

CELIAC DISEASE

and Gluten-Related Conditions

Psychological Health Training Program

A toolkit for medical and mental health care practitioners to identify and treat patients living with celiac disease and other gluten-related conditions

Prepared by

The Celiac Disease Program at
Children's National Health System

The Celiac Disease Foundation

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"Living a gluten-free life is just the beginning for young people diagnosed with celiac disease. While the gluten-free diet is absolutely critical, at the same time, we often overlook the emotional impact on children who are alienated by their peers because they can't eat the same foods. Without learning how to cope with this alienation, children can withdraw and become prone to depression."

— Peter Resnick, father of a child living with celiac disease and Celiac Disease Foundation board member

Welcome Letter from Blair Raber

Founder, Celiac Disease Program at Children's National Health System



After countless trips to the doctor and 14 years of having a daughter who “just didn’t feel well” much of the time, it took a nutritionist one visit to diagnose gluten as the culprit. We removed gluten from her diet and were astonished by the marked improvement in her health. We allowed ourselves to believe that we had finally conquered the suffering that goes with years of undiagnosed celiac disease. Little did we know that we still had a long road ahead. Indeed, the psychological impact of celiac disease can be just as elusive as the disease itself.

We take for granted that food and mealtime are social rituals in which we nourish ourselves physically and emotionally. We express thoughts and tell stories; we share laughter and love—and food. For children with celiac disease, meals can trigger anxiety and fear of social situations and of the food itself. Instead of sharing in the experience, children feel “different” and excluded. Perhaps they choose isolation and decide not to communicate their problems because they believe they’ve already caused enough “problems” and don’t want to “burden” their parents any more.

Depression and anxiety follow on the heels of diagnosis all too often, and parents might feel overwhelmed or question their instincts: How did I miss this? What else am I missing?

The psychological impact of celiac disease cannot be ignored or underestimated. Chronic illnesses and their physical symptoms require monitoring by a medical doctor. The day has come for such monitoring by mental health professionals to be accepted as well. The insidious nature of celiac disease lies in its ability to mimic other conditions, including those in the mental health field. In this time of fantastic technological advances, we cannot forget that we must treat the whole child. Only then can we prepare our children to face the challenges of their disease and help them make a smoother transition into their “new normal.”



Welcome letter from Rhonda Resnick

Celiac Disease Foundation Board of Directors



How does a mother explain that no doctor would acknowledge an illness existed until her child could not get out of bed? How does a mother explain why doctor after doctor said, "Oh, your daughter has severe depression and anxiety," as the source of her stomach problems?

How does a mother explain picking up her 3-year-old daughter at school only to see dark bags around her eyes, hear "Mommy, my head hurts," and then witness her vomit and pass out in the back seat of the car? I rushed her to the emergency department, and the doctor told me that my little girl had experienced a terrible migraine. She suffered from acute migraines for the majority of her childhood. She was so terribly sick and fatigued that she couldn't get out of bed in the morning. The mornings turned into afternoons. The days turned into weeks. School days were missed, not to mention playtime with friends, and so much more. My little girl was robbed of her childhood.

I knew something was wrong with her health. I knew the doctors hadn't found it, and I knew as her mother that I wouldn't stop until I found the answer. One doctor went as far as to speculate that I had Munchausen Syndrome by Proxy, a mental illness where the caretaker of a child, usually the mother, makes up fake symptoms to make it appear as if the child is sick.

At 13 years old, her migraines, fatigue, and general bad feeling were constants. If that weren't enough, she suddenly stopped growing. She was 4'6" and 65 pounds. Then, through a serendipitous introduction with a stranger one back-to-school night, I was introduced to an amazing physician, Dr. Fran Kaufman, at Children's Hospital in Los Angeles. After her initial examination, Dr. Kaufman said, "No child should suffer like this. We're going to find out what's wrong with her."

Within a week, she called me to tell me that she believed my child had celiac disease, but she needed a biopsy to confirm. Finally, a preliminary diagnosis! But what was celiac disease? It was explained to me that it was an autoimmune disorder and that whenever someone with the disease eats wheat, rye, or barley, the body begins to attack the villi in the small intestine, which stops the body from ingesting essential nutrients.

By the time my daughter was diagnosed, her villi had been so destroyed that she'd been malnourished for years, thus explaining her chronic fatigue, migraines, and her stunted growth. No wonder she was always sick! The real wonder is that she could function at all.

But now what? How would she get better? What medication would she take? How long would it take? I learned there was no pill, no medication. Eliminating gluten from the diet was the only treatment. I also was told something that rocked my world – that maintaining a gluten-free diet would be the easy part. The hard part would be the emotional side effects of being sick for so many years and of missing so many critical social development years. The hard part would be how my daughter's peers might treat her when she went to parties and couldn't eat pizza, cake, or even salad because of the dressing.

That was almost 10 years ago and there seemed to be very few people who actually understood what it meant to lead a gluten-free life. Even the dietitian at the hospital spent a mere 15 minutes with us explaining what my daughter could and could not eat. Fortunately, somewhere in the information that the dietitian gave me was the phone number for Celiac Disease Foundation (CDF). I immediately called the number, and the most wonderful, compassionate, and understanding woman answered the phone. It was Elaine Monarch, the founder of CDF, and my daughter's new guardian angel.

Elaine was filled with such empathy. She helped me understand celiac disease and what we as a family needed to do next. I will never forget Elaine's kindness, patience, and the guidance she provided.

Today, some 10 years since my daughter was diagnosed, she still suffers from fatigue, migraines, and chronic sinus infections even though she strictly adheres to a gluten-free diet. And, just as her doctor cautioned 10 years earlier, the emotional and psychological impact of celiac disease still lingers. My daughter's quest to lead a healthy and fulfilling life continues. Her strength and persistence encourages us.

As my husband and I reflected on our daughter's journey, we wondered how many other young people have faced the same emotional and psychological challenges of living with celiac disease that our daughter faced. How many other young people felt

isolated, depressed, and anxious? We wondered why there wasn't a program that trains doctors and mental health care professionals to proactively treat the psychological challenges young people face once they embarked on their gluten-free lifestyle. That's when we approached Marilyn Geller at CDF. Coincidentally, or perhaps serendipitously, Marilyn told us she had always envisioned a similar program, and the only impediment to moving forward was the funding. We wanted to help.

As the initial donors to CDF to make this manual possible in partnership with the Celiac Disease Program at Children's National Health System, we are delighted to see this critical program take shape. Our goal is to reach the point where the positive impact of this program will be delivered to young celiac disease patients across the country.

"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 a 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."

— Marilyn Geller, Celiac Disease Foundation CEO

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INTRODUCTION

The goal of this manual is to increase medical and mental health providers' awareness of celiac disease and other gluten-related conditions in pediatric populations. Despite being a relatively common condition, celiac disease is still considerably underdiagnosed (Rubio-Tapia et al., 2012) and can often be misdiagnosed as its symptoms may not be apparent, can mimic other conditions or can be varied and can affect many different parts of the body. We encourage providers to take a thoughtful and thorough approach to differential diagnosis and include celiac disease as a consideration for both medical and mental health assessments. In addition to improving the recognition of celiac disease, we emphasize the importance of

looking at the whole child and identifying and treating the emotional, as well as the physical, health of youth with celiac disease or a gluten-related condition.

More specifically, this manual will focus on three main areas: a) helping medical providers know when to refer youth diagnosed with celiac disease for mental health services; b) educating mental health providers about when to refer youth for medical evaluation of potential celiac disease or a gluten-related condition; and c) preparing mental health professionals to support youth with celiac disease or a gluten-related condition by understanding their unique psychological needs.



ABOUT CELIAC DISEASE

What is Celiac Disease?

Celiac disease is a genetic, autoimmune condition that causes inflammation of the small intestine and interferes with the absorption of dietary nutrients. About one in 100 people has celiac disease, making it one of the more common health problems in North America.

People who have celiac disease are permanently intolerant to gluten, a protein found in all forms of wheat, rye, and barley. Although a common belief is that gluten is found only in foods, the protein is actually used in many everyday products including medications, vitamins, and cosmetic products such as lotions, shampoo and lipstick. Because of gluten's wide use in a variety of products, knowledge of the gluten-free diet and the places in which gluten can be hidden is imperative.

HOW IS CELIAC DISEASE DIAGNOSED?

Three types of testing are used to evaluate patients for celiac disease.

Serology: The first-line screening tests are serologic tests to measure the presence of specific antibodies, which are caused by an autoimmune intestinal injury, which is triggered by gluten.

The initial screening tests for celiac disease are:

- Quantitative immunoglobulin A (IgA)
- IgA anti-tissue transglutaminase antibodies (tTG-IgA)

If a child has an autoimmune disease such as type 1 diabetes mellitus, an IgA anti-endomysial antibody is also ordered. This additional test helps with specificity since there is a greater rate of false positive tTG-IgA values in children with autoimmune disease.

Genetic Testing: There is no genetic test yet available to diagnose celiac disease; however there are some tests, which may help to determine if further screening is necessary. The most commonly ordered tests are the HLA DQ2 and DQ8 alleles. One or both of these alleles are found in almost all patients with celiac disease but they are also found in about 40 percent of the general population so that a positive test is not helpful in diagnosing celiac disease.

However, if both HLA DQ2 and DQ8 are negative in a patient, the likelihood of that patient having celiac disease is very low. This testing is sometimes done if a patient with suspected celiac disease is already on a gluten-free diet or to screen first-degree relatives.

Small Intestinal Biopsy: Although the screening serologic tests have a very high predictive value, upper endoscopy with duodenal biopsies remains the 'gold standard' test.

Note: The European Society of Pediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) recently proposed that a subset of patients with celiac disease can be diagnosed solely by serologic methods. To meet the ESPGHAN criteria for diagnosis, a child would need to meet four criteria:

1. Symptoms consistent with celiac disease;
2. A 10-fold or greater elevation in the IgA Anti-tTG antibody;
3. A positive IgA Anti-Endomysial Antibody;
4. And the presence of either or both HLA DQ2 and DQ8 alleles.

As of the publishing of this manual, the North American Society of Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) has not adopted this proposal until a more thorough evaluation of the efficacy is completed.

Ongoing Screening:

Celiac disease can develop at any time in life. Even if previous tests for celiac disease have been negative, repeat testing is required if symptoms persist or new symptoms develop.

TREATMENT

The only treatment for celiac disease is strict adherence to a lifelong gluten-free diet, which means eliminating all forms of wheat, rye, and barley from a patient's diet. Patients who strictly follow the gluten-free diet can begin to experience relief of symptoms as soon as one week after starting the diet, although it often takes six to 12 months for the small intestine to heal in children and up to two years to heal in adults.

Routine follow-up with a medical provider is very important after a celiac disease diagnosis. After the

initial diagnosis, patients are usually seen in follow-up at six and 12 months and then annually thereafter if everything is going well. If symptoms persist despite initiation of the gluten-free diet, the patient should follow-up sooner with a gastroenterologist.

The follow-up visits also can be used to check for the normalization of the tTG antibody levels as an indicator for healing of the intestine. Annual testing for possible associated problems like the development of autoimmune thyroid disease is also performed.

In addition, testing can be done to be sure that abnormalities involving nutrients such as folate, iron and vitamins D, E, and B12 have resolved on the gluten-free diet.

What Happens if Someone with Celiac Disease Eats Gluten?

Gluten is considered toxic to people with celiac disease. Although those with celiac disease will not experience anaphylactic shock if they eat gluten, they may experience symptoms, which can include diarrhea,

vomiting, severe abdominal pain, lethargy, skin rashes, or headaches. Failure to adhere to the diet can cause long-term damage to the small intestine and lead to on-going symptoms, malnutrition, increased risk of cancer and the development of other autoimmune conditions later in life.

There is no medical therapy to stop the gluten-induced reaction once a person has consumed gluten. Reaction length varies from person to person and can last from a few hours to several days.

SYMPTOMS OF CELIAC DISEASE

The symptoms of celiac disease (CD) vary greatly among patients and can affect almost any part of the body. One child may experience severe diarrhea and abdominal pain while another may have skin, liver, neurological, dental, or other problems. Many children with celiac disease are underweight and have short

stature compared to their non-celiac peers. Patients can also have the intestinal inflammation with no overt manifestations.

The most common typical and atypical celiac disease symptoms include:

Gastrointestinal

Diarrhea
Lactose intolerance
Abdominal distention
Wasting
Change in appetite
Constipation
Dyspepsia
Bacterial overgrowth
Malabsorption
Flatulence
Reflux disease/heartburn
Hepatitis
Bloating
Vomiting
Ulcers – mouth, esophageal, stomach, upper small intestine
CD can be confused with Irritable Bowel Syndrome (IBS) and Inflammatory Bowel Disease (IBD)

Behavioral/Psychiatric

Depression
Hypochondria
Inability to concentrate, "brain fog"
Anxiety
Neurosis
Moodiness
Obsessive-compulsive disorder
Attention-deficit/hyperactivity disorder (ADHD)
Autism Spectrum Disorder
(Although no studies have shown a definitive link between celiac disease and ADHD and Autism, many families feel their children have improved on a gluten-free diet)

Autoimmune

Type 1 diabetes
Hypothyroidism (especially Hashimoto's Disease)
Hyperthyroidism (Grave's Disease)
Secondary hyperparathyroidism
Sjogren's Syndrome
Dilated (congestive) cardiomyopathy
Alopecia areata rheumatoid arthritis
Fibromyalgia
Collagen-vascular disease
Apthous stomatitis
Multiple sclerosis
Systemic lupus erythematosus
Reynaud's Syndrome

Nutritional

Weight loss
Stunted growth
Poor weight gain,
“failure to thrive”
Obesity
Hypoglycemia

Neurological

Seizures
Migraines/headaches
Brain atrophy and dementia
Peripheral neuropathies,
including paresthesias
Paraplegia
Ataxia

Skeletal

Osteoporosis/osteopenia
Joint, bone, muscle pain
Dental enamel defects
Clubbing

Dermatologic and Mucous Membranes

Dermatitis herpetiformis
Eczema
Psoriasis
Vitiligo
Acne
Rosacea
Urticaria
Vasculitis

RELATED CONDITIONS

Non-Celiac Gluten Sensitivity (NCGS)

NCGS is a condition with symptoms similar to those of celiac disease but which has no clearly defined diagnostic test. The symptoms of those with NCGS improve when gluten is eliminated from the diet.

People with gluten sensitivity can experience symptoms such as abdominal pain, bloating, diarrhea, constipation, headaches, depression, ADHD-like behavior, altered mentation (“foggy mind”), bone or joint pain, and chronic fatigue when they have gluten in their diet but other symptoms also are possible.

Since there is currently no diagnostic test for gluten sensitivity, the only way to be diagnosed is to undergo the screening and diagnostic tests required to confirm celiac disease. Individuals who have been diagnosed with gluten sensitivity do not experience the small intestine damage or develop the tissue transglutaminase (tTG) antibodies found in celiac disease or have evidence of wheat allergy. The diagnosis relies on the absence of positive results for celiac disease or wheat allergy tests, as well as improvement of symptoms on a gluten-free diet. Further evidence of the diagnosis is the return of symptoms when gluten is reintroduced into the diet. There is no cure for gluten sensitivity, and the only treatment is to follow a gluten-free diet.

Dermatitis Herpetiformis (DH)

Dermatitis herpetiformis, also known as DH and Duhring’s disease, is a skin manifestation of celiac disease. The classic findings are pruritic (itchy) nodules, which appear bilaterally, especially on the forearms, elbows, knees and buttocks.

DH nodules can resemble herpetic lesions, but are not caused by the herpes virus. Symptoms of DH usually wax and wane and can be confused with eczema. Symptoms normally resolve when patients are on a strict, gluten-free diet.

DH affects 15 – 25 percent of people with celiac disease who typically have no digestive symptoms. DH can affect people of all ages but most often appears for the first time in those between the ages of 30 and 40. The condition is somewhat more common in men than women, and men are more likely to have atypical oral or genital lesions.

Type 1 Diabetes Mellitus (T1DM)

There is a known association between T1DM and celiac disease; about 5 – 10 percent of children with T1DM also have celiac disease. The standard recommendation is that all patients diagnosed with T1DM should be screened for celiac disease.

There are additional challenges encountered by families managing both T1DM and celiac disease, including how to manage carbohydrate-counting and insulin doses, while on a gluten-free diet. Many prepared gluten-free foods have increased carbohydrate contents as compared to gluten-containing products. Therefore, patients with diabetes may find their blood glucose running higher than normal, and they may require subsequent adjustments to their insulin regimen. A close working relationship between the child's gastroenterologist, endocrinologist and dietitian provides the most optimal management for the child.

There is no established link between celiac disease and type 2 diabetes.

Trisomy 21 (Down Syndrome)

Children with Trisomy 21 also have an increased risk of developing celiac disease, which is about the same as for children with T1DM. The standard recommendation is that children with Trisomy 21 should also be screened for celiac disease.

KEY POINTS ABOUT CELIAC DISEASE

✓ **Celiac disease can be difficult to diagnose** because it is often not considered. It mimics many other conditions and has hundreds of possible symptoms. Celiac disease can affect any system of the body at any time in life.

✓ **There are three tests for celiac disease:** serology, genetic testing, and small intestine

biopsy. Serology is the first step-screening tool and the biopsy remains the "gold standard" for diagnosis. Genetic testing can be used as a tool to help rule out celiac disease in individuals already on a gluten-free diet.

✓ **The only treatment for celiac disease is a strict lifelong gluten-free diet**, which means avoiding all forms of wheat, rye and barley.



SECTION 2

For Medical Providers

KNOWING WHEN TO REFER FOR MENTAL HEALTH SERVICES

A wide range of psychological problems can arise for patients with untreated celiac disease or a gluten-related condition. These can include difficulties adjusting to a new diagnosis of chronic illness as well as dealing with adherence to a gluten-free diet and other aspects of disease management. Protracted duration of emotional or behavioral symptoms, greater

severity of symptoms, and/or significant impairment in functioning are indicators of potential need for mental health treatment. Below is a list provided by the American Psychological Association of emotional and behavioral changes that signal when mental health evaluation and treatment may be warranted:

CHANGE YOUR MIND ABOUT MENTAL HEALTH WEBSITE

From American Psychological Association — www.apa.org/helpcenter/change.aspx

Certain experiences, thoughts, and feelings signal the presence of a variety of mental health problems or the need for help. The following signs are important to recognize:

- finding little or no pleasure in life
- feeling worthless or extremely guilty
- crying a lot for no particular reason
- withdrawing from other people
- experiencing severe anxiety, panic, or fear
- having big mood swings
- experiencing a change in eating or sleeping patterns
- having very low energy
- losing interest in hobbies and pleasurable activities
- having too much energy, having trouble concentrating or following through on plans
- feeling easily irritated or angry
- experiencing racing thoughts or agitation
- hearing voices or seeing images that other people do not experience
- believing that others are plotting against you
- wanting to harm yourself or someone else

SCREENING INSTRUMENTS

The use of screening measures with patients with celiac disease and other gluten-related conditions can further assist in identifying children and adolescents in need of

further mental health evaluation and/or treatment. The table below provides several behavioral health screens that can be used in various health care settings.

Measure	For Age	Who completes	Developed By
Behavioral Health Checklist (BHCL)	4 – 7 8 – 12	Parent report Parent report	Children’s Hospital of Philadelphia ¹
Pediatric Symptom Checklist (PSC)	4 – 16	Parent report	Massachusetts General Hospital ²
Pediatric Symptom Checklist – Youth Report (Y – PSC)	11 – 18+	Youth self-report	Massachusetts General Hospital ²
Strengths and Difficulties Questionnaire (SDQ)	2 – 4 4 – 10 11 – 17	Parent, Teacher report Parent, Teacher report Parent, Teacher and Youth self-report	Robert Goodman, MD ³

¹ Contact Thomas J. Power, PhD (power@email.chop.edu) for availability and use

² http://www.massgeneral.org/psychiatry/services/psc_forms.aspx

³ Youth in Mind website at www.sdqinfo.org

CASE EXAMPLES

The following are three case examples of children and adolescents with diagnosed celiac disease who would benefit from mental health evaluation and

treatment. Names and details have been modified to protect confidentiality.

DANIEL

Daniel is a 14-year-old boy who was diagnosed with celiac disease at age 8. He had previously been adherent to a gluten-free diet, however, since starting ninth grade this year, his parents noticed that he had developed more abdominal pain, bloating, and diarrhea. After continued presence of symptoms, his parents suggested that Daniel see his pediatrician for evaluation, and he disclosed that he had been eating foods with gluten since beginning his new school. Daniel expressed feelings of anger and frustration that he had to follow a special diet and that he wanted to ‘be like everyone else.’ Although his parents had worked with the school to put a 504 Plan** in place,

Daniel was adamant about not disclosing his diagnosis of celiac disease and gluten-free diet to his new friends (or their parents), with whom he has been spending more time. Initially, Daniel’s parents thought this was a phase and Daniel would return to previous good adherence, however, after an entire semester of the same behaviors, they became increasingly concerned.

Continued intentional consumption of gluten (especially in the presence of physical symptoms), refusal to disclose diagnosis and gluten-free diet, and growing feelings of anger and frustration related to coping with celiac disease are signs that a mental health referral is appropriate.

A customized education plan for students with special health care needs in public schools; please refer to Section 5 ‘Securing a 504 Plan for Gluten-Free School Lunches’ for more detailed information

LIZ

Liz is a 12-year-old girl with type 1 diabetes and celiac disease (diagnosed at ages 10 and 11, respectively). Liz has a history of Generalized Anxiety Disorder (GAD) and Attention-Deficit/Hyperactivity Disorder (ADHD), which had previously been well-managed on medication (escitalopram and methylphenidate). However, in the last six weeks, her father noticed that Liz had been increasingly more anxious. Despite her health being stable, Liz complained of stomachaches and had difficulty going to school. Liz's father noted that Liz was more hesitant to eat outside of the home

and no longer wanted to spend time at friends' homes due to concern about gluten exposure. Liz also had difficulty sleeping at night, was clingier towards her parents, and experienced academic decline due to difficulties concentrating and missed school.

Exacerbation of worrying, difficulties with concentration, hesitance to eat outside of the home, social withdrawal, missed school, and academic decline are signs of increased anxiety with functional impairment, which suggest the need for further mental health care.

SAMUEL

Samuel is a 5-year-old boy who was recently diagnosed with celiac disease. Samuel's mother requested a meeting with a psychologist for guidance on how to explain celiac disease and a gluten-free diet to Samuel. In particular, she was concerned that Samuel would not understand or comply with a gluten-free diet because he had never experienced overt symptoms related to celiac disease. Samuel's mother also wanted ideas on working with the school and how to talk with extended family about celiac disease.

While there are no specific signs of psychological distress, this is a great example of a parent proactively seeking consultation about how best to help her child cope with a new diagnosis and ongoing management of celiac disease. Including a mental health provider as a part of a multidisciplinary team emphasizes a focus on both the medical and mental health needs of children and adolescents.

KEY POINTS FOR EARLY RECOGNITION OF PSYCHOLOGICAL PROBLEMS

 **The following are some of the psychological difficulties related to celiac disease and gluten-related conditions:** coping with a chronic health condition, adherence to treatment (gluten-free lifestyle), disruptions to school and social life, challenges to family functioning, dealing with other physical symptoms or illness.

 **Evaluation and treatment of comorbid psychiatric illness is important to address in**

order to improve overall health, but also to avoid potential negative impacts on adaptive coping with celiac disease and other gluten-related conditions.

 **Introduction of mental health providers as part of a multidisciplinary team promotes an integrated model of care,** and treating the whole child. Inclusion of mental health providers from the beginning also encourages preventative care and helps normalize involvement with mental health.

SECTION 3

For Mental Health Providers

KNOWING WHEN TO REFER FOR A MEDICAL EVALUATION

Initially, youth with celiac disease or non-celiac gluten sensitivity may be misdiagnosed with a psychiatric illness due to some of the neurological and psychiatric symptoms that can be seen in untreated celiac disease or gluten sensitivity including:

- Irritability
- Mood changes
- Anxiety
- Fatigue
- Difficulties with concentration and attention
- Sleep difficulties
- Decreased appetite

It is important to pay particular attention to:

- Eating Disorders and Avoidant/Restrictive Food Intake Disorder: A child with restrictive eating patterns should be screened for celiac disease or non-celiac

gluten sensitivity in order to make a clear differential diagnosis. EXAMPLE: "I try to eat just a little bit at a time, only when I am at home and don't need to go anywhere, in case I feel sick."

- "Somatic" Symptoms (stomach aches, headaches, shakiness, tingly sensations, etc.). EXAMPLE: "I sometimes feel shaky and tingly for no reason, even when I am just sitting in class not doing anything stressful."

Since mental health providers may be the initial contact for children and adolescents with undiagnosed celiac disease and other gluten-related conditions, they can play a vital role in identifying youth who may need medical evaluation. Encouraging mental health providers to maintain a broad scope of differential diagnoses, including consideration of possible celiac disease or other gluten-related conditions,

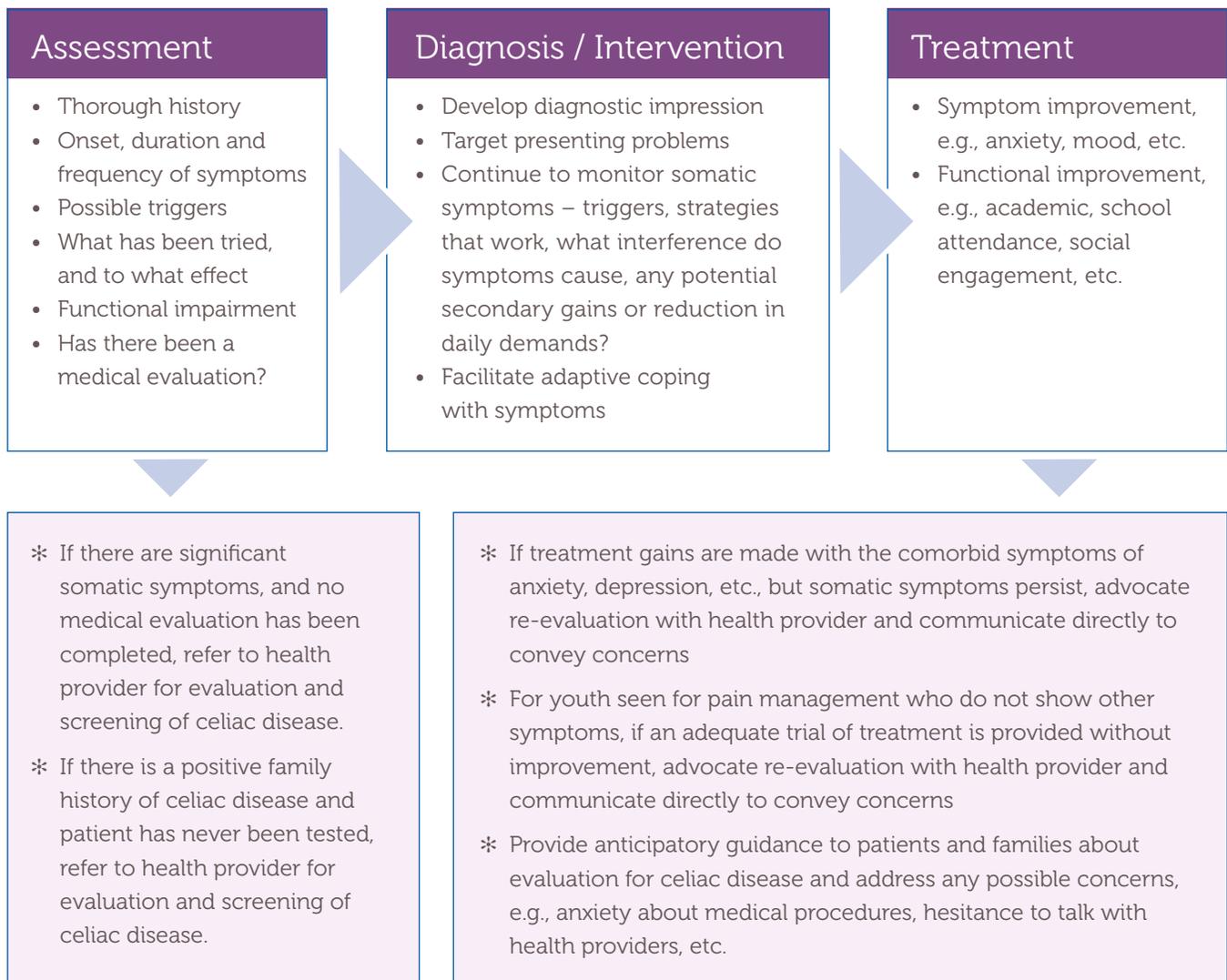


and increasing awareness and education about the conditions, can help improve detection of youth who should be referred for medical evaluation. The appropriate referral source, e.g., pediatrician, primary care provider, or gastroenterologist may depend on what medical assessment has already been completed, availability of providers, and the family's preference.

In the absence of an identified organic etiology, physical symptoms such as appetite changes, fatigue, pain, etc. are often attributed to psychiatric origins. However, given how underdiagnosed and misdiagnosed celiac disease is, it's possible that the disease was not included in the initial medical

evaluation. If a youth is referred for mental health services and has not yet been assessed for possible celiac disease, it is strongly advisable to refer to a medical provider to rule it out. Another time to consider the potential benefit of medical evaluation for celiac disease is when there is lack of response or sufficient progress following a reasonable course of empirically-supported psychological and/or psychiatric treatment.

Below is a guide of factors to consider when deciding whether to refer a patient for medical evaluation of celiac disease or other gluten-related conditions.



CASE EXAMPLES

The following are three case examples of patients seen for mental health treatment, for which a referral for evaluation of celiac disease or other gluten-related condition is recommended. Again, names and details have been modified to protect confidentiality.

MARTHA

Martha is a 12-year-old girl who comes for mental health treatment with a previous diagnosis of Generalized Anxiety Disorder (GAD) and “Chronic Shyness Syndrome” (which is not an official mental health disorder, per the DSM) by her primary care doctor. Martha presents with social shyness, chronic stomachaches, fear of vomiting and anxiety about being sick in front of others. Parents also are concerned Martha’s physical symptoms are used as an excuse from responsibilities such as completing household chores and attending school. Martha’s therapist recommends Martha see a gastroenterologist to rule out medical causes of her symptoms, however Martha and her parents hesitated as they were informed Martha would require an endoscopy, which scared them. Over the course of treatment, Martha’s anxiety improved but her physical symptoms persisted.

The presence of gastrointestinal symptoms and lack of thorough medical evaluation are indicators that Martha should be referred for medical evaluation. Additionally, the continued presence of physical symptoms despite improvement in anxiety also raises concern about other potential causes of her symptoms.

GABRIELLA

Gabriella is a 16-year-old female referred for psychiatric evaluation by her pediatrician due to concerns about depression. Initial medical assessment had not found any organic etiology for Gabriella’s recent increased fatigue, decreased appetite, and low mood. Parents are concerned that Gabriella is growing increasingly more socially isolated and struggling to attend school consistently. Gabriella expresses frustration that “something doesn’t feel right,” and she does not think therapy is the solution. Gabriella’s family history also is notable for autoimmune disorders on the maternal side including an aunt with celiac disease and cousin with type 1 diabetes.

While a psychiatric evaluation is reasonable given the presenting symptoms, it also is recommended that Gabriella be evaluated for possible celiac disease or other gluten-related condition given her symptom profile, as well as family history of celiac disease and other autoimmune disorders.

JASON

Jason is an 8-year-old boy who presents for a first psychiatric evaluation for concerns about inattention, academic decline, and oppositional behavior. Parents report Jason's grades have dropped during third grade, and he is experiencing more disciplinary problems at school (e.g., talking out of turn, not following directions, out of his seat). Parents described Jason has been eating less, partly because he is active and can't sit still, but he also complains of stomachaches and feeling uncomfortably full after eating very little. Jason has never been a 'great eater' and has always been small for his age. Parents also noted Jason has a history of skin picking, especially around his fingers,

but more recently, he's also had skin irritation around his knees, which has been more bothersome. The stomachaches and skin problems do not interfere with Jason's daily functioning. He still attends school regularly, wants to spend time with friends, and enjoys video games and playing outside.

While Jason presents with symptoms that are concerning for potential psychiatric illness, celiac disease or other gluten-related condition should also be a diagnostic consideration given his presentation of attentional difficulties, stomachaches, uncomfortably full feeling after eating, small size, and skin irritations.

KEY POINTS FOR THE ROLE OF MENTAL HEALTH IN CELIAC DISEASE

✓ **There can be many barriers to appropriate medical care for families**, e.g., fear of medical procedures, lack of knowledge, poor follow-up, discomfort with asserting themselves with providers, and past negative experiences in medical settings. Addressing these difficulties and advising families on how to advocate for their children and adolescents' needs is important.

✓ **Collaboration is key.** Mental health providers can facilitate communication between families and medical health providers, especially when there is concern further medical evaluation is needed. Health providers may be more receptive to pursuing medical evaluation knowing that a patient's psychological needs are also being addressed.

✓ **While continued research and study is needed to improve our understanding of how and why changes occur, most youth diagnosed with celiac disease report improvement of symptoms, including psychiatric symptoms, with adherence to a gluten-free diet.** Therefore, mental health providers who are trained to recognize symptoms of possible celiac disease can play a critical role in helping youth receive the medical evaluations they need.



Unique Psychological Challenges Related to Celiac Disease in Pediatric Populations



DIAGNOSIS

Being diagnosed with celiac disease may generate mixed emotions. For some children and adolescents who experience numerous medical evaluations and misdiagnoses, a confirmed diagnosis of celiac disease or a gluten-related condition may provide a sense of relief and an explanation. However, for those patients who experience the subtler symptoms of the disease, diagnosis may be unexpected and confusing. The realization of having a chronic illness that requires life-long adherence to a gluten-free lifestyle can also be a challenge. Some of the goals of psychological intervention at this initial stage are to help children and adolescents attain a developmentally appropriate understanding of celiac disease and its treatment, provide assistance in accepting the diagnosis, and begin to feel empowered in coping adaptively with the disease.

EXAMPLES OF DEVELOPMENTALLY-APPROPRIATE EXPLANATIONS OF CELIAC DISEASE

5-year-old:

Eating foods with gluten can cause problems for your belly and make it hard for your body to grow and stay healthy.

10-year-old:

Celiac disease is a condition when eating gluten (found in foods like bread, pizza, cupcakes) can cause a reaction in the body that damages a part of your digestive tract (villi) that helps absorb nutrients. When your body can't absorb these important vitamins and nutrients, you may feel sick and your body has trouble growing and staying healthy.

15-year-old:

Celiac disease is a chronic disorder in which eating gluten causes your immune system to react and damages the villi in the small intestine. The damage interferes with your body's ability to absorb vitamins and nutrients and can cause you to feel sick, disrupt your growth, and lead to other complications.

MAINTAINING A GLUTEN-FREE LIFESTYLE

Adapting to a gluten-free diet requires many skills including: knowing how to read nutrition labels and find safe products at the grocery store; considering whether cross-contamination might occur in home food preparation and discerning whether cross-contamination might have occurred in manufactured products; cleaning out the kitchen to create gluten-free areas; and planning for dining out in restaurants and travel. As with many other chronic illnesses,

adherence to treatment can be difficult for children and adolescents with celiac disease and other gluten-related conditions. For some youth with celiac disease, keeping a gluten-free lifestyle can invoke anxiety about accidental gluten exposure or future health concerns, fatigue from maintenance over time, and negative emotions (e.g., frustration, disappointment, sadness, etc.). Below is a list of some of the ways to promote adherence.



WAYS TO SUPPORT ADHERENCE

Planning and preparing foods in advance

Learning about celiac disease and effective management

Utilizing social supports: family, friends, community

Addressing any associated emotional or behavioral **concerns**

Having appealing **gluten-free alternatives** available

Advocating for structural and/or academic supports, e.g., a 504 Plan in public schools, support from cafeteria workers, school nurses, teachers and other appropriate school staff.

DEVELOPMENTAL STAGES

Coping with celiac disease and treatment presents different challenges at varying developmental stages. For younger children, parents have more responsibility and control over their child's day-to-day life, but as children mature, they have greater independence and autonomy. Also, as children grow older, schools, social

circles, and other systems become increasingly more relevant, so addressing the impact of celiac disease and other gluten-related conditions and management in these arenas is important as well. Below are some of the different needs that may arise throughout the various developmental stages:

Early Childhood	School-aged	Adolescence	Young Adulthood
Parents take greater responsibility of disease management since they are more involved in all aspects of daily life	Children begin to learn skills, e.g., looking at labels, talking to others about having celiac disease, asking questions about whether food or products are safe	Adolescents have greater desire for independence and autonomy	Young adults begin to be more involved in their medical care, e.g., providing their own health history, making appointments
Parents need to share information and educate other adults/caregivers who will be spending time with the child	Involve the school – 504 Plan in public schools; but if not available, communicate closely, and educate teachers and school staff	Adolescents acquire more skills, e.g., identifying safe foods and products, planning ahead for their needs, communicating directly with others about celiac disease and management	Transition to living independently includes greater responsibility, e.g., shopping for gluten-free foods and products, planning and preparing meals
	Children/families manage celiac disease while participating in extracurricular activities – sports, clubs, teams, etc.	Parents and providers help teenagers navigate social situations	Learn how to effectively advocate for oneself
	Plan ahead for social events – play dates, parties, etc.	Families should anticipate non-adherence, which is common in adolescence, so acknowledging and working with teenagers to address barriers to adherence is important	Navigate social, educational and work environments

SOCIAL IMPACT

Celiac disease and other gluten-related conditions have a significant social impact. Some children experience physical effects related to celiac disease such as short stature, chronic fatigue, abdominal pain, loose stools, headaches, seizures or skin changes. Support in coping with these symptoms and minimizing their disruption to social, academic, emotional and behavioral functioning is an important component of psychological intervention.

As many social activities involve food and eating, these situations can be a source of stress for children and adolescents with celiac disease and other gluten-related conditions, as well as their parents. It's common for youth to feel socially isolated or different from peers due to their gluten-free diet. Acknowledging, and normalizing these feelings, is a good first step to helping youth cope more adaptively and begin to find ways to take control of their disease and health. Children's needs may vary according to their age and developmental functioning, e.g., younger children may need more scripts on what to say and how to respond to questions, and adolescents may benefit from help

in being assertive with others about maintaining a gluten-free diet. Regardless of age, it's helpful to include children and adolescents in decisions about sharing information with others (who will be told, what will be disclosed) to help them maintain a sense of control.

Another social impact of celiac disease and other gluten-related conditions is in the family. Decisions about whether to integrate a gluten-free diet for individuals or the entire household, effect on siblings when parents have to give more attention and time to one child, or parents' guilt about late diagnosis or misdiagnosis for their child are examples of some of the concerns that may arise. Other considerations include how to divide responsibilities, such as food shopping, meal planning, communicating with schools and other parents, and coordinating medical care such as appointments. Helping families communicate, plan, problem-solve and process their thoughts and feelings around these issues may be a target of psychological intervention. As with any treatment, understanding the specific needs and context of each family is critical in developing solutions that are most useful for that family.

FOSTERING ADAPTIVE COPING

Below are strategies to support adaptive coping in youth with celiac disease and gluten-related disorders, and their families. It is helpful to tailor tools for each youth, and for younger children, make lists or note cards as concrete reminders of their coping tools. Also, keep developmental context in mind in considering which tools are most relevant and helpful for a child or adolescent.

As you are working with patients, it's important to help them remember that this is most likely a temporary situation that will become better as time goes on. It's important to remember that your patient will feel better in direct relationship to their diet adherence.

Identifying and Expressing Feelings

- Talk with others, journal, write a letter
- For younger children, expressing feelings may be better achieved through play, drawing or acting
- For families, communication is important and parents set an example for encouraging expression of feelings, and ways to do so
- Role playing can be a concrete way for children to practice how to speak to others, e.g., about having a gluten-free diet or how they feel about having a gluten-related disorder

Relaxing and Managing Stress

- Deep breathing, visual imagery, progressive muscle relaxation
- Physical activity (e.g., walking, yoga)
- Counting, listening to music, etc.

Engaging in Enjoyable Activities

- As a constant reminder, create a list in advance so it's easy to remember when needed, and have as varied a list as possible so you can choose what activity works best in different situations: reading, drawing, computer games, playing with favorite toys, outdoor activities, watching television, listening to music, spending time with friends, etc.

Cognitive Strategies

- Use self-talk to coach yourself through difficult situations or feelings
- Maintain balanced thinking (avoid all-or-none thinking; see positive and negative)
- “Change channels” – distract yourself by switching to a new topic or activity
- Learn problem solving skills – set appropriate expectations and goals, evaluate pros and cons of options, and consider consequences/results

Utilize the Resources Around You

- Connect with others with celiac disease via support groups, camps, etc.
- Engage with the larger community through cooking classes and gluten-free expos

Other Complications

Since the symptoms related to celiac disease can impact so many different areas of the body, it is important to continue monitoring physical health, including considering potential comorbid diagnoses, when appropriate. Those youth who are symptomatic prior to celiac disease diagnosis may see improvement or resolution of symptoms following elimination of gluten. However, some youth may continue to present with symptoms even after maintaining a gluten-free lifestyle. Persistent presence of symptoms, especially in the context of good gluten-free adherence may signal the need for medical re-assessment. Symptoms such as fatigue, pain, and feeling sick frequently, or for lengthy periods, can be a challenge and cause disruption to daily life.

In addition to medical evaluation to explore potential causes for ongoing symptoms, the following are strategies for fostering adaptive coping and minimizing functional impairment.

Physical Body	Follow-up for medical evaluation to rule-out possible contributing factors / co-morbidities Learn how to pace yourself, structure your time, and work with the energy level that you have
Within Academic Settings	Reduce work load, flexible deadlines Adjust schedule, e.g., late arrival or early departure Extend time for classwork and tests Homebound tutoring, if unable to attend school Close communication with teachers and school staff
Extracurricular Activities	Modify participation, if possible Work closely with instructors, coaches, leaders, etc. to raise awareness of specific needs to help youth participate as much as possible Know when to discontinue, if needed
Extracurricular Activities	Find ways to stay connected with peers and friends, e.g., through play dates, parties, messaging, e-mail or video conference, if it's difficult to see them in person Modify activities as needed for your energy level

SECTION 5

Advocacy and Community Support

Celiac disease and other gluten-related conditions are chronic health conditions that require a lifelong commitment to a gluten-free diet. Our experience shows that patients and their families have better rates of diet adherence – and therefore fewer complications and a better quality of life – when they are equipped

with proper guidance, tools and resources at the point of diagnosis. Medical providers are the frontline advocate to a patient starting a successful gluten-free diet. Below are several ways to connect patients to celiac disease support programs.

REFERENCE DOCUMENTS

When a patient is first diagnosed with celiac disease, it is critically important that they are immediately scheduled to see a dietitian to receive information about the transition to a gluten-free diet. In Appendices A and B, you will find resources, 'The Gluten-Free Diet: A Basic Overview' and 'Preventing

Cross Contamination,' created by Children's National Health System that can be used or modified for your patients. Additionally, 'Your Gluten-Free Grocery Store Guide' and 'School Cafeteria Gluten-Free Tips' can also be found at www.childrenscookingclasses.org/celiac-disease-program.

JOINING A SUPPORT GROUP AND CAMPS FOR CHILDREN

Support groups offer newly diagnosed patients a way to connect with other families living with celiac disease and managing a gluten-free diet. The Celiac Disease Foundation oversees a nationwide network of support group chapters that help families begin a gluten-free lifestyle through providing community education programs, monthly meetings and peer-to-peer support. Please visit www.celiac.org to find a listing of local groups that are overseen by the Celiac Disease Foundation. Additionally, some cities have groups that are independently operated by active community members, hospitals and other non-profit organizations.

Many children with celiac disease and other gluten-related conditions miss out on typical childhood experiences such as attending camp due to the limited availability of safe resources available to them. The Celiac Disease Foundation provides opportunities for children to attend a gluten-free sleep away camp, thus allowing them to enjoy the camp experience in a safe environment. More information about their program can be found at celiac.org/camp.

NUTRITION EDUCATION AND COOKING CLASSES

Families living in the Washington, DC, metro area can participate in the Children's National Nutrition Education and Cooking Class Program. Classes are offered monthly and include topics like getting started on a gluten-free diet, baking with alternative grains, balancing and optimizing a gluten-free diet

and traveling on a gluten-free diet. Families who live outside of the Washington, DC, area can still participate by watching videos of the classes at www.childrenscookingclasses.org/videos. You can also check with your local grocery stores to see if they offer gluten-free cooking classes.



ATTENDING GLUTEN-FREE EXPO EVENTS

Gluten-free expos are held annually in many cities in the United States. These events give families the opportunity to sample gluten-free products, purchase their favorite items at a discount, interact with food manufacturers and meet other gluten-free individuals in their hometowns. Many of these events also include educational sessions where patients can learn about the latest developments in celiac disease and gluten-free diet research from leading medical professionals. Below are some of the most popular events in the United States:

- **Celiac Disease Foundation National Conference & Expo** (expo and educational session held annually in Los Angeles, CA and sponsored by the Celiac Disease Foundation). More information at www.celiac.org
- **Children's National Health System's Washington DC Gluten-Free Expo** (expo and educational session held annually in Washington, DC). More information at www.DCglutenFreeExpo.com
- **Gluten & Allergen-Free Events** (expos in Arizona, California, Georgia, Illinois, Massachusetts, New Jersey, Texas, and Washington). More information and dates at www.gfafexpo.com
- **Gluten & Allergen-Free Wellness Events** (expos in Connecticut, Florida, Missouri, Nevada, and North Carolina). More information and dates at <http://gfafwellnesspresentations.blogspot.com>

LEARNING HOW TO GROCERY SHOP

The first trip to the grocery store after receiving a celiac disease diagnosis can be completely overwhelming for a family. To make the transition easier, many grocery stores have created gluten-free product guides that highlight gluten-free products available in their stores and where to find them. The Celiac Disease Program at Children's National offers a comprehensive guide for navigating the grocery store that can be downloaded at www.childrenscookingclasses.org

Retail Stores

Most grocery stores offer a variety of gluten-free specialty products. Please check with your local grocery stores for specific gluten-free offerings.

Online Shopping

If families prefer to buy products in bulk or online, there are many great options including the Gluten & Allergy-Free Marketplace. Created by the Celiac Disease Foundation, this online marketplace connects gluten-free consumers to safe and reliable products. Each product contains a description and a way to add it to a shopping cart. Once the cart is complete, users can checkout and purchase the items through the Amazon.com system.

SECURING A 504 PLAN FOR GLUTEN-FREE SCHOOL LUNCHES

Section 504 of the Rehabilitation Act of 1973 promises equal opportunity for Americans with disabilities, including those with celiac disease. It guarantees full accommodation in federally funded programs and services, which includes public school meal services. If a child attends a public school, the parents can file a 504 Plan to arrange for gluten-free meal options.

Medical documentation is required to apply for special dietary accommodations under the National School Lunch Program. The specific requirements will vary by state, but in general, parents will need to provide:

- Proof of diagnosis
- An explanation of how celiac disease restricts a child's diet
- A statement explaining how celiac disease could negatively affect the child's education
- A list of foods that are unsafe and require substitution
- Description of specific accommodations that a child may need

The Celiac Disease Foundation provides examples of wording for the 504 Plan as well as guidance on writing a new plan. Please review their documents at www.celiac.org/resources for additional information.



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Celiac Disease Foundation

<http://celiac.org/>

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Non-Celiac Gluten Sensitivity

Celiac Disease Foundation
<http://celiac.org/celiac-disease/non-celiac-gluten-sensitivity/>

Psychological Health

American Psychological Association
Change Your Mind About Mental Health website
<http://www.apa.org/helpcenter/change.aspx>

Behavioral Health Checklist (BHCL)
Children's Hospital of Philadelphia
Contact Thomas J. Power, PhD (power@email.chop.edu)
for availability and use

Power, T.J., Koshy, A.J., Watkins, M.W., Cassano, M.C., Wahlberg, A.C., Mautone, J.A., Blum, N.J. (2013). Developmentally and culturally appropriate screening in primary care: development of the behavioral health checklist. *Journal of Pediatric Psychology*, 38 (10), 1155-1164.

Pediatric Symptom Checklist (PSC)
Pediatric Symptoms Checklist – Youth Report (Y-PSC)

Massachusetts General Hospital website
http://www.massgeneral.org/psychiatry/services/psc_forms.aspx

Strengths and Difficulties Questionnaire (SDQ)
Youth in Mind website
<http://www.sdqinfo.org/a0.html>

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Appendix A

The Gluten-Free Diet: A Basic Overview

CHILDREN'S NATIONAL HEALTH SYSTEM CELIAC DISEASE PROGRAM

WHAT IS GLUTEN?

Gluten is a protein found in all forms of wheat, rye, and barley. It is most commonly found in food, but it also hides in medicine, vitamins, and make-up. The first thing anyone should do when starting a gluten-free diet is schedule a meeting with a skilled dietitian or nutritionist. A well-trained professional can help teach the basics

of a gluten-free diet and help find ways to adapt to the new lifestyle.

When at home or at the grocery store, a quick guide to ingredients can be a helpful tool for quickly determining if a packaged product is safe.

SAFE GLUTEN-FREE INGREDIENTS

Eliminating wheat, barley, and rye from a diet may seem like a daunting task, but it's important to remember that there are still hundreds of grains and other foods that can be eaten. Staples like fresh fruits

and vegetables, meats, poultry, seafood, and most types of dairy are all gluten-free in their natural forms. Examples include the following:

Acorn Flour	Calrose	Cornstarch	Hominy	Potato Starch	Sunflower Seeds
Almond Flour	Canola	Cottonseed	Instant Rice	Quinoa	Sweet Rice Flour
Amaranth	Cassava	Dal	Kasha	Red Rice	Tapioca
Arborio Rice	Channa	Dasheen Flour	Lentils	Rice Bran	Tapioca Flour
Arrowroot	Chestnut	Enriched Rice	Millet	Rice Flour	Taro Flour
Baker's Yeast	Chickpea Flour	Fava Bean	Modified Corn	Risotto	Teff
Basmati Rice	Coconut Flour	Flax	Starch	Sago	Tofu
Bean Flours	Corn	Flax Seeds	Modified Tapioca	Sesame	White Rice Flour
Brown Rice	Corn Flour	Garbanzo	Montina	Sorghum	Xanthan Gum
Brown Rice Flour	Corn Gluten	Glutinous Rice	Peanut Flour	Soy	Yeast
Buckwheat	Corn Meal	Guar Gum	Potato Flour	Soybeans	Yucca



SAFE FOOD ADDITIVES

When purchasing packaged foods, there will likely be many ingredients listed that sound unfamiliar or strange. Below is a list of food additives that are safe for a gluten-free diet:

Acacia Gum	Caramel Coloring	Invert Sugar	Pectin	Sucrose
Adipic Acid	Carboxymethyl	Karaya Gum	Polysorbate	Sugar
Algin	Carob Bean Gum	Lactic Acid	Propylene Glycol	Tartaric Acid
Annatto	Cellulose	Lactose	Psyllium	Tartrazine
Aspartame	Corn Syrup	Lecithin	Sodium Benzoate	Titanium Dioxide
Baking Yeast	Cream of Tartar	Malic Acid	Sodium	Vanilla Bean
Benzoic Acid	Dextrose	Maltodextrin	Metabisulphite	Vanilla Extract
Beta Carotene	Distilled Vinegar	Maltol	Sodium Nitrate	Xylitol
BHA	Ethyl Maltol	Mannitol	Sodium Sulphite	Yam
BHT	Fructose	Methylcellulose	Sorbitol	Yeast; Autolyzed
Brown Sugar	Fumaric Acid	Monosodium	Spices (100% pure)	Autolyzed Yeast
Calcium Disodium	Gelatin	Glutamate	Stearic Acid	Extract
Carrageenan	Glucose	Papain	Sucralose	Nutritional Yeast

UNSAFE FOODS

Below is a list of basic food items that contain gluten. It's important to note that this is **not a complete list of gluten-containing foods**. If ever unsure about the safety of a product, call the manufacturer directly.

Barley	Bulgur Wheat	Graham	Malt Syrup	Semolina
Barley Extract	Croutons	Hordeum Vulgare	Malt Vinegar	Sprouted Wheat
Barley Grass	Couscous	Hydrolyzed Wheat	Matzo	Tabbouleh
Barley Malt	Durum	Protein	Mir	Triticale
Barley Pearls	Einkorn	Kamut	Rice Malt	Wheat
Bran	Emmer	Macha	Rye	Wheat Starch
Bleached Flour	Farina	Malt	Seitan	
Bulgur	Fu	Malt Flavoring	Spelt	

QUESTIONABLE FOODS AND PRODUCTS

There are many food items that appear on grocery store shelves that may or may not contain gluten. Unfortunately, because of varied manufacturing processes, it is impossible to generalize about any of these products. The only way to ensure one of these products is in fact safe is to check the food label or contact a manufacturer directly. Below is a list of questionable products that must be double-checked.

- Beer (all forms are unsafe except those labeled gluten-free)
- Beef/Chicken/Fish/Vegetable Stock (may contain wheat)
- Bouillon (may contain wheat)
- Brewer's Yeast (depends on whether it's a by-product of the brewing process [unsafe] or made from sugar beets [safe])
- Dextrin (could be made from wheat, corn, potato, arrowroot, rice or tapioca)
- Fillers (could be wheat, corn, potato or other starch)
- Lipstick/Lip Gloss/Lip Balm (may contain wheat or barley)
- Malted Grains (any grain can be malted. For example, gluten-free beer manufacturers use malted sorghum as an ingredient. This is considered safe. A malted grain would be unsafe if the malted ingredient is wheat, rye or barley)
- Marinades (may contain wheat)
- Miso (may contain barley)
- Multivitamins/supplements (may contain wheat starch)
- Mustard Powder (may contain wheat)
- Oats (may be cross-contaminated due to storage and transportation methods)
- Play Dough (may contain wheat)
- Rice Syrup (could be made using barley)
- Soy Sauce (may contain wheat)
- Spices (combination spices may contain wheat)
- Toothpaste (dental products may have malted products in their additives and stabilizers)
- Yellow Mustard (may contain wheat)
- Yogurt, flavored (may contain dextrin or barley extract)



Appendix B

Preventing Cross Contamination

CHILDREN'S NATIONAL HEALTH SYSTEM CELIAC DISEASE PROGRAM

PREVENTING CROSS-CONTAMINATION IN YOUR KITCHEN

When you're on a gluten-free diet, staying safe means avoiding any potential sources of cross contamination. It can happen very easily and unintentionally, so it's important to understand the many ways in which cross contamination can occur in your own home. While a household does not need to be entirely gluten-free in order to be safe, there are several measures you and your family can take to ensure that utensils, condiments, frying oil, boiling water and food preparation surfaces are sterilized to be safely gluten-free. It's not any more difficult than preventing against bacteria...just remember to keep your kitchen elements clean!

- **BOILING WATER:** Gluten-free pasta and gluten-containing pasta **cannot** be cooked in the same water. Gluten from the gluten-containing pasta will contaminate the water and make those with celiac disease sick. The same applies to cooking gluten-free items such as quinoa, rice, vegetables, or potatoes in boiling water that has already come into contact with gluten-containing ingredients. Additionally, if the food being prepared requires straining, be sure that only gluten-free items go into one strainer while gluten-containing foods are strained in a separate colander, or be sure gluten-free foods are strained first.
- **CONDIMENTS:** Any condiment that it is used as a dip with a utensil should not be used with both gluten-free and gluten-containing foods. Particles from gluten-containing ingredients easily contaminate jars of peanut butter, cream cheese, butter, etc. that were dipped in it. To be extra cautious, in a mixed gluten household, consider buying separate condiments and labeling one set as gluten-free. Those eating gluten-free foods should only use the gluten-free set of condiments. Otherwise, have a conversation with the family and/or housemates about scooping out a portion of the item onto a plate before spreading it onto the gluten-containing item to ensure only a clean knife has been dipped into the container once. For other condiments like ketchup, mustard, mayonnaise, and relish, consider buying squeeze bottles to prevent cross contamination from dipping into the containers.
- **CUTTING BOARDS:** Thoroughly scrubbing a plastic or glass cutting board before and after each use makes it completely safe to share with gluten-free and gluten-containing items, assuming they're not being used at the same time. However, it often helps to have two sets of cutting boards in the kitchen to be absolutely safe. Consider picking a different color cutting board for the gluten-free set, so families can easily identify which board is safe to use. It also is the safest to use plastic or glass cutting boards whenever possible. Wooden cutting boards can absorb foods like gluten, and in turn, could lead to cross-contamination even after washing.
- **FRYING:** Never fry gluten-free and gluten-containing items in the same oil. Particles from the gluten-containing items will fall into the oil and contaminate the gluten-free foods. Even if the oil looks clean, don't trust it. Always use clean oil for gluten-free foods. This issue is particularly important in restaurants. When ordering fried foods, always ask if the restaurant uses separate oil for gluten-free and gluten-containing items.



- **POTS AND PANS:** Always wash pots and pans thoroughly between each use. As long as they are washed properly, it is safe to cook both gluten-free and gluten-containing items in the same pots and pans. Think of it this way: if pots and pans are washed well enough to prevent food-borne bacteria from spreading, then they also are sufficiently cleaned to prevent gluten contamination.
- **SHELVES AND DRAWERS:** Consider designating space within the kitchen storage areas for gluten-free foods. This will help to visually separate the items that need to be kept free of cross-contamination. If gluten-free and gluten-containing items must be in the same shelves and drawers, always store the gluten-free products above the gluten-containing items. This method will prevent gluten particles from falling into the gluten-free products.
- **TOASTING:** Crumbs quickly accumulate in every toaster. There is no way to prevent it. Bread crumbs and creates a massive problem for cross-contamination. If using a **toaster oven** that is thoroughly cleaned between each use, there is no reason to have separate toasters. Another option for using a toaster oven is to **always** line the racks with foil when toasting gluten-free items. This will prevent cross-contamination and limit the in-between-use cleaning. However, if using a **pop-up toaster** that is unable to be easily cleaned out, it's recommended to have a designated gluten-free toaster.
- **METAL OR PLASTIC UTENSILS:** As with each and every other piece of kitchen equipment, the same metal or plastic utensils cannot be used with gluten-free and gluten-containing items without a thorough cleaning. Either make the decision to always wash the utensils in between use or purchase a second set of designated gluten-free items.
- **WOODEN BOARDS, BOWLS, AND UTENSILS:** Never use wooden kitchen equipment with both gluten-free and gluten-containing foods. Gluten can stick in between the wood grains, and even a thorough washing cannot properly get it out. Either purchase two sets, or avoid wooden equipment all together if living in a shared kitchen space.

