RETHINK FABRY™ DOCTOR DIALOGUE GUIDE

Talking about Fabry disease with your care team

Making the most of your doctor appointments

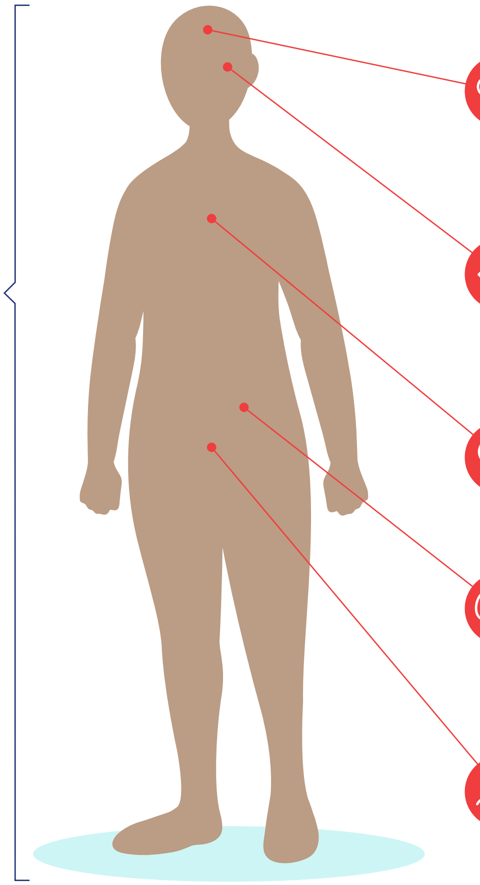
Fabry disease is a complex condition. Appointments with your health care providers (HCPs) may feel overwhelming, and it can be hard to know what questions to ask. Keep in mind that your appointments are your time to make sure that you understand what's going on with your condition and your care.

The **National Fabry Disease Foundation** recommends you follow a multidisciplinary approach to your care. This means you should have a group of different HCPs helping you with your care.

CORE CARE TEAM

Your **primary care physician** may be the first of your HCPs to notice the signs of Fabry disease, and the person you speak to first about changes in your body that you are noticing.

A **genetic counselor** is vital to everyone with Fabry disease because a genetic counselor will understand the genetic impact this disease has on the patient and their extended family.



EXTENDED CARE TEAM

Neurologist
Stroke is a common manifestation of Fabry disease and may appear even in young patients; for some it could be the first disease event related to Fabry.

Ophthalmologist
Eye problems such as *corneal opacities* happen in up to 95% of males and 88% of females who have the gene that causes Fabry.

Cardiologist
Fabry can cause heart-related disease—the most common cause of death in people with Fabry.

Nephrologist
People with Fabry are at high risk for kidney problems that can cause *end-stage renal disease* in their 30s to 50s, and as early as their teen years.

Gastroenterologist
A majority of patients with Fabry may experience pain and digestive or *gastrointestinal* problems.

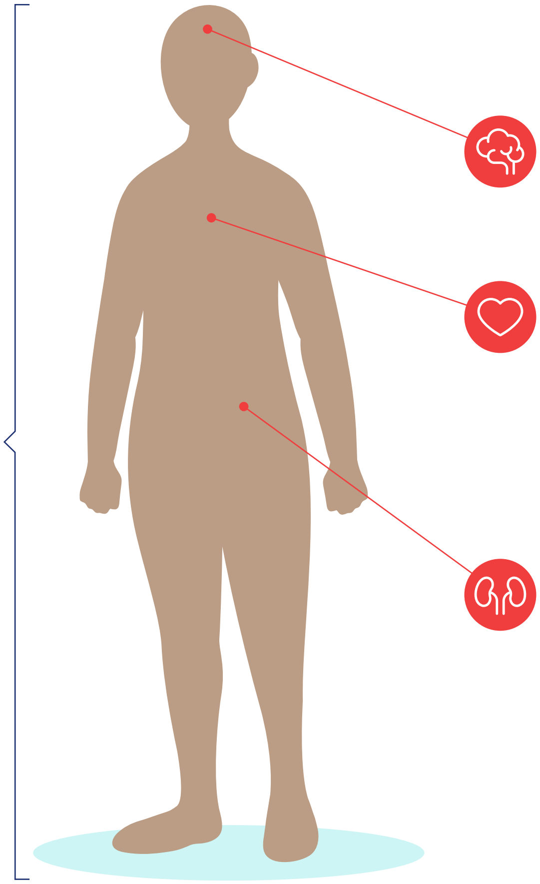
You may not need all of these specialists today. But Fabry is a **progressive disease**, meaning that it gets worse over time. Because of this, it's very important to understand your disease—and take proactive steps to fight it. The right care team can help answer your questions.

It may help to choose one care team member to be your point person—someone who can help coordinate your care, and who is the first person you go to with any general question you have. You can choose someone in the specialty of your most severe symptoms, or just the HCP you feel most comfortable speaking with.

Keep reading to find out how to ask your care team members what you need to know →

Having productive conversations with your care team

Use these questions to help get your conversations started and help you to ask well-informed questions at your next visit. This will help you stay on top of your symptoms and treatments.



Consider these questions for your core care team:

Primary care physician

- How will Fabry disease treatment impact my other medications?
- Will my Fabry disease affect my other conditions?

Genetic counselor

- Who in my family should I suggest get tested for Fabry disease?
- Are there any support groups you can recommend for me?
- How should I manage symptoms like fatigue, brain fog, etc?
- Which of my Fabry symptoms should I pay closest attention to? Is there anything I can do to help delay the progression of this symptom?
- Are there any other specialists you would recommend for me to add to my extended care team?

Consider these questions for your extended care team:

Neurologist

- How will I know, and what should I do, if my condition is getting worse?
- What should I do if I'm experiencing pain?

Cardiologist

- Is there anything I can do to better protect my heart?
- What type of monitoring do I need to check on my heart? And how often?
- What signs and symptoms should I keep an eye out for and be most concerned about?

Nephrologist

- How will Fabry disease impact my kidneys?
- What type of monitoring do I need to check on my kidneys?

Consider these general questions for any of your care team members:

- What symptoms should I be keeping an eye out for?
- What should I do if I notice a new symptom?
- How will I know if any new symptoms are related to Fabry disease?
- How can I stay on top of new updates about Fabry disease management?
- Are there daily care activities I can do to help deal with the progression of my disease?
- Are there things that can help my overall health as a Fabry patient, such as diet, exercise, or vitamins?

In addition to talking to your care team, you can also visit rethinkfabry.com for more information about Fabry disease—and the soaring new possibilities on the horizon.

References available upon request.

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Global Rare Diseases