

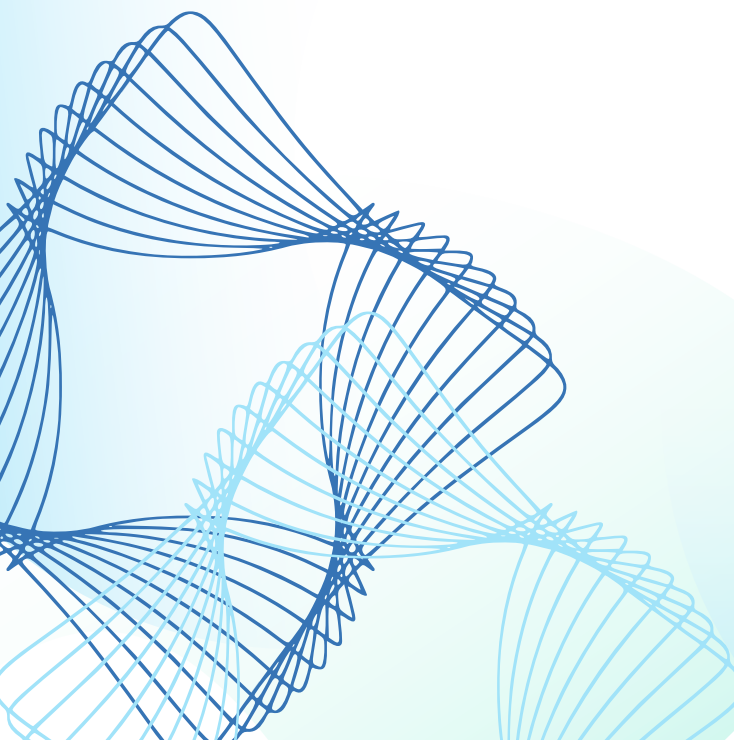


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# NAVIGATING DISABILITY BENEFITS WITH CMT:

A Step-by-Step Guide  
for Charcot-Marie-Tooth



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Checklists  
included!

[hnf-cure.org](https://hnf-cure.org)

# Navigating Disability Benefits with CMT: A Step-by-Step Guide

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## Introduction

Living with Charcot-Marie-Tooth disease (CMT) means navigating challenges that most people don't see: the exhaustion after simply walking to the mailbox, the frustration of not being able to button a shirt, or the embarrassment of tripping in public. These daily realities can make working full-time—or sometimes at all—nearly impossible.

The disability benefits process is often confusing, slow, and discouraging. Many people apply multiple times before being approved. But you are not alone. This guide is designed to walk you step by step through the process, with practical advice, examples, and checklists you can follow. Along the way, we'll also highlight resources like **disability lawyers and advocacy organizations** who can fight on your behalf.

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## Step 1. Understand the Two Main Programs

Before applying, it's essential to know which program fits your situation:

### SSDI (Social Security Disability Insurance)

- For people who have worked and paid Social Security taxes (FICA).
- Benefits are based on how much you earned while working.
- You must have enough “work credits” (usually 20 credits in the last 10 years for adults).
- After approval, there's a 5-month wait for benefits to start and a 24-month wait for Medicare.
- Example: *If you worked full-time for 15 years before symptoms forced you to stop, SSDI is likely your path.*

## SSI (Supplemental Security Income)

- For people with little or no work history.
- Strict income and asset limits (\$2,000 for an individual).
- Provides smaller monthly payments, but Medicaid begins immediately.
- Example: *If CMT prevented you from holding steady work or you're under 26 and just starting adult life, SSI may be the better option.*


### Step 1 Checklist

- Confirmed whether I have enough work credits for SSDI.
  - Checked my finances against SSI's strict limits.
  - Understand that SSDI = insurance from past work, SSI = safety net for financial need.
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## Step 2. Gather Medical Documentation

A diagnosis alone is not enough. The SSA wants to see how your CMT affects everyday functioning.

- Collect neurologist records, PT/OT reports, genetic test results, and EMG studies.
- Ask your doctor for **functional statements**: “Patient cannot walk more than 100 feet without rest” is much stronger than “Patient has CMT.”
- Keep a **symptom diary**. Even short daily notes like “tripped walking into kitchen” or “needed help opening jar” create a real-world record.
- Example: *One patient won their case after their diary and doctor's notes showed how frequent fatigue forced them to nap multiple times a day, making sustained work impossible.*


 **Step 2 Checklist**

- Collected all neurologist, PT/OT, and test results.
  - Requested at least one functional impact statement from a doctor.
  - Started and maintained a daily symptom diary.
  - Organized records in a folder or binder.
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## Step 3. Track Your Work History & Finances

Your financial profile determines which program(s) you qualify for.

- For SSDI: Request your **Social Security Statement** at SSA.gov to confirm work credits.
- For SSI: List all income, bank accounts, property, and household resources.
- Example: *A patient applied for SSI but was denied because they forgot to report a small savings account over \$2,000. Double-check details before applying.*

 **Step 3 Checklist**

- Printed or downloaded my Social Security Statement.
  - Listed all income sources and assets.
  - Double-checked assets against SSI's \$2,000 limit.
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## Step 4. File Your Application

Applications can be started at [SSA.gov](https://www.ssa.gov) or at your local Social Security office. :

## Tips

- Use **plain language**: Instead of “CMT neuropathy causes distal weakness,” write “I drop cups frequently because I can’t grip.”
- Be thorough—include all conditions, not just CMT (anxiety, depression, arthritis, back problems). Multiple conditions can strengthen your case.
- Example: *One applicant was denied when they only listed CMT. After adding related issues like chronic pain and anxiety, they were approved.*

## Step 4 Checklist

- Submitted application online or in person.
  - Described my struggles using real-life examples.
  - Listed all health conditions, not just CMT.
  - Saved copies of everything I submitted.
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## Step 5. Expect a Denial (and Appeal Quickly)

More than 70% of applicants are denied the first time. It’s frustrating, but it’s normal.

- You have **60 days** to file an appeal (called a Request for Reconsideration).
- Keep sending in updated medical information.
- Example: *One patient was denied twice but approved at the hearing level when a judge listened to their testimony.*

## Step 5 Checklist

- Marked the 60-day appeal deadline on my calendar.
- Filed appeal paperwork if denied.
- Continued updating SSA with medical records.

- Reminded myself: a denial doesn't mean I'm not disabled.
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## Step 6. Get Professional Legal Help

A disability lawyer knows the system and dramatically improves your chances. Most charge nothing up front and only get paid if you win.

- **Atticus** – Free service matching you with vetted disability lawyers nationwide.
- **NOSSCR** – Directory of specialized disability attorneys.
- **Legal Aid Societies** – Some states offer free representation.
- Example: *With a lawyer's help, many patients win at the hearing level because the lawyer knows exactly what judges look for.*

### Step 6 Checklist

- Contacted Atticus ([atticus.com](https://atticus.com)).
  - Looked up lawyers at [NOSSCR.org](https://NOSSCR.org).
  - Checked for state-based Legal Aid.
  - Chose a lawyer who only charges if I win.
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## Step 7. Prepare for Your Hearing

This is often where approvals happen. It's not about proving you *have* CMT—it's about showing how it affects daily life.

- Judges may ask: “How far can you walk?” “Can you prepare meals?” “How long can you use your hands before pain sets in?”
- Be honest, specific, and consistent with your medical records.

- Example: *A patient explained: "I can only stand for 10 minutes to cook, then I must sit. Meals take an hour because of this." That specific detail was persuasive.*

### Step 7 Checklist

- Gathered updated medical reports.
  - Collected caregiver or family statements.
  - Practiced describing daily struggles simply and clearly.
  - Prepared to answer questions without exaggeration.
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## Step 8. After Approval

Once approved, you'll receive a benefit award letter.

- Review payment amounts and start dates carefully.
- Learn about **Continuing Disability Reviews (CDRs)**—SSA will recheck your case every 3–7 years.
- If you want to work again, research **Ticket to Work**, which allows trial employment without losing benefits right away.
- Example: *One CMT patient used Ticket to Work to try part-time online teaching, then paused without losing benefits when fatigue became overwhelming.*

### Step 8 Checklist

- Reviewed award letter carefully.
- Learned how CDRs work.
- Researched Ticket to Work options.
- Set reminders to update my medical records.

## Resources & Support

- **Hereditary Neuropathy Foundation (HNF):** Advocacy, education, and patient support – [hnf-cure.org](https://hnf-cure.org)
  - **Atticus:** Free lawyer-matching service – [atticus.com](https://atticus.com)
  - **NOSSCR:** National directory of disability lawyers – [nosscr.org](https://nosscr.org)
  - **Social Security Administration:** Application and resources – [ssa.gov](https://ssa.gov)
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### Final Note

The disability benefits process can be slow, confusing, and emotionally draining. But you don't have to face it alone. Keep copies of everything, track your progress with the checklists, and lean on support—from your doctors, from lawyers, and from the CMT community.

Remember: applying for disability isn't asking for a favor. It's asking for the support you deserve so you can live your life with dignity and stability.