

# Celiac Program Roadmap

## For new patients

Our mission is to partner with you and your family to provide the best care and be a resource on the diagnosis and treatment of celiac disease so you can live the fullest, healthiest life you can live.

### Clinic visit schedule and what to expect

Celiac Disease Clinic occurs twice a month on Tuesdays, once in Seattle and once in Bellevue.

Appointment	Who will you meet with?	What to expect?
First	MD/APP and RD group for nutrition teaching	Discuss diagnosis, possible causes and treatment with gluten-free diet
Second - 1 to 2 months after first visit	RD	Revisit gluten-free diet
Third - 6 months after first visit	MD/APP and RD follow-up	General maintenance and check-in
Fourth - every 6 to 12 months after third visit	MD/APP and RD follow-up	General maintenance and check-in

### At each visit we will:

- Ask you questions about your stomach hurting.
- Let you know if blood draws are needed before or at the clinic visits.
- Send a detailed update to your primary care provider after the visit.

### Tests that may be scheduled

We may recommend that you have some tests to learn more about your response to celiac disease:

- Blood test to check for antibodies in response to celiac disease. These may include tissue transglutaminase IgA (TTG-IgA) and deamidated gliadin peptides (DGP, IgG).
- Blood tests to check for anemia, nutritional markers, liver enzymes and thyroid hormones.
- Bone density scan
- Upper endoscopy

1 of 2

### To Learn More

- Gastroenterology  
206-987-2521
- Ask your child's healthcare provider
- [seattlechildrens.org](http://seattlechildrens.org)

### Free Interpreter Services

- In the hospital, ask your nurse.
- From outside the hospital, call the toll-free Family Interpreting Line, 1-866-583-1527. Tell the interpreter the name or extension you need.

### Team members to partner with you

You will meet with these team members when you visit the Celiac Disease Clinic:

- **Medical Provider (MD)** - the doctor who will direct your care.
- **Advance Practice Care Provider (APP)** - includes advanced registered nurse practitioners (ARNPs) and physician assistants (PAs). These providers conduct medical work-up for diagnosis, educate and monitor celiac disease and associated symptoms.
- **Registered Dietitian (RD)** - works with you on a plan for nutrition health, growth and development. Provides guidance on foods to eat and foods to avoid since a gluten-free diet is essential to treating celiac disease.
- **Registered Nurse (RN)** - a licensed nurse who provides and coordinates most of your daily care and education. This is your main point of contact for communicating with the GI team.

You may also meet with these team members during a clinic visit:

- **Psychologist** - a mental health provider skilled in the psychological impact of gastrointestinal diseases. Celiac disease is a chronic illness that will require lifelong care and we hope to prevent added stress to you and your family with lifestyle adjustment with celiac disease.
- **Social Worker** - a skilled counselor who works with families to provide emotional support and get the resources they need. Assists you with barriers to treatment (such as medical costs, transportation and school), and helps with other concerns with lifestyle adjustments with celiac disease.
- **Child Life Specialist** - focuses on your emotional and developmental needs and explains a diagnosis or treatment in words you can understand. Can create a coping plan you can use during a medical test or procedure and offers support during and after medical procedures.

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### Resources

To learn more about celiac disease or to meet and connect with others who have it, visit or join these groups.

- Visit Celiac Disease Foundation at [celiac.org](http://celiac.org)
- Visit Gluten Intolerance Group at [gluten.org](http://gluten.org)
- Visit Eat Live Celiac at [eatliveceliac.org](http://eatliveceliac.org)
- Join Seattle Children's Hospital Celiac Program's quarterly support group. Email [celiac@seattlechildrens.org](mailto:celiac@seattlechildrens.org) to join listserv.
- Join a Facebook online support group like Pacific Northwest Celiac Kids.
- Our team will also share the latest in celiac disease research with you.