

# LET'S TALK FA

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**A guide to communicating  
with others about  
Friedreich's ataxia (FA)**

Part of living with FA is knowing how to talk about the disease with people you may interact with every day. The information in this brochure was created based on insights and experiences from real FA patients. You'll find the following information that can help:



Talking with your doctor about FA



A glossary of commonly used FA terms



Talking with people in your life about FA

For more information, watch videos featuring FA patients that focus on managing FA at different times after diagnosis, the importance of emotional support during the FA journey, and the relationships FA patients have with their doctors.

Visit [ConnectFA.com](https://connectfa.com) to watch these videos.

The information in this brochure is not intended to be medical guidance. Always talk to your doctor if you have any questions about your health.

## BE YOUR OWN ADVOCATE

Being a strong advocate for your own health and wellness is important. That means knowing all you can about FA and making sure you speak up about how you're feeling or any questions you may have about the condition.

Here are some tips for how you can be a strong advocate for yourself:



**Learn all you can about FA.** Being informed can help you and your doctor be on the same page about your health.



**Connect with others who have been diagnosed with FA.** You are not alone in your FA journey. By sharing experiences with others who have FA, you can help each other learn more.



**Speak up about how you're feeling with family and friends.** Your family and friends care about you and how you're feeling. Be open and honest with them if you are having a rough day.



**Ask questions of your doctor and entire care team.** There is a lot to discuss at doctor's appointments. Be sure to come prepared to your appointments with questions if you don't understand something. The Doctor Discussion Guide on the next page can help.



**Encourage your doctors to communicate and work together.** As you learned in the Care Circle Flashcard, there are a lot of different doctors involved in your care. It is important that they work with each other and share information so that you can receive the best care possible.

Keep reading to learn how to talk to your doctor about FA.

# HAVING HONEST CONVERSATIONS ABOUT FA

Remember, FA is a rare disease. Finding a doctor who is willing to seek out another healthcare professional for advice or learn more about FA is important.

## 1. Knowing which doctors to see

Neurologists or general practitioners are usually the primary care providers for FA. They can also help coordinate visits with an FA specialist at a Collaborative Clinical Research Network (CCRN) site (<http://CureFA.org/care>). The CCRN is an international network of centers that work together to advance care for people with FA.

## 2. Managing symptoms

Currently, there is no cure for FA. But there are ways to manage some of the symptoms of FA. It's important to be proactive about discussing bothersome symptoms during doctor's appointments because symptoms can only be managed if doctors are aware of them.

## 3. Planning for the future with FA

Whether it's going to college, getting a new job, or starting a relationship, it's important to be open about these goals. Discuss them with others, such as doctors, other people with FA, and members of the FA community. Share their recommendations with the care team, who will likely offer you guidance on how to achieve those goals and prepare for a future with FA.

## 4. Monitoring symptoms

The care team can provide guidance on which symptoms need to be monitored and when evaluations should take place.

## 5. Transitioning to a walking device or wheelchair

The care team can help assess if a walking device is necessary or if it's time to transition from a walking device to a wheelchair.

## 6. Finding FA support groups and local resources

A great place to find support is through the Friedreich's Ataxia Research Alliance, or FARA. FARA is an organization dedicated to providing resources and finding a cure for FA. Local support groups and/or resources include:

- FARA Ambassadors—a community of patients with FA who share their experience with other patients
- FA Parents' Group—for parents of patients with FA
- FA Facebook Group—only for patients with FA (no caregivers)

**It is important to maintain an honest conversation with all members of the care team. They are the primary resource in managing FA.**

## WHAT EXACTLY DOES *THAT* MEAN?

Your care team may use medical terms that may not always be familiar. Here is a glossary of commonly used words you may hear from your FA care team:

<b>Ambulatory:</b>	able to walk
<b>Areflexia:</b>	lack of reflexes
<b>Ataxia:</b>	loss of coordination
<b>Cardiomyopathy:</b>	a condition in which the heart becomes weak and enlarged, making it hard for the heart to pump blood through the body
<b>Cerebellum:</b>	part of the brain that controls balance, coordination, and movement. It's in the back of the brain and near the spinal cord
<b>Dysarthria:</b>	having a hard time speaking, slurred speech
<b>Dysphagia:</b>	having a hard time swallowing
<b>Frataxin:</b>	reduced levels of this important protein found in human cells is the cause of FA



<b>HbA1c:</b>	measurement in diabetes of glycated hemoglobin over a 3-month period
<b>Neuropathy:</b>	a medical term for disease of the nervous system
<b>Nystagmus:</b>	a condition in which the eyes make involuntary, rapid, and repetitive movements
<b>Pes cavus:</b>	a foot with an abnormally high arch
<b>Proprioception:</b>	being able to sense the way your body is positioned in your environment
<b>Scoliosis:</b>	abnormal curve in the spine
<b>Spasticity:</b>	spasms in the muscles



## TALKING WITH YOUR FRIENDS ABOUT FA

Living with FA is your own personal journey. Whether you choose to tell your friends about your condition or keep it to yourself is entirely up to you. Your close friends care about you and can play a significant role in your support system.

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### HERE ARE SOME TIPS FOR HOW TO TALK TO YOUR FRIENDS ABOUT FA:

- Tell them the reason you're talking with them about FA is because you care about them and want them to know what's going on with you
- Explain what FA is and how it makes you feel
- Encourage them to ask you questions about FA so that they understand the disease and how they can support you
- Tell them that their support means a lot to you

**Your friends may have questions about FA.  
Use the information on the next page to help  
them learn more about FA.**

# HELPING YOUR FRIENDS UNDERSTAND FA

## What is FA?

FA, or Friedreich's ataxia, is a rare disease that mainly affects the nervous system and heart. FA damages the nerves in the brain and spinal cord, impacting the communication between the brain and the body.

## How common is FA?

FA is a rare condition that occurs in about 1 in every 50,000 people in the United States. It is estimated that FA affects about 15,000 people worldwide.

## What are the symptoms of FA?

The damage to the nerves and spinal cord causes a loss of muscle control, causing awkward and unsteady movement. Having a hard time walking and general clumsiness are usually the first symptoms to appear.

## How do people with FA manage their disease?

Right now, there is no cure for FA. People living with FA can manage the disease by eating well and trying to live a healthy lifestyle, including exercising and staying socially engaged.

## How can you help a person who has FA?

People with FA might need some support if they're having a hard time. Even though you can't completely understand what they're going through, it can help to have someone who listens and is there as a friend. It's always nice to send a text or call to chat.



## HELPING YOUR TEACHER OR BOSS UNDERSTAND FA

Just because you have FA doesn't mean you should be treated differently from everyone else at your school and/or job. But there may be times you're not feeling so great. By knowing a bit about FA, your teacher or boss may be more understanding about your condition and may be able to give you the help you need to be the best student or employee you can be.

### HERE ARE SOME TIPS FOR HOW TO TALK TO YOUR TEACHER OR BOSS ABOUT FA

- Tell them the reason you're talking with them about FA is so they can understand what you are going through
- Give a brief and simple explanation about what FA is and how it can make you feel
- Tell them you will be open and honest with them if you're having a bad day so together you can figure out what is needed
- Ask them if they have any questions about the disease

**Giving your teacher or boss some basic information about FA can help them understand the disease. Use the information on the next page to help them learn more about FA.**

# HERE ARE SOME WAYS TO HELP YOUR TEACHER OR BOSS UNDERSTAND FA

I have Friedreich's ataxia, or FA. It is a rare condition that occurs in about 1 in every 50,000 people in the United States. FA mainly affects the nervous system and heart. It damages the nerves in the brain and spinal cord, impacting the communication between the brain and the body. This causes me to have a hard time walking and general fatigue.

1. Currently, there is no cure for FA. I have a care team of specialists to help me manage my symptoms.
2. Sometimes I have difficulty walking or appear clumsy and lose my balance.
3. FA can cause me to have slow or slurred speech.
4. There may be times when I need some flexibility, or accommodations may be necessary.
5. If you want to learn more about FA, be sure to visit the Friedreich's Ataxia Research Alliance (FARA) website at [CureFA.org](http://CureFA.org).





## LETTING THE EMERGENCY DEPARTMENT KNOW YOU HAVE FA

With FA, there may be times when you have to go to the emergency department for care. Having a friend or loved one with you to talk to physicians about your condition may be helpful. Because FA is so rare, many of these physicians may not understand what FA is and how it impacts your body. This can lead to misunderstandings and can delay getting the appropriate care.

### TIPS FOR WAYS TO ALERT THE EMERGENCY DEPARTMENT THAT YOU HAVE FA:

- Make sure to have your regular doctor's contact information readily available, in case the emergency department staff needs to reach out to him/her
- If possible, bring a friend or loved one with you to the emergency department. Even if you can talk for yourself, it helps to have someone there with you to help explain FA and the symptoms you are experiencing. Having someone there with you makes sure the staff knows what is going on
- Medical test results that are "normal" for a person with FA might appear "abnormal" to an emergency department doctor. Prepare a medical information packet that you can bring with you to help the doctor understand your normal baseline (for example, troponin levels, diabetes, and arrhythmias). For more information, visit <http://www.faparents.org/fapg/Medical/emergencies.cfm>

**Some doctors won't know as much as you do about FA. Use the information on the next page to help the emergency department understand FA.**

# INFORMATION TO SHARE WITH THE EMERGENCY DEPARTMENT

## What is FA?

Friedreich's ataxia, or FA, is a rare condition that occurs in about 1 in every 50,000 people in the United States. FA mainly affects the nervous system and heart. It damages the nerves in the brain and spinal cord, impacting the communication between the brain and the body. This causes people with FA to have a hard time walking and slowed or slurred speech.

## What are the symptoms of FA?

The damage to the nerves and spinal cord causes a loss of muscle control, causing awkward and unsteady movement. Common symptoms include:

- Problems with speech and swallowing
  - This is important for the nurses to know if you will be served food while you are there
- Trouble walking and frequent tripping
- Heart issues, including cardiomyopathy and arrhythmia
- Diabetes
- Hearing and vision problems
- Muscle spasms
- Reflex and sensory loss

**Let the emergency department doctors and nurses know of any medications and supplements you are taking.**



## LETTING PEOPLE IN LAW ENFORCEMENT KNOW YOU HAVE FA

An important part of living with FA is being prepared. There may be times when you interact with a police officer or another member of law enforcement who doesn't know that you have FA. He or she may not understand that you have a disease that impacts the way you walk and may cause slurred speech. Below are some tools to support your communications with law enforcement.

### TIPS FOR WAYS TO ALERT LAW ENFORCEMENT THAT YOU HAVE FA:

- Explain what FA is, and how it affects the way you walk and causes slurred speech
- Carry a letter from your doctor in your car's glove compartment explaining what FA is, and a phone number to contact your doctor, if necessary
- Contact your local Department of Motor Vehicles (DMV). Some states can enter a medical condition into the computer information for a state-issued ID card (driver's license). Police officers will be notified of this information when they check your documents

**The information on the next page can help law enforcement understand that you have FA.**

I have Friedreich's ataxia, or FA. It is a rare condition that mainly affects the nervous system and heart. It damages the nerves in the brain and spinal cord, impacting the communication between the brain and the body.

As a result of my condition, I may show the following symptoms:

- Trouble walking and frequent tripping
- Slurred speech
- Problems with swallowing
- Hearing and vision problems
- Muscle spasms
- Reflex and sensory loss

You can contact the following person to confirm my diagnosis and provide information you may need about my condition.

Name: \_\_\_\_\_

Relationship to me: \_\_\_\_\_

Phone number: \_\_\_\_\_

# LET'S TALK ABOUT FA

The information in this brochure was created based on insights and experiences from real FA patients. See inside for:

- Ways you can be your own advocate for your health
- How to talk with your doctor about FA
- A glossary of terms you may hear from your FA care team
- Advice for talking with people about FA

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