Navigating care **after diagnosis**

Receiving a diagnosis of Danon Disease can be overwhelming and intimidating. There are many aspects of care to consider. Below are tips to help you navigate your next steps.

Find a cardiologist you trust

- A cardiologist specializes in identifying and treating heart conditions; because cardiomyopathy* can be a significant issue related to Danon, your cardiologist is often your care quarterback and main source of information about Danon
- Seek a cardiologist who will listen to your concerns and answer your questions
- If possible, find a cardiologist who has experience with Danon or is part of a center of excellence for rare or cardiovascular disease

* **cardiomyopathy** – a disorder that weakens the heart muscle, making it harder to pump blood throughout the body

Explore a list of Danon Disease specialists on the Resources page at **DanonFoundation.org**

Build your team of specialists

Given the complexity of Danon, your care team will usually have more than one type of doctor. Talk to your cardiologist or primary care doctor about specialists and when to see them, as they can help refer you. Some of the types of doctors you may need on your team include:

Primary care provider (PCP)
Treats a range of conditions and often can help refer you to a specialist

Electrophysiologist
Expert in your heart's electrical system and can help identify and address arrhythmias (irregular heartbeats)

Pulmonologist
Specializes in the respiratory system and helps manage lung function and respiratory muscles

Neuropsychologist
Expert in diagnosing and treating issues with behavior, mood and thinking skills

Orthopedic
Specializes in the body's ability to move (ex: muscles, ligaments, and tendons) and can help assess muscle strength, refer to a physical therapist, if needed

Ophthalmologist
Specializes in eye and vision care; eye care is important as the retina is typically affected in most people with Danon

Geneticist
Expert in genetics and family traits and can provide testing and counseling to help families plan

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Questions to consider asking as you build your care team

→ The following questions may be helpful to ask specialists as you meet with them.

Remember to bring all of your medical records to each meeting so that the doctor can review all relevant information.

1. **Do you have experience with Danon?**
2. **Are you willing to connect me with other providers who have experience treating Danon?**
3. **What do I need to look or watch out for?**
4. **What tests do I need, including any baseline evaluations?**
5. **What information do I need to track to help better manage care?**
6. **What medications, devices or surgeries should I consider? (depending on the specialist)**
7. **Are there clinical trials of investigational therapies that may be right for me or my child?**
8. **Are there other research opportunities that may be right for me or my child?**
9. **How often should we meet to help manage my care?**

For more resources about Danon Disease, visit DanonFoundation.org

Support along the way

The Danon Foundation boldly empowers people living with Danon Disease, providing trusted information, resources and support to help navigate life, from diagnosis to treatment.

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