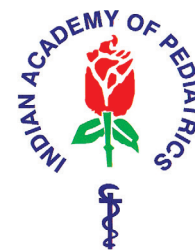


Indian Academy of Pediatrics (IAP)



## GUIDELINES FOR PARENTS

# Caring for a Child with Celiac Disease

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### 10 FAQs on CARING FOR A CHILD WITH CELIAC DISEASE

1. What is celiac disease and why did it affect my child? Could I have done something to avoid it?
2. Apart from diarrhea and poor growth, what other problems could alert a parent to consult a doctor to rule out celiac disease?
3. How will I know for sure that my child has celiac disease? Does my child really need endoscopy and biopsy for diagnosis?
4. What is the treatment of celiac disease (CD)? Does my child continue needing gluten-free diet (GFD) even when he/she is not having symptoms anymore? What will happen if we do not continue to follow GFD?
5. How do we set up a gluten-free kitchen at home and protect the meals from contamination?
6. Is celiac disease different from wheat/other food allergy?
7. How do I explain celiac disease to my child? How can we manage gluten-free diet at school/picnics, canteens, and hostels?
8. Once my child is diagnosed with CD, what monitoring is necessary and for how long?
9. How do we cope with the various social issues such as parental burden and GFD at parties and events?
10. Are there any support groups for parents dealing with celiac disease in children?

**Under the Auspices of the IAP Action Plan 2021–2022**

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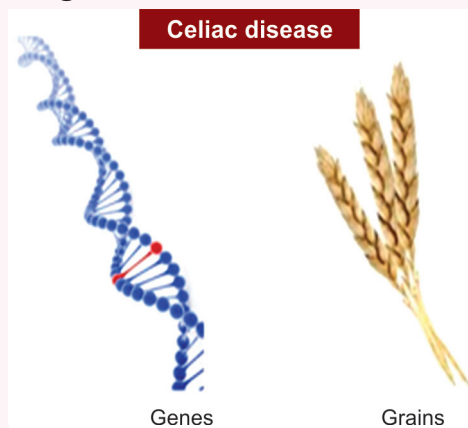
# Caring for a Child with Celiac Disease

## Q1

### What is celiac disease and why did it affect my child? Could I have done something to avoid it?

Celiac disease (CD) is common worldwide and may affect up to 1% of North Indian population. Ingestion of gluten (a protein found in wheat, barley, and rye) causes damage to the lining of the small intestine (gut) by an immune response wherein the body makes antibodies against itself.

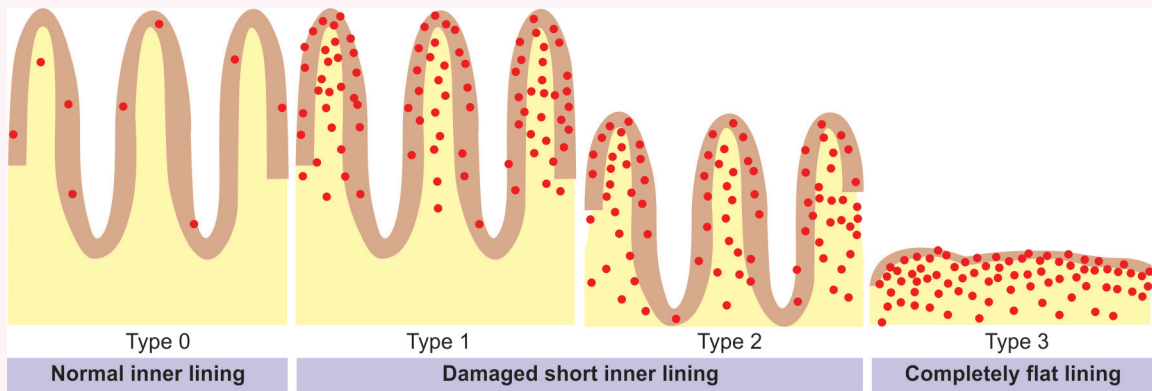
Celiac disease could have affected your child because of a combination of reasons, where symptoms are triggered when wheat (gluten) is consumed in a child with a genetic tendency to develop CD (**Fig. 1**).



**Fig. 1:** Interplay of genes and grains responsible for development of celiac disease.

Celiac disease can develop *at any age after* a child starts eating wheat and other gluten-containing products. A first-degree relative (parent, child, and sibling) of such a patient has a higher (10%) risk of developing CD. *Realistically speaking, you could not have done anything to avoid it.*

In this disease, the inner finger-like lining of the gut is progressively damaged by gluten to an almost flat surface (**Fig. 2**). Hence, nutrient absorption is seriously impaired.



**Fig. 2:** Progressive damage to the inner lining of the gut in celiac disease (CD).

**Q2**

**Apart from diarrhea and poor growth, what other problems could alert a parent to consult a doctor to rule out celiac disease?**

In India typically, a child with celiac disease (CD) comes in a malnourished state with chronic diarrhea, anemia, and poor growth (short stature). The child may complain of stomachache, may have abdominal bloating, oral ulcers, and rickets or occasionally skin lesions. Children are often diagnosed between 1 and 3 years of age. These are easily recognizable features and lead to an early diagnosis of CD (**Table 1**).

However, >50% may not be that easily recognizable and present with atypical symptoms. Diagnosis is often delayed in such cases by several years.

**TABLE 1:** Common typical and atypical symptoms of celiac disease.

Typical symptoms	Atypical symptoms
Diarrhea	Stomachache
Abdominal distention	Constipation
Short stature	Bone pains
Tiredness (anemia)	Delayed puberty

**Q3**

### How will I know for sure that my child has celiac disease? Does my child really need endoscopy and biopsy for diagnosis?

- Once celiac disease (CD) is suspected in a child, a simple screening blood test called anti-tissue transglutaminase immunoglobulin A (TTG-IgA) is performed. It measures the level of gluten antibodies in the body.
- If level of these antibodies is high, CD is suspected but we need to be absolutely sure about diagnosis, which is done by seeing damage to the small intestine by looking at tissue samples under the microscope. Biopsy of small pieces of gut tissue is obtained through endoscopy (Camera test).
- Parents are often unnecessarily apprehensive about endoscopy. This is a simple painless procedure, done under mild sedation and takes <10 minutes. The biopsy report takes about 4–5 days.
- Your child must get an endoscopy and biopsy for diagnosis of CD because gluten avoidance is for entire life! A biopsy report confirms the diagnosis, and hence no doubt is left in the doctor's or the parents' mind. If gluten-free diet (GFD) is started based on blood tests without doing a biopsy, it is noted that the adherence or compliance to GFD is very poor. In the Indian scenario, there are many other conditions where blood test (TTG) may be falsely positive. Therefore, starting GFD without biopsy is not at all justified.
- Endoscopy and biopsy must be done only when the child is taking a normal diet including gluten-containing foods. The biopsy may be falsely negative if the child has already been put on GFD.

**Q4**

**What is the treatment of celiac disease (CD)? Does my child continue needing gluten-free diet (GFD) even when he/she is not having symptoms anymore? What will happen if we do not continue to follow GFD?**

Currently, the only treatment of celiac disease (CD) is a permanent (life-long) avoidance of gluten in the diet.

Gluten is present in wheat (*gehun* in Hindi) and barley (*jaun* in Hindi). Western countries also have a gluten-containing cereal called rye, which is to be avoided. Rye is not readily available in India and is often confused with mustard seeds (*rai* in Hindi) which is mistakenly avoided in CD due to similar sounding names. Oats (*jai* or *jav* in Hindi) is likely to be contaminated with gluten during harvesting, and hence unless purity is assured, it should be avoided.

- Children affected with CD can consume all cereals, pulses, seeds, fruits, dry fruits, spices except asafetida (*heeng*) oils and vegetables.
- All dairy and unprocessed nonvegetarian products are also permitted.

**Table 2** lists common Indian food permitted in children with celiac disease. **Box 1** lists food items *not* allowed in celiac disease.

<b>TABLE 2: Common Indian foods permitted in celiac disease.</b>	
<b>Pulses (Dals) and other cereals</b>	<div style="display: flex;"> <div style="flex: 1; padding-right: 10px;"> <p>Moong, masoor (kali malka and lal malka), chana, lobhiya, kabuli chana (chole), chana dal, rajma, arhar/tuwar, moth, matar, soyabean, bajra, jowar, ragi, corn quinoa, etc. May be used by cooking, soaking, and sprouting or frying.</p> </div> <div style="flex: 1;">  </div> </div>
<b>Rice and rice preparations</b>	<div style="display: flex;"> <div style="flex: 1; padding-right: 10px;"> <p>All varieties of rice (brown, black, par-boiled) are permitted. Vegetarian or non-vegetarian pulav, lemon rice, soyabean pulav, rice papad, vadiyan, murmura, kheel, chivda, and all other home-made rice preparations.</p> </div> <div style="flex: 1;">  </div> </div>

<p><b>Vegetables</b></p>	<p>All vegetables (roots and green leafy vegetables) such as potato, beet root, onion, tomato, beans, methi, palak, bathua, sarson ka saag, karela (bittergourd), peas, cabbage, cauliflower, bell-peppers, green peppers, cucumber, garlic, ginger, gooseberries, jackfruit, sweet potato, mushrooms, etc. Green/dry herbs such as coriander, mint, tulasi, sage, dill, oregano, and galangal.</p>	
<p><b>Non-vegetarian foods</b></p>	<p>Home-cooked meat, chicken, fish, pork, poultry, soups, etc. <i>Maida or bread flour should not be used for thickening or coating.</i></p>	
<p><b>Dry fruits</b></p>	<p>Peanuts, almonds, cashews, walnuts, hazelnuts, pine nuts, currants, dry dates, and coconut. Dry fruits should not have any polish or coating on them. <i>Seeds:</i> Sésame, flax, sunflower, chironji, and pumpkin seeds.</p>	
<p><b>Milk and milk products</b></p>	<p>Milk, cottage cheese, processed cheese, white/yellow butter, malai, cream, khoya, milk powder, lassi, ghee. Sweets made at home with milk such as kheer, peda, barfi, milkcake, etc.</p>	
<p><b>Oils</b></p>	<p>Mustard, coconut, peanut, sésame, sunflower, soyabean. Commonly used refined oils such as Saffola, Fortune, Dhara, Vital, Olive oil, Rice-bran oil, ghee, and hydrogenated oils.</p>	

**All kinds of whole/ground spices**

Dhania, zeera, turmeric, chilli, cloves, ajwain, cardamom, cinnamon, nutmeg, mace, white/black salt, pepper, garam masala, tamarind, gelatin, guar gum, vinegar (nonmalted).



**Desserts**

Homemade desserts are the safest. Desserts such as burfi, rasmalai, rasgulla, and other milk-based mithai made at a shop may contain maida/suji, and hence contain gluten.



**BOX 1: Prepared food absolutely not allowed in celiac disease.**

- **Grains:** Items made of wheat, barley, maida, suji such as roti, poori, samosa, bhature, etc.
- **Breakfast items:** Bread, bread-rolls, oatmeal, all bakery items, cornflakes, upma, seviyan, etc. (Note: Bakery products are always contaminated with wheat.)
- **Snacks:** Patty, burger, kulcha, naan, biscuits, cutlets, cakes, samosa, mathri, pizza, bread crumbs, soup-sticks, etc.
- **Commercially prepared:** Noodles, pasta, and seviyan.
- **Beverages:** Barley water, hot chocolate, Complian, Horlicks, Boost, Bournvita, Protinex, soup cubes, or soup made of a powder mix.
- **Fruits:** Processed fruits and commercial sweets made of fruit extracts, and commercial juices.
- **Sweets/Indian mithai:** All sweets prepared in the market are unsafe. Some ice creams such as plain vanilla and strawberry flavors are safe and sometimes even labeled gluten-free.
- **Non-vegetarian items:** All non-vegetarian food prepared/available in the market may contain wheat or maida. For example, meat kebabs, steak, sausages, etc. Boiled eggs available on the roadside become unsafe when combined with bread kept along with them.



### Q5

#### How do we set up a gluten-free kitchen at home and protect the meals from contamination?

Ideally, a gluten-free kitchen should not have wheat or wheat-containing items such as *maida*, *dalia*, or *suji*. If possible, a separate space or area should be marked out for the gluten-free cooking. All utensils and appliances should be separate including *tawa*, *chakla*, and *belan*. The surface of the kitchen counter has to be scrupulously clean.

*Preventing contamination* with wheat products is of extreme importance.

- Ideally, the oil/ghee is in a separate container so that contamination does not occur.
- The toaster, butter dish (crumbs-stick) should also be separate.
- A separate shelf in the fridge is marked for gluten-free food.
- Cleaning materials such as mops, dusters, and dish-washing scrubs to be kept separate.
- Strict handwashing before preparing food is necessary.
- Prepare the gluten-free meals first and store it away before making the regular food, if a separate kitchen space is not available.
- Buy a personal *chakki* or a flour grinder at home and prepare your own flours. It is safest to use home-made flours and spices also to ensure that they are gluten-free/contamination-free.

### Q6

#### Is celiac disease different from wheat/ other food allergy?

Celiac disease and wheat allergy are thought as being the same disease; however, these two are different entities. Celiac disease is a multisystem and autoimmune disease characterized by damage to intestinal lining due to a *permanent intolerance to gluten*.

Wheat allergy is similar to dust, pollen allergy, and other food allergies. It is an immunologic reaction to proteins in wheat and in a mild form, the symptoms are short lived and managed by taking antiallergic medicines. A rare and severe form occurs in some people within seconds to minutes of eating wheat causing skin rash, difficulty in breathing, and shock.

## Q7

## How do I explain celiac disease to my child? How can we manage gluten-free diet at school/picnics, canteens, and hostels?

### Young Child

Help your child make the connection that gluten makes them feel sick. Parents may need to go gluten-free too sometimes, for a short while. Informing people, for example, in daycare (especially those who may be involved in feeding/caring of children) is important.

### Older Child

Explain that it is only gluten-free diet (GFD) which can make them feel better. Explain that their tummy aches and gets hurt if/when they eat foods such as bread, pasta, cake, etc. because these contain gluten and that there is no medicine that will heal the gut. Give them examples they understand.

### At School

The teacher should be informed and made aware of the child's problem and the need for gluten-free diet (GFD). Plan in advance for special occasions so your child does not feel left out. You can keep some nonperishable GF food with the teacher. A lot of food items in Indian cuisine are invariably gluten free. For residential schools/overnight camps, let the cook know in advance of special GFD requirements and share a written information sheet on GFD with the person in-charge.

### Adolescent:

- Treat adolescents as young adults and encourage them to take responsibility of their health and diet.
- Do supportive, frequent, and sensitive communication.
- Tell them what they *can* have, rather than constantly saying what they should not.
- Provide plentiful home-made snacks to a hosteller.
- Teach them to read labels on packaged food.

Q8

## Once my child is diagnosed with CD, what monitoring is necessary and for how long?

Monitoring by the pediatrician/gastroenterologist/dietician is a crucial and critical component of CD management.

*In the first visit* generally after a week, the comprehension and acceptance of GFD by parents is tested by giving them a structured or verbal questionnaire. The food diary is checked to assess the frequency and the adequacy of the GFD.

*Second counseling* is done a month later, and the following issues are assessed:

- Child's condition and height/weight charting
- Adequacy of GF diet/food diary review
- Need and duration of micronutrients and supplements
- Difficulties faced by the caregiver
- Sibling and parent screening

### Subsequent Visits

The child can now come for a 3-monthly review for a year followed by 6-monthly/yearly reviews later.

### **Points to be emphasized on each visit:**

- Strict compliance to nutritious GFD is a must.
- Small amounts of gluten ingestion are harmful, may or may not produce immediate symptoms; adverse effects take time to appear.
- Repeat blood test (TTG) only if advised by your doctor.
- Gluten-free snack must be carried along when going out.
- In readymade foods, food labels must be read carefully for gluten-free status.
- When in doubt, it is best to avoid that food.
- Do not panic, if there is inadvertent gluten intake. Be more careful next time.
- Make sure to continue taking the supplements/medicines, which have been advised to you alongwith GFD.
- Consult a psychologist to deal with social and psychological stress.
- Contact your doctor, if the child is sick or symptoms reappear, or a sibling starts having similar problems.

## Q9

**How do we cope with the various social issues such as parental burden and GFD at parties and events?**

Diagnosis of celiac disease (CD) does come as a shock to many families, since it has several social implications and several associated doubts further increase its burden.

*Initial feeling "why me?"* gradually fizzles out over time as one realizes that CD is indeed a very common disease and there are many celiac children around doing very well on GFD. The doctor and dietician help the parent to join Support groups/WhatsApp groups consisting of motivated parents of celiac children. These groups provide social support for the newly diagnosed families, share information regarding GFD, flours, recipes, and help them cope with disease stress.

*Parents are educated* regarding the importance of adhering to strict GFD and the special precautions to be taken while attending gatherings or parties. Most parents can cope well at social gatherings.

- *For unavoidable meetings*, wherever possible the host is made aware of the dietary need of the celiac child so that there is a special arrangement of GFD with a distinct label. If this is not possible, parents could carry along some pre-cooked or ready to eat GFD so that the child does not feel left out.
- *For bigger gatherings* as in Indian marriages, the menu is elaborate and generally contains the option of rice and dal, fruits, etc. that can be readily consumed by the celiac child.

**Q10**

**Are there any support groups for parents dealing with celiac disease in children?**

Worldwide, there are numerous support groups to help families and children with CD lead a better quality life.

As food choices happen to be different in different states in India, individual and local support groups have sprung up which are largely run by individuals. These groups are providing help to the inexperienced celiac parents and patients.

Patients are advised to create their chat groups with other like-minded parents of celiac children. They can share their problems, difficulties, and diets, and if needed, call upon a medical expert to address their issues.

Celiac Support Organization is a non-government organization (NGO), which is run largely by professionally qualified doctors and dieticians which has been providing help and support to patients and parents for the past 10 years.

**CELIAC DISEASE FACTS**

- From the Indian perspective, only wheat, barley, and oats need to be avoided in gluten-free diet.
- Gluten-free food can be easily prepared at home without any extra cost.
- Celiac disease is a lifelong condition and not cured when the child's symptoms have improved.
- Consuming occasional gluten will harm your child.
- Food labels should be checked for ingredients and additives, and whether an item has been prepared in a gluten-free environment.
- There are no proven alternative therapies for the cure of CD till date.
- There are several hidden sources of gluten, which inadvertently creep in the diet including food additives, preservatives, and cosmetics too.