources

Supporting Children with Celiac Disease



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An Overview of the 504 Plan



At Beyond Celiac, we believe that celiac disease shouldn't stand in the way of children living happy lives alongside their peers. Celiac disease does bring unique challenges that parents and students need to navigate on a daily basis. With the help of this toolkit, you can learn to use legal protections that will enable you to seek accommodations to ensure that the school environment does not compromise your child's long-term health and ongoing safety.

What's a 504 plan?

A 504 plan stems from Section 504 of the Rehabilitation Act of 1973. This section prevents discrimination against public school students in grades K through 12 because of disabilities. A 504 plan is meant to "remove barriers" to learning by providing a specific outline on how to make accommodations or modifications on a student-by-student basis.

What's the Rehabilitation Act of 1973?

The Rehabilitation Act of 1973 applies to all institutions receiving federal financial assistance, such as public schools. Under this law, public schools *must* provide a free, appropriate public education and not discriminate against disabled students.

This law acknowledges that the disability may not require special education services, but a plan is needed to ensure the student receives an appropriate education accommodating the disability within the classroom. This law must accommodate a special diet, including the gluten-free diet for children with celiac disease.

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Does your child need a 504 plan?

This decision is entirely up to you as a parent or guardian. Some parents find that informal discussions and accommodations have been sufficient for having the child's needs met at school. However, having a formal 504 plan in place is valuable, especially as teachers and staffing may change. The 504 plan guarantees by law that your child's needs are met throughout their school career and not just in certain classrooms. You can choose to utilize your 504 plan accommodations at any time and having them in place before you need them can save important time and resources if your child develops symptoms from gluten exposure or if you are having trouble with consistent accountability.

How do you get a 504 plan started?

To get started, you'll need to contact your child's school. The 504 plan team should include:

- Primary classroom teacher
- School nurse
- 504 plan coordinator
- School counselor or psychologist
- Director of foodservices

You'll also need a doctor's note to show that your child has been formally diagnosed with celiac disease or non-celiac gluten sensitivity ('gluten sensitivity'). This note should outline the accommodations required to maintain your child's health, enabling him or her to have equal access to public education.

What information is included in a 504 plan?

Generally, you'll need to provide information about your child's diagnosis and needs, including:

- Year of diagnosis
- Amount of time on a gluten-free diet
- Details on why a 504 plan is needed (including how a restricted diet affects a major life activity)
- Child's developmental level and needs (Are they self-reliant in managing the diet? Do they need strict supervision? Etc.)

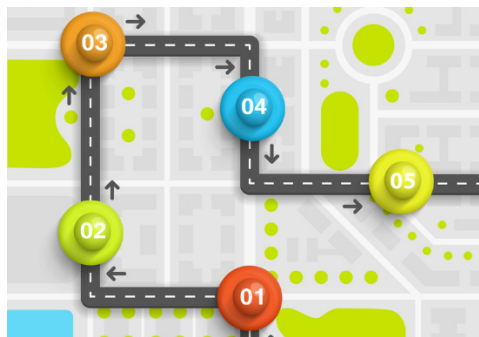
A 504 plan will specifically outline all of the details of how your child's celiac disease needs to be managed in the classroom. For example, you and the 504 plan team can develop an action plan for:

- Navigating school lunches
- Birthday parties
- Snacks
- Art class

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The plan will lay out specific accountabilities. Having a 504 plan in place will also make it much easier to apply for disability accommodation in college.



Where can you learn more about the 504 plan?

To learn more about the 504 plan and how it can help your child, visit www.Understood.org. Understood is an organization that is made up of 15 non-profits that have joined together to support children of parents with learning and attention issues. This group provides in-depth information on

504 plans. Continue reading to learn more about specific accommodations that could help your child in the classroom.

The 504 Plan: A Roadmap for the Accommodation of a Child with Celiac Disease

Now that you know how a 504 plan can be used to help your child in the classroom setting, it's time to think about the actual accommodations that your child will need. The below is a guide to the types of information and accommodations that can be incorporated into a 504 plan. Each child has different needs, so use this as a jumping off point for your specific situation.

Must Haves

- Written documentation of celiac disease and the list of prohibited foods (see Beyond Celiac's free [Getting Started: A Guide to Celiac Disease and the Gluten-Free Diet](#) for a list of common unsafe ingredients)
- Snack bag at school (allergen-friendly snacks can be shared with children that have food allergies. Check out Enjoy Life and Dr. Lucy's cookies)
- Hand sanitizer

Overview of the Child's Condition

Provide the child's history with celiac disease:

- Year of diagnosis
- Amount of time on a gluten-free diet

Basis for the determination of the disability:

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- Refer to letter from doctor initiating the 504 plan

Disability that affects a major life activity:

- Restricted diet, gluten-free

Child's developmental level and needs:

- Self-reliance for the student in managing their diet and disease. This fluctuates individually and developmentally. Some indicators of a child's readiness: The student is always able to visually recognize the allergen in all its hidden forms or part of another food (starch, malt, play dough, etc.).
_____ Yes _____ No
- The student is always able to read labels for gluten.
_____ Yes _____ No
- The student is always able to verbally communicate body discomfort associated with a reaction.
_____ Yes _____ No
- The student always knows to wash his/her hands well with an approved soap and warm water before eating.
_____ Yes _____ No
- The student always knows to eat only food brought from home (if arranged).
_____ Yes _____ No
- The student always knows not to trade food with classmates and adults.
_____ Yes _____ No
- The student always understands how a safe food may be exposed to cross-contact with gluten.
_____ Yes _____ No

Goals of the 504 Plan: Examples

1. Adhering to all aspects of the 504 plan to avoid gluten.
2. Assisting the child to maintain a stable physiological state void of gluten reactions through preventative measures.
3. Recognizing the signs of a reaction and treating it promptly in all school contexts.
4. Striking a balance between safety and social normalcy, providing the same opportunities and conditions as the child's peers and offering encouragement to the child.
5. Encouraging open and ongoing communication among adults about food intolerance issues and doing so discreetly and in the appropriate forum.

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Part F of the 504 Plan: Food Allergy Education, Awareness and Reaction Prevention

The basic question to be answered and discussed in this section of the 504 plan: What kind of training needs to take place to promote education, awareness and reaction prevention in the school context?

Types of Education, Awareness and Reaction Prevention:

- Label reading
- Proper hand washing
- What is cross-contact and how can it be avoided?
- Effective table and desk washing with appropriate chemicals and materials
- Positive role modeling (Example: A positive role model would not make statements to parents and students such as, "We cannot have a holiday party because of "Suzy Celiac" and her food allergies. A positive role model would say, "We are going to have a holiday party and we will make it fun and safe for everyone.")
- Promotion of positive self-esteem for child with celiac disease
- Promotion of peer support for child with celiac disease

Communication Management

- Parent and teacher will work together to monitor classroom events that may include the use of food.
- An alternative to using food treats for students' birthdays can be selected.
- Class activities using envelopes will be minimized and child reminded not to lick any stickers in class.
- Student should be allowed bathroom privileges when necessary.
- Student must be careful with use of the following materials for classroom projects or completely avoid their use: play dough, paper mache, fruit loops and other gluten-containing food, pasta, flour, paste, and stamp adhesives. Hands and surfaces must be completely washed after the use of these materials. Parents will provide a list of alternative materials if the class plans to use any of these materials.
- The teacher will communicate with parents about upcoming projects that may require alternative foods or materials.

Art Room

- Food will not be distributed in the art classroom.

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- Products commonly used in the art room will be reviewed to determine that they are gluten-free. Any changes in art products will be communicated prior to instituting the change (for example, paper mache and play dough).
- Student must be careful with use of the following materials for classroom projects or completely avoid their use: play dough, paper mache, fruit loops and other gluten-containing food, pasta, flour, paste, and stamp adhesives. Hands and surfaces must be completely washed after the use of these materials. Parents will provide a list of alternative materials if the class plans to use any of these materials.

Foodservices

- Food handling procedures that introduce gluten-free foods and prevent cross-contact are essential. Beyond Celiac has a training program in place for schools called GREAT Schools, Colleges and Camps. More information can be found at www.greatGFkitchens.org.
- Assimilation: A goal of this is to assimilate the child into the regular structures of the school.
- Separate is often unequal and kitchens are encouraged to have students on a gluten-free diet have the same choices as other students, just in a gluten-free version.
- It is the parents' responsibility to review food and approve items.
- The kitchen then is responsible to appraise parent of changes.
- Some options tried by other schools:
 - All side items are gluten-free
 - One day a week one entrée is gluten-free but available for everyone.
 - Bring in quick items to substitute: hamburger buns or pizza crust.
- Parent and Foodservices will work together to arrange procedures when student is ordering school lunch or bringing food from home that will require heating in the cafeteria (for example, warming in the oven on a separate foiled cookie sheet).

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Field Trips

- Teachers will communicate to parent if food will be provided as part of field trip. Parent will determine whether food is gluten-free and/or provide student with a safe alternative. Parents will have the option of keeping a child home if no provisions can be made without penalty to the student.

Nurse or Medical Department

- Faculty and staff training regarding the plan.
- Provide presentation and or information to staff and class on celiac disease and the gluten-free diet.

Other Topics to Be Considered in This Section

- Safety snack box provided by the family to be kept in classroom
- Birthdays
- After school events such as pizza night: consider utilizing one of the many companies now providing gluten-free options (don't forget to double check cross-contact policies!).
- Holiday parties

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- In case of reaction: access to bathroom.
- Emergency kits: If your school has kits for emergencies or evacuation, then what supplies will be provided for those on a gluten-free diet and by whom?

Celiac Disease and the Older Child

Once your child is out of elementary school, there are new challenges that require research, communication and diligence.

Some of those challenges are listed here, but your child's network will have individualized needs.

In the Cafeteria

Regardless of whether you choose to send lunch or seek foodservice accommodations for your child's school, he or she will be exposed to risks every day.

- **Sending Lunch:** Even though you send lunch every day, your child may wish to purchase additional food at school if they have access to loose change. Make sure your child can identify packaged foods that may be available in the school cafeteria or vending machines that are labeled gluten-free.
- **Purchasing Lunch:** If you are lucky enough to have safe gluten-free options available in the cafeteria, make sure your child is comfortable having "the talk" with foodservice staff, since mistakes can easily happen in a fast-paced environment when you are serving hundreds of meals an hour. Coach your child in asking questions without apologizing or feeling like an imposition. Make sure your child knows that it's always important to check visual cues to ensure that the meal is gluten-free.

Sports, Music and Extracurricular Activities

The coach, teacher or group leader is your ally when it comes to structured travel.

- Give the group leader a copy of our [Getting Started Guide](#) so that they fully understand your child's needs.
- Provide a list of packaged products that your child (and the rest of the group) enjoys.
- Offer a list of both local and chain restaurants that your child frequents so they can consider hosting celebrations at a safe location.

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- Practice the elevator speech. As your child gets older and is able to better communicate his or her needs, it is appropriate to revisit the conversation.
- Always, always send backup. Backup that your child actually likes. Backup that can keep your child nourished when under extra pressure and expending extra energy. Make sure there is backup for the backup.

Dances, Proms and Catered Events

It will be much easier to navigate catered events by talking directly with the foodservice manager or caterer. Find the contact at your school that is addressing the meal options. Ask for:

- A copy of the menu
- Name, phone number and email address of foodservice manager on location
- Name, phone number and email address for someone who your child can speak with onsite during the event (from the school)
- Name of foodservice staff caterer assigns to oversee your child's meal preparation and delivery

You must determine if they have the ability to understand clear instructions on what and how to serve your child and the importance of getting it right.

- Ask about the options available and how they are prepared.
- If you are uncomfortable with the answers, ask if they would considering bringing in a single-serving frozen food that could be prepared in a microwave in the package.
- Ask if your child can be served first so that if there is a problem, there is time to correct it before the event is over. Always have your child bring a nutritionally dense back up just in case.
- Always bring backup.

Navigating Everyday Life

Developing an elevator speech will help your child to become confident in talking about his or her needs. This can also be an opportunity to educate people within your child's network. Revisit your child's elevator speech over time so that it will develop as your child's knowledge and comfort level increase.

Anatomy of the Elevator Speech

- I have celiac disease, it can be serious.
- I usually can't share food that other people make or bring.

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- But I can... (examples, eat some foods that are wrapped in packages, share what I've brought, eat fruits and vegetables, etc.)
- If I am exposed _____. This can be delicate if you have a symptomatic child who may be embarrassed or who could embarrass other children by providing too much information. Gender will likely play a role in your older child's comfort in discussing the consequences of gluten exposure. Role play comfortable ways to talk about what happens when your child is exposed. Asymptomatic children might have an especially hard time explaining why they can't even have a little.

GREAT Training: How It Can Help Your Child Eat Safely at School

As a parent, you want your child to feel included at school *and* be able to eat safely. Beyond Celiac has the solution: GREAT Schools, Colleges and Camps, an adaptation of our popular GREAT Kitchens program.

What is GREAT Schools, Colleges and Camps?

Beyond Celiac is proud to offer the GREAT Schools, Colleges and Camps program, a comprehensive training course designed to teach foodservice professionals how to safely prepare gluten-free food for kids living with celiac disease. Short for Gluten-Free Resource Education and Awareness Training, GREAT Schools is designed to teach school nutrition professionals how to properly source gluten-free ingredients, prevent cross-contact, serve students safely and more.



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Kid-Friendly Celiac Disease Vocabulary List

504 PLAN: An outline created by parents and school staff to ensure kids with celiac disease get the same treatment as everybody else, in spite of having a special diet.

ADVOCATE: (noun) A person who publicly supports a cause. (verb) Publicly supporting a cause. By telling other kids about celiac disease, you can be **an advocate** (which means you're **advocating** for celiac disease awareness)!

ANTIBODY: A protein in your blood that is released in response to something in your body. There are lots of antibodies for lots of different things. When you have celiac disease, your body releases an antibody in response to gluten. (It's one of the things the doctor measures when you get a blood test.)

AUTOIMMUNE: When your body releases antibodies that make you sick. Celiac disease is an autoimmune disease. Type 1 diabetes is another autoimmune disease (and some kids with celiac disease also have it).

CELIAC DISEASE: A serious genetic autoimmune disease that affects 1 in 133 Americans. People who have celiac disease cannot eat gluten because it hurts their body.

CROSS-CONTACT: This happens when you are cooking food. It's when a food that's supposed to be gluten-free gets gluten on it. This can happen if a gluten-free food touches something that has gluten in it, like a piece of bread. It can also happen when someone eats a food with gluten, like a sandwich, and then touches a gluten-free food.

DIAGNOSIS: When the doctor tells you that you have celiac disease.

DIET: The food you eat. (That's right – it doesn't always have to do with losing weight!)

DIETITIAN: A person who helps you eat the right foods for your body. They know all about food, vitamins and nutrients, and they can help you stick to your gluten-free diet.

ENDOSCOPY: A test that uses a little camera to look at your insides. Doctors use this to see if your intestine is healthy, which helps them figure out if you have celiac disease.

GASTROENTEROLOGIST: A doctor who specializes in digestive health. They can help diagnose and treat celiac disease.

GENES: These are like tiny pieces to a puzzle that makes you unique. Genes come from your mom and dad, so your family shares some of the same genes. There are two genes that are related to celiac disease.

GENETIC: Something that runs in your family (based on your genes). Celiac disease has a genetic basis, which means if your parents have it, you also might have it.

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GI: Short for gastrointestinal – that means anything that has to do with your stomach and intestine.

GLUTEN: A tiny protein found in wheat, barley and rye. It's what makes people with celiac disease sick.

GLUTEN-FREE: A food, drink or substance that does not have gluten in it. People with celiac disease must eat only gluten-free food to stay healthy.

HEREDITARY: Something that is passed from parents to their kids. It's similar to the word "genetic."

INTESTINE: A long, winding tube inside your belly that helps you absorb vitamins and nutrients from food. When you have celiac disease, gluten damages your intestine. That's why it's important to eat gluten-free,

NUTRIENTS: The parts of food that are needed to help your body stay healthy. Protein, fiber and fat are some of the nutrients your body needs every day.

NUTRITION: The process of giving your body the food it needs to be healthy and strong. Good nutrition comes from eating things like fruit, vegetable, lean meat, nuts and whole grains.

NUTRITIONIST: A person who helps you decide what to eat so you will be healthy. A nutritionist will help you make sure the food you eat has the right vitamins and nutrients.

PEDIATRICIAN: A doctor for kids only.

SUPPORT GROUP: A meeting with people who share a similar experience – like being gluten-free! The meeting helps people meet other people like them. The meeting also teaches people how to stay healthy and about new foods, websites and events that can help.

VILLI: These things look like tiny fingers and are found in your intestine. They help you absorb nutrients from your food. If you have celiac disease, gluten damages the villi and makes it hard for your body to get the vitamins and nutrients it needs.

VITAMINS: Tiny particles in food that your body uses to grow and get stronger. Vitamin C is in things like oranges, and Vitamin D is in things like milk. You need lots of different vitamins to be a healthy kid.