

Friedreich's ataxia

Navigating Friedreich's ataxia in the US: a practical guide to support and financial planning

Essential resources and strategies for managing life with Friedreich's ataxia

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Introduction

Friedreich's Ataxia (FA) is a rare, inherited disease that causes progressive damage to the nervous system, affecting coordination, movement, and balance.

While a diagnosis of FA can feel overwhelming, this guide aims to provide you with practical information and resources to help you navigate the challenges and plan for the future with confidence and hope. We will explore the progression of FA, the importance of building a care team, available support organizations and resources, financial planning strategies, and your legal rights.

Understanding Friedreich's ataxia

FA is caused by a defect in the FXN gene, which leads to a deficiency of a protein called frataxin [1]. Frataxin plays a crucial role in the function of mitochondria, the energy-producing centers of cells. This deficiency primarily affects the nervous system, particularly the spinal cord and the cerebellum, which is responsible for coordinating movement and balance [2].

It's important to remember that FA is the most common form of hereditary ataxia in the United States, affecting about one in every 50,000 people [3]. Early diagnosis and intervention can be crucial in managing the condition and potentially limiting its severity [4].

Symptoms and progression

The symptoms and progression of FA can vary significantly from person to person [1]. This variability is an important aspect of FA, and it's crucial to remember that your experience may differ from others with the condition.

Early symptoms

The first noticeable symptom of FA is often ataxia, which refers to unsteadiness and difficulty with coordination [5].

You might experience:

- Poor balance.
- Unsteadiness while walking, especially in the dark [6].
- The need to position the feet wide apart to maintain balance [6].
- Difficulty with fine motor skills (e.g., handwriting, buttoning clothes) [5].

Later symptoms

As the condition progresses, other symptoms may emerge, such as:

- Slurred speech (dysarthria).
- Muscle weakness, particularly in the legs.
- Stiffness and cramping in the legs.
- Vision or hearing loss.
- Scoliosis (curvature of the spine) [2].

More than 95% of individuals with FA require a wheelchair by the age of 45 [7]. This highlights the progressive nature of the condition and the importance of planning for future mobility needs.

Building your care team and support network

Managing FA involves a multidisciplinary approach. Assembling a team of healthcare professionals with expertise in different areas can provide comprehensive care and support. Equally important is establishing a strong support network to provide emotional and social support.

Care team

- Your care team might include the following professionals:
- Neurologist: Assesses and manages neurological symptoms, such as ataxia, spasticity, and sensory loss.
- Cardiologist: Monitors heart health, screens for cardiomyopathy and arrhythmias, and provides appropriate treatment.
- Physical Therapist: Helps you maintain strength, flexibility, and balance, and adapt to changes in mobility.
- Occupational Therapist: Assists with daily living activities and recommends adaptive equipment to promote independence.
- Speech Therapist: Addresses speech difficulties (dysarthria) and swallowing problems (dysphagia).
- Primary Care Provider: Provides ongoing general medical care and coordinates with specialists.

- Endocrinologist: Manages diabetes if it develops as a complication of FA.
- Orthopedic Surgeon: Addresses scoliosis or foot deformities if necessary.
- Mental Health Professional: Provides counseling and support to cope with the emotional and psychological challenges of living with FA.
- Regular checkups with your care team are essential to monitor your condition, manage symptoms, and adjust your treatment plan as needed.

Support organizations and resources

- Connecting with others who understand the challenges of FA can provide invaluable support and encouragement. Several organizations offer resources, support groups, and advocacy for individuals with FA and their families:
 - Friedreich's Ataxia Research Alliance (FARA): FARA is a leading organization dedicated to research and support for FA. They offer a variety of resources, including educational materials, support groups, and information on clinical trials [12].
 - National Ataxia Foundation (NAF): NAF provides support, education, and research opportunities for individuals and families affected by ataxia, including FA. They offer resources, support groups, and advocate for policies that improve the lives of people with ataxia¹⁴. They also coordinate over 65 support groups across the United States, offering both in-person and virtual meeting options [15].

- Muscular Dystrophy Association (MDA): MDA offers support and resources for individuals with neuromuscular disorders, including FA. They provide information, support groups, and assistance with equipment and services [17].
- The FA Project: This organization provides financial assistance to people living with FA to help cover medical and adaptive equipment needs [15].
- Friedreich's Ataxia Parents Group (FAPG): This is a free international email-based support group for parents and guardians of children with FA or other childhood-onset/undiagnosed ataxias [18].
- FA Hangouts: These are virtual hangouts hosted by FARA ambassadors for adults with any kind of ataxia and their friends, family, or caregivers [18].

In addition to these organizations, the National Ataxia Foundation provides a list of online support groups and media recommendations (podcasts, blogs, books, websites) to provide additional support and information for patients and caregivers [19].

Financial planning

Living with a chronic illness like FA involves not only addressing the physical symptoms but also planning for the financial and long-term support needs that may arise as the condition progresses. Planning for the future can help you manage expenses, access necessary support, and maintain financial stability.

Government assistance programs

Several government programs provide financial assistance to individuals with disabilities:

- Supplemental Security Income (SSI): This program provides monthly payments to individuals with disabilities who have limited income and resources [20].
- Social Security Disability Insurance (SSDI): For individuals with a work history, SSDI offers monthly benefits based on their earnings record [20].
- Medicaid: This program provides healthcare coverage for individuals with limited income and resources [20].

Other financial resources

- **ABLE Accounts: Achieving a Better Life Experience (ABLE)** accounts allow individuals with disabilities to save up to \$100,000 without affecting their eligibility for SSI. These funds can be used for qualified disability-related expenses, such as housing, education, and healthcare [20].
- **State Pharmacy Assistance Programs:** Many states offer programs to help eligible individuals pay for prescription medications [21].
- **Pharmaceutical Company Assistance Programs:** Some pharmaceutical companies offer assistance in covering the cost of medications [21].
- **National Disability Institute (NDI):** NDI offers financial education programs tailored for individuals with disabilities. They focus on promoting financial literacy, asset development, and economic empowerment [22].
- **Easterseals:** This organization provides a range of services for individuals with disabilities, including financial literacy programs and resources aimed at helping individuals manage their finances and achieve independence [22].

Financial planning tools

- **NDI's Financial Resilience Center:** This online hub provides resources and information to help people with disabilities build financial resilience and navigate challenging times [23].
- **U.S. Department of Labor's Secure Your Financial Future toolkit:** This toolkit offers financial literacy tools and resources specifically for individuals with disabilities [24].

Tax benefits

It's important to be aware of the tax benefits available to individuals with disabilities and their families. These include:

- **Disabled Dependent Tax Credit:** Families who care for a person with a disability may qualify for a dependent care tax credit to help offset caregiving expenses [25].

Financial planning tips

- **Create a budget:** Track your income and expenses to understand your financial situation and identify areas where you can save.
- **Plan for future needs:** Consider the potential costs of medical care, adaptive equipment, and long-term support services.
- **Explore assistive technology:** Assistive devices and technologies can help you maintain independence and manage daily tasks.
- **Seek financial counseling:** A financial advisor with expertise in disability planning can provide personalized guidance and support.

Legal rights

The Americans with Disabilities Act (ADA) is a federal civil rights law that prohibits discrimination against people with disabilities in various areas of public life, including employment, education, transportation, and public accommodations [30].

Under the ADA, you have the right to:

- **Equal employment opportunities:** Employers cannot discriminate against you based on your disability and must provide reasonable accommodations to enable you to perform your job [31]. The U.S. Equal Employment Opportunity Commission (EEOC) enforces Title I of the ADA, which covers employment rights [32].
- **Access to public services and accommodations:** State and local governments must provide equal access to programs, services, and activities, such as public transportation, healthcare, and education [33].
- **Reasonable accommodations:** Businesses and organizations that are open to the public must make reasonable accommodations to ensure that people with disabilities have equal access to their goods and services [34].

If you believe your rights under the ADA have been violated, you can file a complaint with the U.S. Department of Justice or the U.S. Equal Employment Opportunity Commission.

Conclusion

Living with Friedreich's Ataxia presents unique challenges, but with the right information, support, and planning, you can navigate these challenges and live a fulfilling life. Remember that you are not alone. By building a strong care team, connecting with support organizations, and utilizing available resources, you can take control of your health and well-being.

This guide has provided a comprehensive overview of FA, including its progression, available support, financial planning strategies, and your legal rights. We encourage you to discuss this information with your healthcare provider and explore the resources mentioned to develop a personalized plan that meets your individual needs.

Maintaining a healthy lifestyle, including regular exercise and a balanced diet, can also play a role in managing FA and improving your overall well-being [35]. While research into potential treatments continues, it's important to approach the use of supplements like idebenone, CoQ10, and vitamin E with a balanced perspective, understanding both their potential benefits and limitations [35].

Above all, remember that there is hope. Advances in research and treatment, along with the support of your care team and community, can empower you to live a full and meaningful life with FA. We encourage you to connect with support organizations, participate in research if you are interested, and advocate for your rights to ensure that you have the resources and support you need to thrive.

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