

DISCUSSING YOUR TYPE 1 GAUCHER DISEASE

Monitoring type 1 Gaucher disease (GD1) is important as it is a disease that progresses, meaning the symptoms can worsen over time, even if you feel fine and do not notice any changes. Regular check-ups, blood tests, and scans can help your care team track the disease, identify early signs of progression, and manage complications.

Even if you feel well, GD1 can progress quietly over time. Regular check-ups can help detect changes early to help prevent complications.

These prompts can help you talk with your doctor about how GD1 is affecting your daily life. If you recognize yourself in any of the statements below, this may be related to GD1 — talk to your doctor so you can explore what it means and what support may help.

Daily Life and Activities

If GD1 is making it harder to keep up with work, school, household chores, exercise, travel, or social events, tell your doctor. Changes in energy levels, pain, or mobility can be signs that your condition needs a closer look.

Emotional Wellbeing

If you've been feeling anxious, stressed, or down about your condition, let your doctor know. Emotional health is an important part of GD1 management, and support is available.

Treatment and Monitoring

If you're unsure whether your current management plan is still right for you, or if symptoms have changed, bring this up at your next appointment. GD1 can progress quietly, even when you feel well.

Planning Your Next Appointment

If there is anything you would like to discuss in more depth, jot it down and bring it with you. No concern is too small.

Energy Levels

If you've been feeling tired or fatigued, even when sleeping well, this can be linked to GD1. Talk to your doctor about how you've been feeling.

Understanding Your Condition

If at any point you feel you don't have the information or resources you need to understand your GD1 confidently, ask your doctor. They can guide you to reliable resources and help clarify anything that's unclear.

Support

If you feel less supported than you'd like — whether by your healthcare team, family, or community — mention this to your doctor. They may be able to connect you with additional support options.

GD1 can feel easier to manage when you have the right tools. Use this toolkit to track your symptoms and keep up with your appointments.

This resource does not replace regular appointments, and you should continue to attend your check-in appointments as advised by your doctor.

YOUR SYMPTOM TRACKER

Track your key symptoms weekly every month to monitor changes and share updates with your care team. Use a ✓ or ✗ to indicate yes/no for symptoms like bleeding or bruising. Use a number scale (1–10) to mark the severity of any fatigue or pain you experience (1 = none and 10 = worst). Use the blank columns to add other symptoms that are relevant to you. Use the notes section to capture anything that you may want to share with your doctor. Bring this symptom tracker with you to your appointments.

Month:

Week	Bleeding ✓/✗	Bruising ✓/✗	Fatigue (1–10)	Abdominal pain (1–10)	Bone pain (1–10)	Other:	Other:	Notes (triggers, changes, or anything unusual)
1								
2								
3								
4								
5								

YOUR APPOINTMENT TRACKER

Use this tracker to help you stay on top of your routine tests and appointments over the next year. Fill in the dates of your doctor visits to help you stay organized.

Test	3 Months	6 Months	9 Months	1 Year	Notes/Next date due
Blood tests					
Spleen and liver imaging					
Bone					
Bone density scans					
Other:					
Other:					

Monitoring for Gaucher disease is lifelong; use this 12-month tracker each year for your regular Gaucher check-ups.

