## Celiac Disease <br> FOUNDATION



## BACK-TO-SCHOOL WITH YOUR GLUTEN-FREE CHILD

Having a child with celiac disease poses unique challenges both for you and your child. The lifestyle changes - and how they are managed - that come with a diagnosis of celiac disease can be difficult during the school-age years. Celiac Disease Foundation has developed this Back-to-School Guide to help you and your child transition safely through these changes. In this Guide, we offer suggestions for ageappropriate ways of managing celiac disease and non-celiac gluten sensitivity at school to ensure good health, proper development, and academic success for your child.

Individuals with celiac disease and non-celiac gluten sensitivity have different needs at different times in their life. Because of these special needs, celiac disease is considered a disability under the Americans with Disabilities Act. This designation is particularly relevant in certain public establishments, like educational institutions. It is important to advocate for your child's needs to ensure that you receive the resources and accommodations that are necessary for your child to live a healthy life and to thrive developmentally and socially.

## PRESCHOOL \& ELEMENTARY SCHOOL

Preschools and other private schools that are not publicly funded might not be required to accommodate disabilities such as celiac disease. Parents and caregivers might need to provide all gluten-free food if the preschool is not equipped or does not demonstrate an understanding of the child's dietary needs.

PRIVATE
SCHOOLS

We recommend starting with a note from your physician that explains:
THE DIAGNOSIS

- How it impacts your child's life and health (his/her symptoms and the risks to growth, brain development, and long-term health of small gluten exposures, even if symptoms are not apparent).
- The accommodations that you are requesting to keep your child gluten-free (see the model 504 Plan at the end of this Guide for an example).

Next, schedule a time to formally meet with the school administrator(s) and your child's teachers, so that you can discuss and document all of your concerns in detail. Resources to assist you in explaining celiac disease and its impact may be found at celiac.org/celiacdisease.


## PUBLIC SCHOOLS AND THE 504 PLAN

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If your child is in a public school system, a 504 Plan is the federally recognized method of detailing any and all accommodations that need to be made by the school system to assure that a child with a disability receives an appropriate education.

Section 504(a) of the Rehabilitation Act of 1973 prohibits discrimination in all institutions receiving federal financial assistance, including public schools, on the basis of disability, including certain diseases. The law requires that public schools remove barriers to learning, which include accommodating a child's gluten-free diet and disability needs.

## DOES MY CHILD NEED A 504 PLAN?

Parents might not think a 504 Plan is necessary if their child does not seem to have barriers to learning at school, or if the school administration is accommodating their child's needs. Know that without this document, however, any verbal conversation you have with teachers and administration does not legally need to be honored. A 504 Plan must be renewed annually and can remain in place throughout the years within a school district, making transitions between grade levels easier.

PRESCHOOL AND ELEMENTARY SCHOOL

In preschool and lower elementary school, a high level of parent involvement is required in managing a child's health condition. Children do not yet understand long-term consequences to their health, nor do they have the communication skills to assert their needs in new environments.

## HOW TO DISCUSS ACCOMMODATIONS WITH YOUR SCHOOL ADMINISTRATION AND TEACHERS

1) Request a 504 Plan meeting from your school administration, and ask if a specific form needs to be completed or if they simply need a letter from your child's physician.
2) Bring the 504 Plan form or a letter signed by your physician that details the following:

- The diagnosis and date of disability (e.g., celiac disease)
- Explanation of why the disability restricts the child's diet or activity
- The major life activity affected (e.g., eating, toileting, learning)
- The child's developmental level in terms of managing his/her celiac disease
- Ability to recognize what food or activity items contain gluten
- Ability to read labels for gluten
- Ability to verbally communicate symptoms when they occur
- Ability to wash own hands before eating
- Understanding that only gluten-free foods brought from home or provided by the school may be eaten
- Understanding that cross-contact with food containing gluten makes a gluten-free food unsafe to eat
- Foods to be omitted (see our list of foods containing gluten at celiac.org/sources-of-gluten)
- Foods to be substituted (e.g., gluten-free bread, pizza, cookies)


3) Outline accommodations for:

## Provision of Celiac Disease Care

- All staff members involved in the care and education of the student must receive training in the management of celiac disease. This includes teachers, classroom assistants, substitute teachers, cafeteria workers, office staff, school nurses, or any other staff who has primary care for the student.
- All staff who interact with the student on a regular basis must understand celiac disease, recognize symptoms of gluten ingestion, and work with other school staff to eliminate the use of gluten-containing foods in the student's meals, educational tools, arts and crafts projects, and incentives.


## Meals and Snacks

- The only treatment for celiac disease is a strict gluten-free diet for life. Gluten is found in wheat, rye, barley, and contaminated oats. Therefore, all foods with wheat, rye, barley, and oats not labeled gluten-free must be eliminated from the diet. This includes the obvious sources, such as breads, pastas, buns, and rolls, but it also includes such items as soy sauce, some broths and meat bases, some soups, gravy thickened with wheat flour, and breakfast cereals that contain malt or malt flavoring, among others. All labels must be carefully reviewed to be sure no gluten-containing grain is used in that food product.
- In addition to the food itself being free of gluten, the food cannot come in contact with or be contaminated by gluten-containing foods. This means the gluten-free foods need to be prepared in a separate area, cooked in separate pans, and served with clean gloves.
- In order to provide a balanced meal containing the four groups necessary for school reimbursement, a gluten-free bread or bread alternative must be offered at all school meals. This would include such foods as gluten-free bread, gluten-free roll, gluten-free cereal, or gluten-free pasta. The meat and meat alternative must also be free of gluten- containing grains such as fillers in hot dogs, poultry injected with wheat or barley, and gluten-containing grains used as an extender in other meat products.
- School food service personnel will develop a system for identifying the student when moving through the cafeteria line so that a member of the staff can ensure the selected food is safe. Some schools require that these students identify themselves to service staff or use specially coded lunch tickets.
- The school will designate a person to be responsible for ensuring that lunch tables and surrounding areas are thoroughly cleaned before and after lunch. It is recommended that a designated sponge or cleaning cloth be used for the gluten-free area to avoid cross-contact with gluten-containing foods.
- Teachers will give the parents/guardians 24 hours notice of any special events at which food will be prepared that is not from the cafeteria. The school will provide parents with a gluten-free food option for the event. Parents may choose to provide appropriate food for the event as well.


## PRESCHOOL \& ELEMENTARY SCHOOL

## Bathroom Access

- Accidental exposure to gluten may cause gas, bloating, and diarrhea; therefore, the student shall be permitted to use the bathroom without restriction.


## Classroom Art Projects

- The student will need access to hand washing facilities after handling art projects or products that contain gluten, such as Play-Doh or Paper Mache.
- Parents will be informed 24 hours in advance of any gluten-containing items being used in a project so the parent can make appropriate substitutions if necessary.


## Field Trips and Extracurricular Activities

- Parents will be notified of upcoming field trip plans that would involve food or food-related activities. The school will provide parents with a gluten-free meal option for any off-campus school-sponsored activity. Parents may choose to provide appropriate gluten-free options as well.


## Communication

- The school staff will keep the student's celiac disease diagnosis confidential, unless the student decides to openly communicate about it with others.
- The school staff will provide reasonable notice to parents/guardians when there will be a change in planned activities, such as field trips or parties.
- Each substitute teacher and substitute school nurse or health aide will be provided with written instructions regarding the student's celiac disease care.
- Prior to the beginning of every school year, the new classroom teacher will receive a copy of the 504 Plan and will review it to ensure that the steps necessary to keep the student safe are clear and understandable. Written documentation of this process will be provided to the parents/guardians before the child enters the classroom.


## Emergency Evacuation and Shelter-in-Place

- In the event of an emergency evacuation or shelter-in-place situation, the student's 504 Plan will remain in full force and effect.

- The parents/guardians shall provide the school with a three-day emergency supply of non-perishable gluten-free foods.


## Parental Notification

The student's parents/guardians shall be notified immediately in the following situations:

- The student has eaten a food item that contains gluten.
- The student has symptoms of gluten ingestion, such as abdominal pain, cramping, diarrhea, headache, fatigue, or any learning or behavioral problems.
- The school will provide the parents/guardians with a copy of the school district's latest Revised Ingredient document of Food and Nutrition Services for food served at breakfast, lunch, and snack.
- Food and Nutrition Services will provide the parents/guardians with a monthly gluten-free menu.


## Emergency Contacts

- Include names, relationship, address, and phone numbers
- Include an out-of-state contact

If your school district does not have a
specific 504 Plan form, you may edit the Model 504 Plan, found at the end of this Guide, to meet your child's needs.

## HOW TO PREVENT CROSS-CONTACT IN THE CLASSROOM

1) Ask for a high level of monitoring at meal times to ensure your child does not ingest any gluten-containing items.
2) Provide a special placemat and teach your child to place his/her food only on the mat.

3) Invest in a lunchbox with compartments, freezer packs, and insulated containers so your child can eat directly from his/her lunchbox.
4) Teach your child to wash hands before meals and after crafts, and to use wet wipes if soap and water is not available. CDF's medical experts do NOT recommend using hand sanitizer because it does not sufficiently remove gluten from hands.
5) Ask for a high level of monitoring during crafts/activities involving gluten:

- Pasta and cereal crafts . Paper Mache
- Play-doh • Paste
- Face paint . Stamp adhesives
- Sand trays

6) Have your child avoid classroom activities involving loose wheat flour.

## HOW TO HELP KEEP YOUR CHILD

INCLUDED DURING \& AFTER SCHOOL

## Parents often worry about peer acceptance of their child's special needs.

 Here is a list of strategies that have worked for CDF parents:
## DURING SCHOOL

- Volunteer in the classroom or get involved in the Parent-Teacher Association to guarantee that your child has a voice in the classroom and school activities.
- Give your child's teacher a back-up supply of gluten-free treats if they like to give out prizes or in case of unexpected birthday parties or celebrations.
- Bring gluten-free treats for the whole class to try - peers will enjoy how good they taste. This works well for sports teams and other extracurricular activities.
- Know that school confidentiality and anti-bullying policies apply to health needs - your child's teacher should not disclose your child's diagnosis or speak about it in a derogatory way. If you choose to share your child's condition with other students or parents, it should be on your terms. The school should also have a no-tolerance policy for bullying by peers. Throwing of food containing gluten and verbal teasing are examples of bullying.
- Encourage your child to use celiac disease for a school project/presentation to educate his/her peers and dispel myths.


## AFTER SCHOOL

- Empower your child to talk about his/her needs, including not eating foods containing gluten when offered - practice role-playing at home and with family members.
- Keep snacks or frozen meals at friends' houses for after-school play dates.
- Call ahead of time to inquire about the menu for parties and other social events. Offer to bring gluten-free options for your child. If this is not feasible, many parents subscribe to the "pre-feed" and "post-feed" practice, making sure their child is well-fed prior to the event and promising them a special treat at pick-up time.

Recognize the psychological and emotional impact of coping with a chronic disease that can alienate your child from their peers. A terrific resource to help you prepare your child and your family to face the challenges of celiac disease is CDF's Psychological Health Training Program Guide and Video Series which may be found at celiac.org/psych-health.

## NUTRITIONAL NEEDS FOR THE GROWING CHILD

Feed your child foods rich in essential nutrients, many of which might be deficient in a child newly diagnosed with celiac disease. Restoring these nutrients to normal levels in the body are essential for your child's brain function, emotional regulation, learning abilities, physical growth, and development. While nutrients are better absorbed from food sources, consult with your pediatrician or dietitian for advice on when supplementation is recommended.

| Nutrient | Function | Food Sources |
| :---: | :---: | :---: |
| Omega-3 <br> Fatty Acids | Building new brain, eye, and cardiovascular cells | - Fortified eggs, milk, yogurt <br> - Flaxseeds, walnuts, chia seeds, soy beans <br> - Salmon, albacore tuna, trout, herring, halibut, shrimp |
| Iron | Essential for energy, concentration, and mood | - Fortified cereals, enriched grains <br> - Red meat, dark poultry, tuna, salmon, eggs <br> - Tofu, beans, peas <br> - Leafy green vegetables |
| Calcium <br> + Vitamin D | Strengthening and growth of bones and teeth | - Both: dairy milk, yogurt, cheese <br> - Both: fortified dairy-alternative drinks, orange juice, cereals <br> - Calcium: leafy greens, broccoli, soy beans/tofu, bony fish <br> - Vitamin D: egg yolks, fatty fish, mushrooms |
| Folic Acid | Growth of new cells and repairing of DNA | - Fortified cereals, enriched grains <br> - Leafy greens, asparagus, broccoli, brussels sprouts <br> - Citrus fruits <br> - Beans and other legumes <br> - Avocado, seeds, nuts <br> - Squash, cauliflower, beets, corn |

- Ask your pediatrician or dietitian about using liquid vitamins in the first year after diagnosis when intestines are still healing to aid in absorption.
- Trust in your child's innate ability to feed him/herself from the gluten-free foods that you provide. Children are intuitive eaters. While every meal might not appear to be nutritionally balanced, children's bodies regulate their intake over longer periods of time.
- Food aversion is common when diagnosed with celiac disease at a young age. Focus on the foods your child likes to promote adequate energy intake. Consider the


## following tactics:

- Include a variety of foods at each meal. Your modeling of normal and balanced eating as a parent will encourage your child to try new foods as time progresses.
- Make meal times fun and enjoyable. Rather than a fight or power struggle, play games and engage in positive conversation:
- Play"I Spy" with foods on the dinner table or plate: identify colors of foods ("Can you point to a red food?").
- Spell foods with your child ("Which foods start with a ' $\mathrm{B}^{\prime}$ ?").

- Practice adjectives with your child (e.g., "Find a food that is sticky," "Find a food that is smelly").
- Discuss favorite parts of each person's day, movies, TV shows, and details of recent and future events.
- Address inappropriate meal behavior, such as disobeying rules, playing with food, poor manners, or refusal to eat, by ignoring instead of punishing to minimize negative experiences associated with meal times.
- Work with an occupational, behavioral, or psycho-therapist as needed if family meals invoke significant emotional distress for the family, and/or if your child's growth pattern changes abnormally from its typical growth curve (i.e., your child stops growing).


## CATCH-UP GROWTH

Children whose growth was stunted by undiagnosed celiac disease should work with their pediatrician and a dietitian to ensure catch-up growth is achieved with adequate nutrition, and to determine if medical intervention is needed.

Weight-gain supplements to include in a gluten-free diet may consist of Pediasure, whole milk, and added fats, such as nut butters and coconut oil.

## KID-FRIENDLY GLUTEN-FREE EATING

Planning gluten-free lunches for your child may require more preparation as some gluten-free foods will not have the same texture or durability as gluten-containing versions (i.e., sandwich bread might crumble or squish). It's important to make your child feel like his/her lunches are just as delicious and fun as those of peers.


Sneak in nutrition if you have a picky eater:

- Blend carrots and spinach into pizza or marinara sauce.
- Add a tablespoon of ground flaxseed to your child's morning smoothie.
- Bake with bean and nut flours to enrich vitamin, mineral, and fiber content beyond what is often available in gluten-free cookies, breads, and crackers.
- Find tips and recipes for enhancing the nutritional value of gluten-free foods at celiac.org/recipes.

Help your child get a balance of vitamins and minerals

- Eat foods from all colors of the rainbow:
- To make a game of it, see if your family can eat one fruit or vegetable from every color of the rainbow to ensure you're all getting the important vitamins and minerals that are often absent from gluten-free snack foods. Your goal can be to eat the entire rainbow either each day or each week, depending on which is more feasible for your family. Use colored stickers on your family calendar to keep track of every color food that you eat each day. A sample day of eating the rainbow could look like this:
- Oranges at breakfast
- Green apples at snack
- Yellow squash sticks dipped in ranch dressing with lunch
- Blueberries with after-school snack
- Tomatoes or tomato sauce at dinner


## LEARNING TO READ FROM NUTRITION LABELS

## Use your child's dietary needs as an opportunity for learning that will mirror their school lessons and developmental age with this fun activity:

1) Start with your child recognizing a "gluten-free" label anywhere on food packages.
2) Next, practice reading allergen warnings on food labels for "Contains: wheat."
3) Finally, graduate to searching for "malt,""barley," or "rye" in the full ingredient list.
4) For advanced readers, ask him/her to identify "oats" as okay only when paired with a "gluten-free" label on the package. While not an exhaustive list, these are the most common ingredients signifying gluten content in a food product, and a good place to start for understanding food labels


## GLUTEN-FREE AT CAMP

Many day and sleep-away camps are experienced at accommodating children with special dietary needs, including gluten-free. Ask thorough questions before choosing a camp, and request to speak to a food service manager for details. Similar to dining out in restaurants or in schools, you may need to explicitly state how food should be prepared and what special accommodations your child will need. See the Model 504 Plan for specific accommodations to discuss.

For more information and resources for children with celiac disease, visit celiac.org/for-parents-and-children.

## DISCUSSING CELIAC DISEASE WITH YOUR <br> SCHOOL ADMINISTRATION \& TEACHERS

The steps to obtaining accommodations for your child are the same as those for preschool and elementary school outlined on pages 3-5 of this Guide. Additional information and accommodations that might be needed at this stage of development include:

- Permission to be excused from activities that use gluten-containing foods or materials (i.e., Home Economics, Food Science).
- Permission to use the restroom whenever needed in case of accidental gluten ingestion and other related gastrointestinal problems.
- Permission to store non-perishable food in lockers or perishable food in a school refrigerator.
- Permission to go to the car for stored food or to leave campus to buy gluten-free food.


## ADVANCED GLUTEN-FREE DIET

## Teens can and should become proficient at reading food labels. Encourage your child to be responsible for all of their food choices.

## MAKE SURE YOUR OLDER CHILD KNOWS THE IMPORTANT ASPECTS

- Check food labels and avoid products that contain: wheat, barley, rye, malt, and oats not labeled gluten-free.
- Understand that foods do NOT have to be labeled gluten-free to be gluten-free; absence of a gluten-free label does not necessarily mean it contains gluten.
- Avoid naturally gluten-free grain-based products that are NOT labeled gluten-free because they might have a higher risk of cross-contact with gluten. This includes corn chips, rice or corn cereals, and oat-based granola or protein bars.
- Ask questions at food service establishments:
- Request a list of gluten-free menu items.
- Ask to see labels of foods if staff are unsure of the ingredients.
- Ask what steps the facility takes to prevent cross-contact between gluten-free foods and other gluten-containing food items. Examples of gluten-free foods that might become contaminated with gluten via cross-contact during food preparation include (but are not limited to):
- Sandwich bread via shared knives • Pizza crust via shared cooking surface
- Cutting boards - Sauce and toppings
- Condiments $\quad$ Tortilla chips or french fries cooked in a shared deep fryer
- Toast via shared toasters and knives . Gluten-free pasta cooked in shared water


## TEEN DINING TIPS

- At salad bars, avoid areas with croutons and other crunchies, unlabeled salad dressing, and flavored nuts which may be coated with gluten.
- Ask questions - avoid anything without an ingredient list or search for the product online to review the ingredients.
- Chips and other snack foods should be labeled gluten-free due to the possibility of cross-contact in food preparation or hidden gluten-containing ingredients like malt.
- Bring your own dish to team dinners, birthday parties, and friends' houses.
- Keep back-up snacks (non-perishable) in backpack, locker, or car, such as gluten-free trail mix, granola bars, protein bars, crackers, and nuts.

> A terrific resource to prepare you and your child is CDF's Psychological Health Training Program Guide and Video Series which can be found at celiac.org/psych-health.

## CHALLENGES IN THE TEENAGE YEARS

1) Teens establish their identity as part of peer groups in middle and high school. Expect conflict that arises from being different from friends or not wanting to follow your advice.
2) Teens sometimes go through a "honeymoon" period where symptoms subside and they might be able to ingest some gluten without feeling significantly ill. Absence of symptoms does not mean the disease is gone; a strict gluten-free diet is still necessary to prevent small intestinal damage. Even if the celiac disease blood test is negative, your pediatrician might advise a follow-up biopsy if your child continues to ingest gluten.
3) Help your teen acknowledge cause and effect: if he/she is defying his/her diagnosis and eating gluten, point out changes in behavior or struggles in school that he/she might not be able to see, such as mood disturbances, difficulty concentrating or performing in school, sleeping longer, or insomnia.
4) Puberty might be delayed if diagnosis is made during this time period or if your child still struggles with low body weight or short stature. Consult with your child's physician and a skilled dietitian; catch-up growth might still be necessary at this age, and a higher calorie diet could be required.

5) Involve a third party, such as a dietitian or psychologist, to counsel your child when he/she feels challenged by his/her diet. Keep your parenting role as a supportive one with firm but compassionate boundaries.
6) Empower your teen to become an advocate for celiac disease and participate in community service.

The CDF Student Ambassador Program offers an advocacy path for your teen to raise awareness of celiac disease as a serious autoimmune disorder. Learn more at celiac.org/studentambassadors.

## FINDING A SCHOOL THAT SUITS YOUR DIETARY NEEDS

It can be overwhelming for young adults to be independent at college, whether they are recently diagnosed with celiac disease or have been living gluten-free for years. Many of the recommendations found in "Advanced Gluten-Free Diet" and "Challenges in the Teenage Years" might still apply to the college years. Consider with your child which gluten-free accommodations below are most important when choosing a school. The following accommodations are desirable when choosing a college to attend:

- Dining halls with gluten-free products (breads, cereals, pasta) and dedicated preparation areas to prevent cross-contact
- Allergen labels on all dishes to easily navigate the dining hall and on-campus eateries
- Local restaurants that have gluten-free menus
- On-campus dining with gluten-free options (which might be operated separately from dining halls and offer very different food options)



## TO DORM OR NOT TO DORM

Many college students decide to live off-campus in order to have their own food preparation space and minimize stress. When considering whether or not to live in a dormitory, ask to speak with a Food Service Manager and Office of Residence Life (housing) Executive who can answer the following questions:

- How does the dining hall accommodate students with celiac disease?
- What efforts do they make to prevent cross-contact with gluten-containing foods?
- Are gluten-free foods prepared in a dedicated area? Offered in a separate area?
- Does the staff use separate cookware and utensils? Change gloves?
- Can gluten-free foods be prepared on a clean grill? Separate fryer?
- Are dedicated toasters available?
- Are allergen labeling and ingredient lists provided?
- Is it possible to waive the dining hall fee if the dining hall doesn't offer adequate or desirable gluten-free options?
- Is there room for a fridge and microwave in dorm rooms?
- Are there dorms with kitchenettes available?
- Do I need to register through the Office of Disability Services to ensure access to gluten-free meals or to obtain preferential housing?


## OFFICE OF <br> DISABILITY SERVICES

Many colleges require registration through their Office of Disability Services to be eligible for dining or other accommodations. This can be a sensitive issue for young adults who don't perceive having celiac disease as a disability in comparison to more severely disabled students. However, in addition to providing dietary accommodations, colleges might offer preferential housing, early registration, additional time to complete assignments, note-taking services, and delayed test-taking when ill. Once the initial hesitancy or embarrassment fades, students are usually grateful for the services provided.

## Be sure to:

- Review the college's website for the registration process and pay attention to deadlines!
- Register and submit the required information, which usually includes a form that must be signed by a physician.
- Meet with Food Service and Housing representatives to review the approved accommodations.
- If granted academic accommodations, meet with each faculty member to review the approved accommodations.
- Re-register in accordance with college policy.


## WHAT IF THE COLLEGE DOES NOT OFFER ACCOMMODATIONS?

Colleges and universities are not required by law to provide access to gluten-free food free from cross-contact to students with disabilities UNLESS they have a mandatory meal plan. This was decided in a 2012 U.S. Department of Justice (DOJ) settlement with Lesley University. The DOJ found that Lesley University had violated the Americans with Disabilities Act (ADA) by refusing to exempt students with celiac disease from paying for a mandatory meal plan that offered no gluten-free options. If the college has a mandatory meal plan, offers no gluten-free options, and refuses to exempt students with celiac disease, it might be required to:

- Provide gluten-free and allergen-free food options in the dining hall food lines in addition to its standard meal options.
- Allow students with known allergies to pre-order allergen-free meals.
- Display notices concerning food allergies and identify foods containing specific allergens.
- Train food service and university staff about food allergy-related issues.
- Provide a dedicated space in its main dining hall to store and prepare gluten-free and allergen-free foods.
- Work to retain vendors that accept students' prepaid meal cards that also offer food without allergens.


## CAMPUS DINING TIPS



## Whether or not the college offers gluten-free options, it is always best to:

- Avoid salad bars with croutons and other crunchies, unlabeled salad dressing, and flavored nuts.
- Check ingredients of scrambled eggs, which may contain wheat or pancake batter.
- Use toaster bags to safely toast gluten-free bread if you do not have access to a dedicated toaster.
- Use individual condiment packets or squeeze bottles to avoid cross-contact with bread crumbs.
- Avoid shared cereal containers/bulk bins due to cross-contact risk.
- Find emergency rations at convenience stores, such as cheese sticks, hardboiled eggs, yogurt, fruit, carrots \& celery with ranch, hummus, peanut butter, nuts, and plain potato chips.


## SOCIAL LIFE IN COLLEGE

College life can be spontaneous. One minute you are studying, the next you are heading to a social event. Follow these tips below to keep you safe from gluten exposure.

- Eat before going out with friends if you're not sure that there will be gluten-free options.
- Keep a snack handy in your purse/pocket.
- Have the alcohol discussion before it's a problem:
- No malted beverages or beer
- All hard liquors are gluten-free
- No cider from a beer tap/keg - choose bottles and cans
- Drinking games pose a risk for cross-contact, and drinking excessively may lead to alcohol poisoning


You never have to go hungry! Keep on hand:

- Gluten-free microwaveable soups
- Hard-boiled eggs and cheese sticks
- Yogurt parfait with gluten-free granola
- Hummus
- Gluten-free pretzels
- Gluten-free crackers
- Gluten-free potato chips
- Gluten-free cookies
- Gluten-free cereal
- Rice cakes
- Gluten-free bread
- Gluten-free muffins
- Gluten-free granola
- Gluten-free deli meat
- Gluten-free instant oatmeal
- Canned tuna
- Gluten-free wraps
- Popcorn
- Fresh fruit
- Fruit cups
- Nuts
- Gluten-free protein bars
- Gluten-free granola bars
- Nut butters
- Jelly/jams


## BECOME A CELIAC DISEASE FOUNDATION STUDENT AMBASSADOR

If your child is an elementary, middle, or high school student with celiac disease and is passionate about raising awareness in his/her community, the Celiac Disease Foundation Student Ambassador Program is a great way to get involved. Through the Student Ambassador Program, children and teens become role models for others with celiac disease while raising awareness in the community and educating their peers. This program is geared toward students who are interested in working with their local schools to present the importance of celiac disease awareness and tolerance in the community.

For more information, visit celiac.org/studentambassadors.

CELIAC DISEASE AND GLUTEN-RELATED CONDITIONS PSYCHOLOGICAL HEALTH TRAINING PROGRAM Living with a chronic illness that requires a lifelong commitment to a strict gluten-free diet can be difficult for anyone. For children and teens, the emotional and psychological impact associated with celiac disease can have particular and profound challenges. The need for strict adherence to the gluten-free diet can cause severe stress on families and social relationships, and can contribute to a sense of social alienation, feelings of worthlessness, low self-esteem, and depression.

Learn how you can help prepare your child face the challenges of celiac disease and make a smoother transition into their "new normal" at celiac.org/psych-health.

## JOIN THE ICURECELIAC® PATIENT REGISTRY AND BECOME A PATIENT ADVOCATE

Your and your child's medical data is incredibly valuable. By aggregating large amounts of data from thousands of patients living with celiac disease and non-celiac wheat sensitivity, we are able to assist researchers in analyzing disease patterns to improve treatments and find a cure.

To add your data, please visit celiac.org/icureceliac.

Do you want to make your voice heard in celiac disease research? CDF Patient Advocates participate in research opportunities to shape celiac disease treatments and help find a cure. To learn more, please visit celiac.org/patientadvocate.

## HOW TO HELP FRIENDS UNDERSTAND YOUR DIET

At any school age, it is important for your child to confidently explain his/her condition to others. Here are some sample answers to common questions:

1) Why can't you eat gluten?

I have celiac disease; it's an autoimmune disorder. It's similar to an allergy to wheat, except the damage is all on the inside and you can't see it on the outside. My symptoms are $\qquad$ . Before I was diagnosed I was always sick.
2) Can't you just have a little?

No, I can't even have one bite. Gluten is poisonous to me. Just one eighth of one teaspoon could make me very sick.
3) Are you faking it?

No, celiac disease is a serious autoimmune condition. Just because you can't see me get sick doesn't mean the damage isn't happening.
4) Did you always have it? Why did it start?

I was born with the genes for celiac disease, and one day they turned on like a light switch. We don't know what it's triggered by, but it won't ever turn off.
5) What is gluten?

Gluten is the protein part of wheat, barley, and rye. It's found in lots of foods like bread, pasta, licorice, and soy sauce.

## OTHER ONLINE RESOURCES

- Access resources and tools for parents and children at celiac.org/for-parents-and-children
- Browse hundreds of delicious gluten-free recipes at celiac.org/recipes
- Learn celiac disease basics at celiac.org/celiacdisease
- Learn what foods to avoid on the gluten-free diet at celiac.org/sources-of-gluten
- Learn about the CDF Psychological Health Training Program at celiac.org/psych-health
- Learn how to become a CDF Student Ambassador at celiac.org/studentambassadors
- Learn how to get involved with Team Gluten-Free at celiac.org/tgf
- Join CDF's patient registry at celiac.org/icureceliac
- Learn how to become a patient advocate at celiac.org/patientadvocate

Celiac Disease Foundation thanks the Weitz Family for their generous support of this Guide.

## MODEL

## SECTION 504 PLAN

This model Section 504 Plan was developed by the American Celiac Disease Alliance (ACDA) and the Disability Rights Education and Defense Fund, Inc. (DREDF).*

## IMPORTANT

This Model 504 Plan is intended strictly as a guide for parents. It illustrates accommodations typically needed by children with celiac disease when they are in the school setting.

## A 504 PLAN MUST BE ADAPTED TO THE INDIVIDUAL NEEDS, ABILITIES, AND MEDICAL CONDITION OF EACH INDIVIDUAL CHILD.

Not all of the accommodations listed are needed for every child with celiac disease. When developing a 504 Plan, include the items from the model that will ensure the specific needs of your child are met. Talk to your medical team about what plan makes sense for your child.
*DREDF is a leading national civil rights law and policy center directed by individuals with disabilities and parents of children with disabilities. DREDF's Children and Family Advocacy program seeks to preserve, strengthen, and enforce the rights of children with disabilities in school, and to ensure their right to a free and appropriate public education in the least restrictive environment by supporting and training parents, caregivers, and child advocates about laws that protect the rights of children and assisting them in navigating the complex process through which these rights are accessed. Additional information about DREDF is available online at www.dredf.org or by phone at (510) 644-2555.

The information contained in this document is for informational purposes only. Every 504 Plan must be adapted to the individual needs, abilities, and medical condition of each individual child.

Model 504 Plan for a Student with Celiac Disease

Section 504 Plan for

School
School Year
$\qquad$ Birth Date

## Grade

Disability Celiac disease
Homeroom Teacher $\qquad$ Bus Number $\qquad$

## Objective of This Plan

Celiac disease is a genetic autoimmune disease that causes damage to the small intestine, interfering with the absorption of nutrients. Left untreated, celiac disease causes multi-system complications, such as diarrhea, constipation, gas, bloating, iron deficiency anemia, decreased bone density, fatigue, failure to thrive, short stature, and behavior problems, among many others. Section 504 of the U.S. Rehabilitation Act of 1973 is designed to help parents of students with physical or mental impairments in public schools (or publicly funded private schools) work with educators to design customized educational plans. A 504 Plan legally ensures that students will be treated fairly at school.

Children and teenagers with celiac disease can face academic and social hurdles for a variety of reasons, but parents can take advantage of the 504 Plan to help ensure their child's special needs are met. This sample 504 Plan discusses each section that can be included in your child's 504 Plan. Please note that your child's 504 Plan should be customized depending on his/her grade and specific needs during school.

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## 1. Provision of Celiac Disease Care

1.1 All staff members involved in the care and education of the student must receive training in the management of celiac disease. This includes teachers, classroom assistants, substitute teachers, cafeteria workers, office staff, school nurses, or any other staff who has primary care of the student.
1.2 All staff who interact with the student on a regular basis must understand celiac disease and be able to recognize symptoms of gluten ingestion. They must also work with other school staff to eliminate the use of gluten-containing foods in the student's meals, educational tools, arts and crafts projects, and incentives.

## 2. Meals and Snacks

2.1 The only treatment for celiac disease is strict adherence to the gluten-free diet. Gluten is found in wheat, rye, barley, triticale, and contaminated oats. Therefore, all foods with wheat, rye, barley, triticale, and oats not labeled gluten-free must be eliminated from the diet. This includes the obvious sources, such as wheat breads, pastas, buns, and rolls, but it also includes such items as soy sauce, some broths and meat bases, some soups, gravy thickened with wheat flour, and breakfast cereals that contain malt or malt flavoring. All labels must be carefully reviewed to be sure no gluten-containing grain or derivative is used in that food product.
2.2 In addition to the food itself being free of gluten, the food cannot come in contact or be contaminat ed by gluten-containing foods. This means the gluten-free foods need to be prepared in a separate area, cooked in separate pans, and served with clean gloves.
2.3 In order to provide a balanced meal containing the four groups necessary for reimbursement, a gluten-free bread or bread alternative must be offered at all school meals. This would include such foods as gluten-free bread, gluten-free roll, gluten-free cereal, or gluten-free pasta. The meat and meat alternative must also be free of glutencontaining grains, such as fillers in hot dogs, poultry injected with wheat or barley, or a gluten-containing grain used as an extender in other meat products.
2.4 School food service personnel will develop a system for identifying the student when moving through the cafeteria line so that a member of the staff can ensure the selected food is safe. Some schools require that these students identify themselves to service staff or use specially coded lunch tickets.

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2.5 The school will designate a person to be responsible for ensuring that lunch tables and surrounding areas are thoroughly cleaned before and after lunch. It is recommended that a designated sponge or cleaning cloth be used for the gluten-free area to avoid cross contact.
2.6 Teachers will give the parents/guardians 24 hours notice of any special events at which food will be prepared that is not from the cafeteria. The school will provide parents with a gluten-free food option for the event. Parents/guardians may choose to provide appropriate food for the event as well.

## 3. Bathroom Access

3.1 Accidental exposure to gluten may cause gas, bloating, diarrhea, and a variety of other symptoms; therefore, the student shall be permitted to use the bathroom without restriction.

## 4. Classroom Art Projects

4.1 The student will need access to hand washing facilities after handling art projects or products that contain gluten, such as Play-Doh or Paper Mache. Hand sanitizer does not remove gluten so may not be used as a substitute for hand-washing.
4.2 Parents/guardians will be informed 24 hours in advance of any gluten-containing items being used in a project so the parents/guardians can make appropriate substitutions if necessary.

## 5. Field Trips and Extracurricular Activities

5.1 Parents will be notified of upcoming field trip plans that would involve food or food-related activities. The school will provide parents/guardians with a gluten-free meal option for any off-campus school-sponsored activity. The parents/guardians may choose to provide appropriate gluten-free alternative options.

## 6. Communication

6.1 The school staff will keep the student's celiac disease diagnosis confidential, unless the student decides to openly communicate about it with others.
6.2 The school staff will provide reasonable notice to parents/guardians when there will be a change in planned activities, such as field trips or parties.

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6.3 Each substitute teacher and substitute school nurse or health aide will be provided with written instructions regarding the student's celiac disease care.
6.4 Prior to the beginning of every school year, the new classroom teacher will receive a copy of the 504 Plan and will review it to ensure that the steps necessary to keep the student safe are clear and understandable. Written documentation of this process will be provided to the parent before the child enters the classroom.

## 7. Emergency Evacuation and Shelter-in-Place

7.1 In the event of an emergency evacuation or shelter-in-place situation, the student's 504 Plan will remain in full force and effect.
7.2 The parents/guardians shall provide the school with a three-day emergency supply of non-perishable gluten-free foods.

## 8. Parental Notification

8.1 The student's parents/guardians shall be notified immediately in the following situations:

- The student has eaten a food item that contains gluten.
- The student has symptoms of gluten ingestion, such as abdominal pain, cramping, diarrhea, constipation, vomiting, or any learning or behavioral problems.
8.2 The school will provide the parents/guardians with a copy of the school district's latest Revised Ingredient document of Food and Nutrition Services for food served at breakfast, lunch, and snack.
8.3 Food and Nutrition Services will provide the parents/guardians with a monthly gluten-free menu.


## 9. Emergency Contacts

- Include names, relationship, address, and phone numbers
- Include an out-of-state contact

