

IT'S IMPORTANT TO KNOW YOU'RE NOT ALONE: YOU CAN GET AN ENTIRE CARE TEAM TO SUPPORT YOU

Your Friedreich's ataxia (FA) care team

Because FA is a complex disease, it requires a team approach with you at the center of care. Your FA care team includes a group of professionals working together to give you the care you need. Each of these individuals focuses on specific aspects of your FA—from heart health to mobility.

You may not have seen all of these professionals, and may never need to. However, they are here for you should you need them. Let's take a closer look at the health care professionals who may play very important roles in your care.

Health care professionals who may be part of your FA care team:

Orthopedist

An orthopedist treats the bones, joints, and soft tissue and treats orthopedic issues, such as scoliosis. An orthopedist can tell you what is the best course of action for you.



Primary Care Physician

A primary care physician is the doctor you see on a regular basis. He or she can learn about FA with you and stay consistent in your care over the years. Your primary care physician can screen you for FA complications, including heart issues, diabetes, and scoliosis. He or she will refer you to the right specialists to help you deal with problems associated with FA. A good GP is willing to learn about FA and stick with the patient over the years.



Endocrinologist

An endocrinologist helps manage any issues you have with your endocrine system, which is made up of glands that make hormones. FA can impact the pancreas, which is part of the endocrine system, causing impaired blood sugar tolerance or diabetes. Your endocrinologist will help guide you about the importance of lifestyle changes and prescribe treatment to control blood sugar levels, if you need it.



Cardiologist

Because people with FA commonly have heart problems, a cardiologist is also a key member of your care team. He or she knows all about the heart and how it works. Your cardiologist will help you manage any heart issues you may have.



Neurologist

Neurologists help people who have problems with their nervous system. Because FA is a disease of the nervous system, your neurologist plays a key role in your care. Your neurologist will look at your muscle weakness, balance, and fatigue and give you routine exams. He or she will also send you to any specialists you may need. A neurologist specializing in the treatment of FA patients can be known as an FA specialist, an ataxia specialist, a neuromuscular specialist, a cerebellar ataxia specialist, or a neurogeneticist.



Keep reading to learn about other possible members of your care team 

Members of your care team may also include:



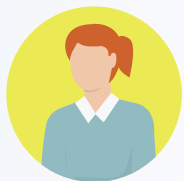
Geneticist/Genetic Counselor

These specialists can review your FA genetic test report, discuss inheritance of FA, and assist with decision-making about performing genetic testing for other family members. It is important to consider the risks and benefits of testing your family members, especially siblings.



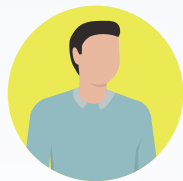
Occupational therapist

An occupational therapist can help you be independent for as long as possible. He or she can recommend mobility aids and give you ways to deal with fatigue and other symptoms of FA.



Social worker

A social worker can provide you with many benefits. He or she can help connect you to certain resources and services you may need, such as applying for disability and finding support groups.



Physical therapist

A physical therapist can help address balance, flexibility, accuracy of limb movements, and help you maintain strength. He or she can evaluate how you're doing and recommend exercises that may help you have a better quality of life while lessening pain and disability.



Speech therapist

Because FA can impact speech and swallowing, a speech therapist can evaluate how well you're communicating and swallowing and recommend certain changes that may make speaking and eating easier.



Ophthalmologist/Audiologist

These are doctors who help with how FA affects your eyes and your ears. An ophthalmologist can help with any eye issues and prescribe medication if you need it. An audiologist can help with your hearing, through listening tactics or even fitting you with helpful listening devices.

FA is a rare disease. As you learn all you can, don't be surprised to find out that you may know more about the disease than your doctor. Finding a doctor who is willing to learn more about FA is important. *If you aren't sure how to talk to any of your care team members, please refer to the Care Circle Discussion Guide for help.*

Be sure to reach out to others who know your journey

Whatever you face with FA, know that you're not alone. Other people living with FA know what you are going through, and they can be your greatest resource. Also, be sure to take advantage of gatherings and activities in your area, such as rideATAXIA fundraisers and FA symposiums.

Visit the Friedreich's Ataxia Research Alliance (FARA) website, CureFA.org/support, for a chance to connect with other patients, see what kind of activities there are in your area, and learn more about FA.