

Communicating with Healthcare Providers

How to Become an Active Member of Your Healthcare Team

You are the best advocate for your health. **Communicating clearly** with healthcare providers will help to ensure that you or your loved one receive the **proper and necessary care**. While it may not always be easy to talk to healthcare professionals, a partnership based on mutual trust and respect can smooth the rare disease journey.

Below are a few tips and reminders:

Dos

1. Do your homework.

Learn as much as possible from reliable medical and scientific sources and stay up-to-date on the latest research so you can be an advocate during your appointments. Advocacy groups are a great resource, too.

2. Do ask questions.

Take the time to write down questions you may have about your symptoms or treatment before your visit. If you can, write down the answers to these questions during your visit, or bring a loved one with you to take notes. Ask about next steps and how your doctor prefers to stay in touch.

3. Do stay organized.

Keep copies of all documents. Create a **folder or binder** of the most important documents and keep it up-to-date. This is especially important if you are seeing multiple specialists and taking many medications.

4. Do be mindful of your words.

If you don't understand something, use statements like, "I don't understand," or "I would like to discuss this further..."

5. Do be specific.

When providing details about symptoms, be specific. Use numbers to explain things like pain level, temperature, how many times it happens, etc. It will help paint a more complete picture for the doctor.

6. Do share your medical history.

Supply your healthcare providers with a list of your doctors and their contact information, medications, symptoms, and family history, as well as a short summary of your disease and journey. See our template on page 2.

Don'ts

1. Don't be afraid to repeat yourself.

If there is something you want to make sure your healthcare providers know, repeat it. If you want to make sure you understand, it's ok to ask them to repeat what they said, or re-state it and ask them for confirmation.

2. Don't exaggerate or minimize.

Don't downplay symptoms, but also don't make them seem worse than they are. Share facts when describing your medical history and be realistic about your experiences.

3. Don't forget to let your loved one speak for himself or herself, when they can.

If you are a caregiver, it's important that your loved one learns about their condition and how to advocate for themselves. This can help ease child to adult transitions down the road.

4. Don't rule out a second opinion.

Not all doctors will provide you with the same medical advice. Seek opinions and gather medical advice to find the best treatment options.

5. Don't be afraid to change healthcare providers.

You should feel comfortable and confident in how a healthcare provider is handling your care or the care of your loved one. Building the right healthcare team may take time, so keep looking until you find the right fit for your family.

6. Don't be the middleman.

Ask healthcare providers to speak to each other so they are on the same page and can work together to provide you or your loved one the best medical plan.

For more information, check out the "Keys to Effectively Communicate with Healthcare Providers" **webinar** from Global Genes.

Medical History

Disease & Journey Overview

Healthcare Provider Contact Information

Name	Phone	Email

Symptoms

Symptom	Description	Frequency

Allergies

Current and Past Medications

Medication/Treatment	Dosage	Frequency

Surgeries/Procedures

Date	Surgery or Procedure	Hospital or Clinic Name

Family History

Family Member	Disease/Condition	Medication/Treatment