

MANAGING YOUR FRIEDREICH'S ATAXIA (FA)

Take control and stay engaged by knowing
as much as you can about FA.



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Learn as much as you can about FA

After being diagnosed with FA, you probably have a lot of questions. You may even feel overwhelmed with all you'll need to learn about FA. This brochure was created based on insights from real FA patients and can help give you some information about managing FA.

You won't learn everything about FA overnight. But this is a good place to start as you'll learn more as time goes on. The more information you have, the better able you'll be to manage FA and be an active member of your care team. There are also informative videos featuring FA patients that focus on topics such as 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** to watch these videos.

The information in this brochure is not intended to be medical guidance. Always talk to your doctor or nutritionist about any changes to your diet or exercise regimen.

CHECK OUT THESE INVALUABLE WEBSITES FOR FA SUPPORT AND INFORMATION



Friedreich's Ataxia Research Alliance (FARA)

FARA is on a mission, and they have people like you in mind when they set goals they want to achieve. FARA is an organization dedicated to the pursuit of research to find treatments and a cure for FA. They are committed to raising money for research, promoting public awareness about FA, and working with a host of professionals in order to further their mission to find treatments and a cure.

At CureFA.org, you'll find information and resources to help you learn as much as you can about FA. You'll also find ways to get involved in fund-raising events. Most important, here is where you'll find others just like you—people living with FA.

You can find support groups in your area or read articles by people with FA. At CureFA.org you'll find the **Consensus Clinical Management Guidelines for Friedreich's Ataxia**, which is designed to extensively cover nearly all symptoms and issues relevant to FA. Within this brochure we'll highlight certain information that can be found in these guidelines.

To find FA education, support, and the guidelines, visit the FARA website at [CureFA.org](https://www.curefa.org).



National Ataxia Foundation (NAF)

The NAF is dedicated to improving the lives of people living with ataxia through support, education, and research.

At ataxia.org you'll find many free publications to help you stay informed on FA management topics, such as the importance of exercise and the reasons for following dietary guidelines specifically for ataxia. Within this brochure we'll focus on some of these topics highlighted at ataxia.org.

To learn more, visit ataxia.org.

To find an ataxia clinic near you, visit ataxia.org/neurologists-and-specialty-clinics.



Muscular Dystrophy Association (MDA)

An organization committed to improving the lives of people with neuromuscular diseases through innovations in science and care.

To learn more, visit mda.org.

HEAR FIRSTHAND FROM OTHERS LIVING WITH FA

The Living with FA video series features how people living with FA have managed their disease, how they've discovered the value of emotional support, and how they've built a lasting relationship with their doctors.

See the videos at ConnectFA.com.



Managing FA

Hear how other individuals with FA are managing life with their disease



Emotional support

Hear firsthand how others found value in having the right emotional support for their journey with FA



The doctor-patient relationship

Listen to individuals with FA talk about their experiences with their care team and the importance of the relationship with their doctor

PUTTING TOGETHER A STRONG CARE TEAM IS KEY

Because FA is such a rare disease, it may be hard to find people who understand what you are going through. At times you may feel isolated and lonely, so it's important that you know you're not alone.



Your doctors and other professionals

Since FA is a complex disease, it requires a team approach, involving various professionals working together to deliver the care you'll need. Each member of your care team focuses on a different symptom of your FA.

For a list of healthcare professionals that can play an important role in your care, see the [Care Circle Flashcard](#) for information about each member of your care team.



Your family and friends

Although your disease may make you feel different from others, it's important not to isolate yourself. Surrounding yourself with a support system, including family and friends, will be critical throughout your FA journey. Your support system can help you both emotionally and in your everyday life. If you're not sure how to talk to your friends and family about FA, see the [Let's Talk FA Brochure](#) and [Information Cards](#).



And other FA warriors just like you!

Where better to find support than from people who know exactly what you're going through! Even though FA is rare, there are ways to connect with people just like you. By connecting with FA warriors like you, you can share your experiences, learn from one another, and just be there as a friend.

For a list of support groups, visit the FARA website at CureFA.org/support.

Additional support groups can be found on Facebook and at FAparents.org/fapg.

EXERCISE CAN HELP KEEP YOUR BODY MOVING

Being active is important for people of all ages to be as healthy as possible. Exercise can help you feel better, sleep better, and even improve strength and reduce fatigue. The amount and relative difficulty of any exercise you do depend on your level of physical ability. Be sure to talk with your doctor and/or physical therapist about which exercises work best for you.

Because FA impacts coordination and balance, exercises focused on improving your ability in these areas can be helpful. Below are examples of exercises that are specific to these goals. You may also want to consider core-strengthening exercises, which will help with your balance.

Exercise 1: Kneeling position

Move your body into a kneeling position. Then move 1 leg forward without touching the ground with your toes. Move your body back into kneeling position.

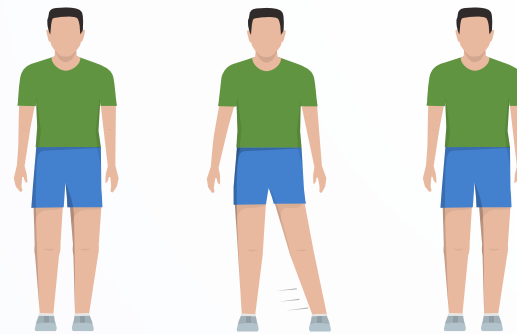
Repeat this exercise 5 times with each leg.



Exercise 2: Side-steps

Stand upright with your feet hip-width apart. Then take a big step to the side. Go back to the original position.

Repeat this exercise 20 times with each leg.



Exercise 3: Step forward

Stand upright with your feet hip-width apart. Then take a big step forward. Go back to the original position.

Repeat this exercise 20 times with each leg.



Exercise 4: Step backward

Stand upright with your feet hip-width apart. Then take a big step backward. Go back to the original position.

Repeat this exercise 20 times with each leg.



Exercise 5: Cross-step

Stand upright with your feet hip-width apart. Then cross your legs in front of you. Go back to the original position.

Repeat this exercise 20 times with each leg.



Did you know? Some individuals with FA have been able to cycle, swim, do yoga, and do low-impact weight training; many consider these lifelong activities outside of their daily exercise regimen.

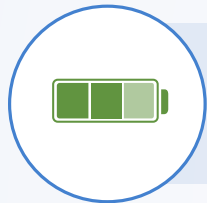
Everyone's physical ability is different. If you want more difficult exercises, talk to your doctor and/or physical therapist about which exercises are best for you.

For additional information, see the NAF Coordinative Physiotherapy for Patients with Ataxia Fact Sheet at ataxia.org.

IT'S IMPORTANT TO PAY ATTENTION TO WHICH FOODS YOU EAT

It's important for people living with FA to maintain a healthy, balanced diet. Making the right food choices can help you better manage FA. Healthy eating can help you maintain a good body weight so that your body can move better. Eating right can also help ease the stress on your joints.

Healthy eating can also:



Increase your energy so that you feel less tired



Help with bowel movements (by eating foods high in fiber)



Improve your overall mood

Always talk to your doctor or nutritionist about any changes to your diet or exercise regimen. To maintain a healthy weight, try to consume around the same number of calories that you burn off during the day through exercise and daily activities. For some ideas on how to stay active, check out the recommended exercises on pages 10 and 11 of this brochure.

A diet low in simple carbohydrates and high in fiber may help

Here are ways to have a healthier, balanced diet:



Eat protein, fats, and complex carbohydrates, such as unsweetened fruits, starchy vegetables, legumes, rice, and pasta



Be sure to drink plenty of liquids. Try to drink 6 to 8 big glasses per day, avoiding sugar and diet drinks, as well as fruit drinks loaded with sugar or artificial sweeteners



Talk to your doctor about adding more fiber to your diet. Adults should eat about 30-40 grams per day. If you're not getting enough fiber, your doctor may recommend adding a fiber supplement



Avoid simple carbohydrates. Limit your amount of cookies, cupcakes, candies, pastries, white flour, and fruit juice



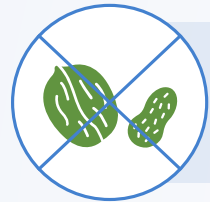
Avoid processed meats with additives and preservatives

For additional information, see the NAF Diet for Ataxia FAQ at ataxia.org.

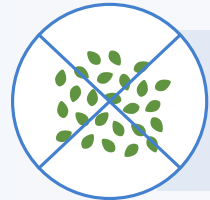
IT'S ALSO IMPORTANT TO PAY ATTENTION TO THE *TEXTURE* OF FOODS YOU EAT

If you have difficulty swallowing, watch what kinds of food you eat

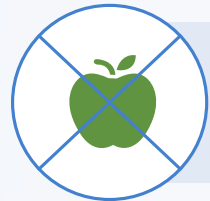
Remember that it's not just about which foods you eat. It's also about the texture of those foods. Because having a hard time swallowing is a common symptom of FA, it's important to be aware of foods that can cause coughing and/or choking:



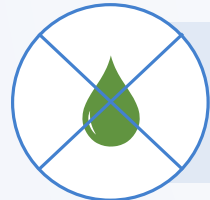
Dry crumbly foods such as biscuits and nuts



Small, easily inhaled foods such as sesame seeds



Foods that are hard to chew/break down such as steak and apples



Thin liquids are not as easy to swallow; consider drinking thicker liquids or adding a thickening agent

**Diet plays a critical role in managing your FA.
Try to make smart, healthy choices as often as possible.**

Be sure to work with your primary care physician and/or a speech therapist about which foods could be a problem for you.

For additional information, see the [Consensus Clinical Management Guidelines for Friedreich's Ataxia](#) at [CureFA.org](#).

VITAMINS TO TAKE—AS RECOMMENDED BY THE NAF

Even if you're eating all the right foods, sometimes you may need to take vitamins and minerals to help your body get the nutrients it needs. Taking a multivitamin can help with fatigue and your general health.

If you're not getting the recommended amount of these nutrients from the food you eat, your doctor may have you take a specific vitamin or mineral supplement. Talk to your doctor about which vitamins and/or minerals you may need. He or she may have you talk to a nutritionist or a dietitian.

Here is a list of some of the nutrients the body needs on a daily basis:

Vitamins & minerals	Major function	Foods found in	Recommended dosage*
Vitamin B₁₂	Helps with red blood cells and function of nervous system	Fish, oysters, milk	100-400 mcg/day
Vitamin C	Essential for health of bones, teeth, gums, and blood vessels Helps resist infection	Citrus fruits, berries, green vegetables, sweet peppers, new potatoes, melon, tomatoes	500-1000 mg/day
Vitamin D₃	Needed for the best calcium absorption	Fatty fish, eggs, liver, butter, fortified milk, exposure to sunlight	2000 IU/day (50 mcg)
Vitamin E	Antioxidant; protects cell membranes	Salad oils, liver, fortified whole grain cereals, milk, eggs, butter, leafy vegetables	200 IU/day (total source should not exceed 400 IU/day)
Coenzyme Q10	Antioxidant; contributes to cell growth and maintenance	Meat, fish, and whole grains	100-200 mg/day
Calcium	Plays an important role in nerve and muscles; also essential component of bone and teeth health	Milk, yogurt, sardines, salmon with bones, hard cheese, cottage cheese, turnips, collard greens, kale, mustard greens, broccoli, oysters, shrimp	1200 mg/day
Magnesium	May be helpful in muscle cramps	Whole grain cereals, nuts, legumes, meats, milk, leafy vegetables	100 mg/day

*Daily recommended doses depend on a person's age and gender. Talk to your doctor, nutritionist, or dietitian about which dosage is right for you.

For additional information, see the [NAF Diet for Ataxia FAQ](#) at [ataxia.org](#).

MANAGING FA: WHAT YOU NEED TO KNOW

This brochure provides information on managing FA from real FA patients, including resources from FARA and NAF

See inside for:



Helpful websites



Finding support in your care team, friends and family, and others with FA



Diet and exercise information



Vitamins and minerals you may want to take

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