



MYOTONIC
DYSTROPHY
FOUNDATION

Care and a Cure

APPLYING FOR SOCIAL SECURITY DISABILITY BENEFITS

A Toolkit and Guide for People
Living with Myotonic Dystrophy

For more information, visit myotonic.org

Purpose of this Guidebook

If you have myotonic dystrophy (DM) and are unable to work due to a DM-related disability and/or other conditions, you may be entitled to **Social Security Disability Insurance (SSDI)** benefits or **Supplemental Security Income (SSI)** benefits available through the Social Security Administration (SSA). If you are considering applying, you likely have experienced some setbacks in maintaining employment. The Myotonic Dystrophy Foundation (MDF) adapted this guidebook to assist you in deciding whether applying for disability benefits is right for you, and in navigating the complex application process.

SSA Overview

The **Social Security Administration (SSA)** oversees the largest of several federal programs that provide assistance to people with disabilities, including SSDI and SSI.

Social Security Disability Insurance (SSDI) is a federal insurance program run by SSA. It is not a welfare program, because you pay into the system through taxes withheld from your paycheck. SSDI provides cash benefits to replace some of the income you can no longer earn due to disability. You must have sufficient work history and meet disability criteria to be entitled to benefits.

Supplemental Security Income (SSI) is a different program that provides cash benefits to assist people who are very poor, elderly, blind, and/or disabled who have limited means. You do not need to have a work history to qualify, but you must have very little or no income and resources. For more information on SSI, see the Glossary or visit: www.socialsecurity.gov/ssi.

While SSI and SSDI provide different benefits, SSA uses the same disability determination process for both. You can even qualify for both at the same time. This guidebook focuses primarily on the SSDI application process. But if you think you might be entitled to SSI as well, the information provided in this guidebook could help.

SSA field staff use a publication called the Blue Book to help make decisions about disability claims. The Blue Book includes a list of medical impairments with detailed requirements for when SSA staff should judge a medical condition to be disabling. The official name of the Blue Book is Disability Evaluation Under Social Security.

SSA doesn't include myotonic dystrophy on the list of chronic illnesses or impairments provided in its Blue Book. DM is not included in the Blue Book in part because the disease is variable and not all DM patients are unable to work, making a blanket determination impossible, and partially because DM is such a difficult disease to understand.

If any of the following, or other common DM symptoms, prevents you from working, you might qualify for Social Security disability benefits:

- Depression
- Difficulty with walking and other motor skills
- Difficulty seeing
- Difficulty concentrating or completing simple tasks
- Inflammatory bowel disease, including digestive disorders/weight loss and pseudo-obstructions
- Difficulty remembering
- Extreme fatigue, regardless of sleep
- Speech impairment
- Trouble breathing or lung infections
- Persistent or recurrent heart problems, including arrhythmias
- Side effects of medication(s)

Using the Guidebook

As you read through the guidebook, use the margins to take notes and mark important items. But don't feel as if you need to complete the entire guidebook all at once. Use the **Table of Contents** to go through step by step. Pay attention to the **Quick Tips** and **Stop Signs** for important information. Websites are sometimes provided for additional information online. If you do not have internet access, check the library or with family and friends. Or call 1-86-MYOTONIC (866-968-6642) to reach the Myotonic Dystrophy Foundation.

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Step 1 — Determining If SSDI Is Right for You

This section can help determine:

- If you meet the basic SSA requirements for SSDI entitlement.
 - Whether SSDI benefits will meet your financial and healthcare coverage needs.
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Meeting Basic SSA Requirements

SSDI is a cash benefit for people who:

- Have worked and paid enough Social Security taxes.
- Have a **disability** that is caused by disease or injury severe enough to prevent them from working.
- Have a severe disability that is expected to result in death or has lasted or is expected to last for a continuous period of at least 12 months.

You do not necessarily need to be completely disabled to qualify for disability benefits. If you are no longer able to work, you must prove to SSA that your DM-related symptoms and/or other conditions are severe enough that you can no longer perform the physical and mental demands of your past job(s). You also must have an adequate work history. SSA's determination rules are very complex, so it is better to start the application process as soon as you think you might not be able to work. Use these quick SSA tools to see if you will qualify:

- **The SSA Disability Planner.** This resource explains the benefits available, how you can qualify, and who else can receive benefits. It also explains how to apply for the benefits and what happens when your application is approved or denied. Download this resource at: www.socialsecurity.gov/dibplan.
- **The SSA Benefit Eligibility Screening Tool.** SSA's Benefit Eligibility Screening Tool (BEST) can assist you in determining which programs you might qualify for, based on your answers to some questions. Download this resource at: best.ssa.gov.

Income and Work History:

- **Insured status.** Because Social Security is a federal insurance program, SSA first will determine whether you have worked enough, in employment that is covered by Social Security, to have “insured status.” Your insured status is based on what SSA calls “work credits” or sometimes “quarters of coverage.” You earn work credits by working in a Social Security-covered job and paying Social Security taxes. Those are called FICA taxes, or if you are self-employed, SECA taxes. The number of work credits you need depends on your age and when you became disabled. For information on how you earn credits and the number of credits you need to qualify for disability benefits, call SSA or visit: www.socialsecurity.gov/pubs/10072.html.

Quick Tip

SSA will deduct the cost of impairment-related work expenses before determining whether a person is earning no more than \$1,130 in a month. Examples include assistance traveling to and from work, assistance at work with personal functions, or assistance with work-related functions.

- **Income level.** As of 2016, you cannot receive more than \$1,130 per month in wages to qualify for SSDI (this amount is \$1,820 for someone who is statutorily blind). This is not the case for SSI, where the income cap is \$733 per month for one person, or \$1,100 for a couple. However, not all income is considered “countable” against your SSI benefits. See here for examples: <https://www.ssa.gov/ssi/text-income-ussi.htm>.

Quick Tip

Note: For SSDI purposes, SSA does not count income you get from other sources, such as interest or investments.

SSA uses this income cap, called **substantial gainful activity (SGA)**, to assess the impact of your DM symptoms on your ability to work. If you earn more than this amount, SSA will deny your application. SSA increases the SGA income cap annually. SGA applies only to income from work. For SSDI purposes, SSA does not count income you get from other sources, such as interest or investments.

If you have not worked enough, or have not worked recently enough to have the required insured status, you cannot receive SSDI benefits. But if you have limited income and assets, you might still be entitled to **Supplemental Security Income (SSI)**.

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Stop: Before You Take the Next Step



If you do not meet the SSDI work-related requirements, please consider alternative financial planning resources, like those at <http://myotonic.org/resources/toolkits-guidelines>. If you think you might meet SSI eligibility, refer to www.socialsecurity.gov/ssi for information on SSI or **Appendix E: Considerations for Those Newly Diagnosed with DM** for tips on applying at a later date.

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Medical Eligibility:

SSA will ask you for information about your healthcare provider(s), hospital(s), and evidence of your DM symptoms and/or other medical conditions. SSA will then send your information to the **Disability Determination Services (DDS)** agency in your state that will gather your medical records and other evidence. That information will help SSA make the determination about whether you qualify for benefits.

After obtaining your medical information, DDS will determine whether your DM symptoms and/or other conditions are present in the official SSA **Listing of Impairments** and therefore entitle you to benefits. DM isn't specifically mentioned on this listing, but muscular dystrophy is. It isn't enough to just have DM. You must show that you can no longer work.

DDS will consider:

- The limitations from your DM symptoms
- Any other physical or mental medical conditions you might have
- The work you have done in the past
- Your age, education, and work experience

SSA must have medical evidence to support this information and your claim for

disability. It is very important, but not enough, for your doctor(s) to simply say that you are “disabled” or that your DM symptoms make you disabled.

Your doctor(s) should:

- Provide copies of records or a detailed report (or both) with clinical and laboratory findings supporting your diagnosis and the impact of your DM symptoms. Your medical records and other information must show that your **limitations already have lasted or are expected to last for a continuous period of at least 12 months, or are expected to result in death**, in order for SSA to determine that you are disabled.
- Provide a **Medical Source Statement (MSS)** or letter that outlines his or her medical opinion of any limitations your DM symptoms impose on your ability to perform work or major life activities. See page 56 of this guidebook for an example.
- Describe your medical history, any other health conditions, and all of your symptoms, including depression, anxiety, and any side effects of medications. Those might not be DM-specific symptoms but still could prevent you from working.
- Describe the limitations you experience in your daily activities and your ability to do work on a sustained basis—that is, your ability to work eight hours a day and five days a week. If SSA cannot get enough information from your healthcare provider(s), it might ask you to have an additional physical or mental exam, called a **Consultative Examination (CE)**.

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Stop: Before You Take the Next Step



If you do not think you and your healthcare provider(s) can prove that your DM symptoms prevent you from working, contact MDF. You might be able to make changes in your current job, job duties, or other accommodations that will allow you to continue working despite your symptoms. Call the Myotonic Dystrophy Foundation at 1-866-968-6642 for more information.

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Meeting Your Financial and Healthcare Coverage Needs

If SSA approves your SSDI application, you will not receive benefits for five months from the date when your disability began, as determined by SSA. That is called the “waiting period.” The waiting period and the SSA decision-making process take time. Be sure you have income, savings, and/or other means to cover living expenses during that time.

The amount of cash benefits SSDI will pay you is based on the average amount of wages you were paid in your lifetime before you stopped working. Your annual Social Security Statement provides an estimate of the amount of cash benefits you will receive if your SSDI application is approved in that year.

Use these quick SSA tools to find that information:

- **Social Security Statement.** Once a year, SSA mails you a copy of your Social Security Statement with information on the types of SSA benefits for which you are currently entitled, based on work history. To request your estimated monthly benefit amount and/or a copy of your Statement, call SSA or go online at: www.socialsecurity.gov/mystatement.
- **The SSA Benefits Calculator.** Estimate your potential benefit payment using a web-based benefit calculator at: www.socialsecurity.gov/planners/calculators.htm. Use the option for the adult disability benefits calculator.

Maintaining Healthcare Coverage:

If you are currently enrolled in an employer’s group health plan as an employee or dependent of an employee, your continued eligibility for that coverage will likely change if you (or your family member) leave that job. For this reason, it is critically important for you to plan for this possibility and to fully understand your rights to continued coverage. It is also vitally important for you to know and plan for the cost of maintaining your health coverage.

Through a federal law known as COBRA (Consolidated Omnibus Budget Reconciliation Act), most group health plan members and their dependents can stay in their health plan after a job ends for a limited period of time. The maximum length of time you or your dependents can stay covered through COBRA will vary depending on the reason (or ‘qualifying event’) that triggers your COBRA privileges.

However, once your job ends, the employer no longer pays toward your portion of the health plan premium, and anyone who chooses to stay in the plan must pay the full cost of his or her health insurance coverage. Note that the 2010 federal health care reform laws include assistance for some people to help lower the cost of their health insurance premiums. Many details about COBRA's rules could affect you, so plan carefully with the help of your employer, and the U.S. Department of Labor (1-866-4-USA-DOL, www.dol.gov).

If you are entitled to SSDI, you also become entitled to Medicare, but not until two years after your SSDI benefits begin – a full 29 months after you stop working. To learn more about Medicare coverage for people living with disabilities, go to: www.socialsecurity.gov/pubs/10043.html.

If you will lose healthcare coverage and cannot wait for Medicare coverage to begin after the two-year waiting period, talk to an SSA representative about other types of publicly-financed healthcare coverage. In many states (but not all), **Supplemental Security Income** (SSI) provides healthcare coverage through Medicaid. If you are approved for SSI, you could start receiving Medicaid coverage right away. For assistance, call the SSA at 1-800-772-1213 (TTY: 1-800-325-0778) or visit www.socialsecurity.gov/disability.

State Vocational Rehabilitation agencies also furnish a wide variety of services to help people with disabilities return to work. These services are designed to provide individuals with the training or other services they need to return to work, to enter a new line of work, or to enter the workforce for the first time. To obtain more information about the Vocational Rehabilitation agency in your area, call SSA.

Step 2 — Preparing to Apply

Your goal is to be approved for disability benefits with your first application and to avoid the lengthy appeals process. You are your best advocate. You must demonstrate to SSA officials that your DM-related symptoms and/or other conditions result in a disability so severe that you are unable to work. This section can help you:

- Find assistance if you need it
 - Get organized before you apply
 - Prepare for and meet with your doctor(s)
 - Complete all necessary paperwork
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Find Assistance If You Need It

You don't have to do it all on your own. You can ask a friend, family member, or caregiver to help gather your work and medical information or accompany you to visits with your doctor(s) and SSA. You can ask the Myotonic Dystrophy Foundation for guidance. You also have the option of getting a lawyer or other representative to assist you. Anyone can help with any part of your disability benefits application process. However, if you want or need someone to be authorized to act on your behalf or in your absence, or if you are a caregiver completely managing the application for an affected person, you must complete a special form (see **Step 5 — Getting Help with Your Application**).

Quick Tip

Don't delay your application if you cannot complete your general information or work history. Your local SSA field office can help you collect this information. Focus your time on organizing evidence to prove your medical case instead.

Get Organized

Start a Folder:

SSA needs a lot of information to determine whether you qualify for Social Security disability benefits. Thoroughly gather and organize all of your work and medical information into a file. This will help your doctor(s) compile your medical records and help SSA make a faster decision on your claim.

Keep a copy of everything you receive. If you have the originals, keep those and make copies as you need them. File materials in date order.

Include:

- Work and medical records, including all worksheets in **Appendix B**, that can help gather the information you need.
- Letters or testimonials that support your claim from people you see or have seen regularly, such as colleagues, supervisors, and medical professionals. (This information is not required but it can help your claim.)
- Contact information for your healthcare provider(s), SSA, the Myotonic Dystrophy Foundation, and others as appropriate.
- A personal calendar (or journal) to track the application process.
- This guidebook and any other information related to your claim.

Keep a Detailed Journal:

A journal can be helpful whether you are ready to apply for disability benefits today or are considering it for the future. Document how your DM symptoms impact your daily activities and ability to work. Record details from meetings with your doctor(s) and SSA as well as from related conversations with colleagues, supervisors, friends, and family. Make notes when you mail documents and when you make telephone calls (include the date, time, name of person spoken to, and details about the conversation).

Prepare For and Meet with Your Doctor(s)

Medical evidence is the key to being approved for disability benefits. It is not enough for your doctor(s) to tell SSA that you are disabled. Your doctor(s) needs to provide

medical evidence of your condition to SSA. SSA and DDS rely on that information to determine whether you are disabled and entitled to benefits.

Make an Appointment with Your Doctor(s) to Discuss Your Application:

When making an appointment, ask your doctor's office staff to include a note stating that you want to use the appointment to discuss your plans to apply for Social Security disability benefits.

Keep in mind that sometimes it is a good idea to have a medical appointment at the end of the day, so your doctor(s) sees how well you function at that time. Your eye doctor also might want to examine you at the end of the day.

Determine who at your doctor's office will be compiling the information for your application and offer your assistance.

Note: If you can't get an appointment right away, do not wait on this step before continuing with the application process.

Quick Tip

It can be difficult to be approved for SSDI benefits on the basis of cognitive or mental disability alone. SSA could determine that you can perform jobs other than your current or most recent job.

Have a neuropsychological test performed to support your claim and work closely with your mental health providers to build a compelling case for SSA.

Tips for Talking with Your Doctor(s):

Your doctor(s) will be providing SSA with evidence of your disability(s) and other conditions, including how they prevent you from working. The more prepared your doctor(s) is, the better your chances are for being approved for disability benefits.

When Talking with Your Doctor(s):

- Before your appointment, gather all the documents you need for your application and know what information your doctor(s) should provide. Bring a copy of Worksheet 1: Applicant Medical History and make sure your doctor(s) provides any missing information. The medical assistant or nurse also might be able to help confirm medical source information. Bring a copy of Worksheet 3: Physician Medical Information Worksheet. Ask your doctor(s), the nurse(s), or assistant(s) to complete it and send it to you with your medical records.

- Bring this guidebook, your folder of important documents, your journal, and all necessary information with you to the appointment.
- Carefully review the application process and materials with your doctor(s).
- Explain that you are applying for Social Security disability benefits because your DM symptoms prevent you from working. At every visit, brief your doctor(s) on all of your medical issues or disabilities. Explain that medical evidence must document your impairments and your inability to work. See Worksheet 2: How DM Impacts Your Functioning and Ability to Work.
- Work with your doctor(s) to provide your complete medical records and an accompanying Medical Source Statement (MSS) or letter to SSA. A sample letter and guidelines are in Appendix C. Your top priority is to ensure that your doctor(s) writes a thorough and persuasive letter to SSA with medical evidence, including:
 - > Your DM diagnosis and the evidence that supports it.
 - > Your medical history, including the onset date and progression of your DM symptoms and related disability(ies).
 - > The severity of your disability(ies) caused by DM.
 - > The medical treatments you are receiving and have received for DM and related impairments.
 - > Any assistive or orthotic devices and frequency of use.
 - > How medical treatments affect your impairments and related negative side effects.
 - > A medical opinion that, despite these treatments, your disability is permanent, has lasted, or is expected to last at least 12 months.

Quick Tip

Extra Costs. DDS will request (and pay for) all medical records they need and any copies that your doctor(s) mails to them. You also can ask for a copy of all information sent to DDS, but be prepared to pay for all copies you receive.

You are not required to provide copies of medical records with your application, but you can if you have them. Some doctors will charge extra for making copies for patient use.

- > Evidence that your illness, injury, or disability has become more severe over time due to your DM symptoms.
- > Evidence that you cannot work due to DM-related impairments.
- > Evidence of DM-related impairments that could be contributing to your inability to work.
- > Evidence of cognitive problems occurring as a result of fatigue or other DM impacts. The best evidence would be reported in a neuropsychological test, but that is not a requirement.
- Ask your doctor(s) for a complete copy of your medical records as well as the MSS. Give copies of them to SSA when you apply. You can reference them later or use them in your appeal. **Do not, however, delay your application trying to obtain any records.**

You might lose benefits if you wait. If you cannot get your records, SSA and DDS can help get them for you.

Complete All Necessary Paperwork

These materials will assist in preparing you for questions SSA will ask you during your interview:

- Review and complete an **SSA Adult Disability Application Starter Kit** to help prepare for your SSA interview. Call SSA and ask for a kit. You also can pick up a kit from your local SSA field office or download a copy at: www.socialsecurity.gov/disability/disability_starter_kits.htm.
- Review the **DM Listing and Criteria Reference Sheet in Appendix E**. Refer to SSA language and information but describe your DM symptoms in your own words.

Quick Tip

Carefully describe your mental and/or physical abilities to SSA during your application process:

- Use words like occasional, frequent, constant, always, intermittent, nightly, daily, mild, or severe.
- Reference conditions like fatigue, balance, mobility, speech, neuropathy, vision, hearing, bladder, fine motor skills, concentration, or memory.

- Complete **Worksheet 1: Applicant Medical History** to organize your medical information. Your doctor(s) will have most of your medical information in his or her records. Bring the worksheet to the appointment(s) with your doctor(s). Use it to remind him or her what information to collect and to fill any gaps in your own records.
- Complete **Worksheet 2: How DM Impacts Your Functioning and Ability to Work.** To help think about how DM impairs your ability to function at work, use this worksheet to list activities you did at work before you became disabled and activities you can no longer do since your DM diagnosis.
- Remember to give copies of **Worksheet 3: Physician Medical Information** to your doctor(s) to complete and include in the materials he or she will provide to DDS.
- Complete **Worksheet 4: Applicant Work History** to help collect information about your past jobs and wages. You will need a description of the types of work you performed, your job duties, the lengths of time you held the jobs, and your pay. SSA has access to employer and wages information and can help collect any missing information.

Quick Tip

If you have worked until medical conditions caused frequent absences or poor performance, admit it to SSA.

If you were fired, needed extra help at work, were asked to leave, or were encouraged to apply for disability benefits by your employer, explain that too.

If you've had poor job evaluations because of cognitive problems, enclose copies with your application.

Step 3 — Submitting Your Application

Before submitting your application, you should have met with your doctor(s), completed the SSA Adult Disability Starter Kit, and completed the worksheets in this guidebook.

This section can help guide you through the process once you are ready to apply. It includes information on:

- Understanding what happens to your submitted application
 - Arranging an interview with SSA
 - Conducting a successful interview with SSA
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Arranging An Interview with SSA

If you choose to submit an in-person application, start by calling SSA to schedule an appointment. This can help expedite your application process and reduce the wait at your local SSA field office. It can take a considerable amount of time to get an appointment, so proceed with your information-gathering in the meantime.

There are three ways to apply for SSDI:

- 1. In person.** You can apply in person at your local SSA field office. It could help you get to know the person who will submit your application. An in-person conversation also might allow you to share more detail about your circumstances. Keep in mind that DM has many invisible symptoms that might not be apparent to a SSA claims representative during an in-person meeting. If your doctor(s) has prescribed any assistive devices, be sure to use them at the meeting.
- 2. By phone.** If you are unable to go to your local SSA field office, you can apply by phone. A live phone conversation allows you to talk with your SSA claims representative.
- 3. Online.** Applying online will allow you to take your time and save the information as you go. However, it does not develop a personal connection with an SSA claims representative. Online applications also could take longer to complete. If you would like to apply online but do not have internet access, check at the library or with family and friends.

Tips for a Successful Interview

What to Do Before the Interview:

Review all of your completed worksheets from this guidebook, including your medical history and work history. Review the **DM Listing and Criteria Reference Sheet in Appendix E**. Use SSA language and information to help describe your DM symptoms in your own words in the interview.

- Make copies of everything you will submit to SSA. Keep them in your folder. And remember to keep your originals.

In your journal, write down what you'd like to say at the beginning of your interview. Main points could include:

- I have a (or several) severe disability(ies) due to DM
- Due to this/these disability(ies), I cannot work at all
- If a friend or relative is willing, ask them to accompany you or listen in on your phone conversation. They might be able to confirm, clarify, or correct details.

What to Bring to the Interview:

- Your journal to take notes on what the interviewer says
- One form of identification, such as a certified birth certificate, driver's license, state-issued identification card, or passport
- Your folder with all necessary materials. Check this list as you gather everything you need:
 - Disability Starter Kit materials
 - All completed worksheets in this guidebook
 - Supporting documents for your work history:
 - Employers, dates, and salaries
 - Most recent W-2 forms
 - Military discharge papers
 - Any testimonials from colleagues or supervisors

- Supporting documents for your medical history:
 - Copies of medical records (if you have them)
 - Dates of treatments, tests, and prescriptions
 - Contact information for all healthcare providers
 - Any testimonials on your condition

What to Discuss at the Interview:

- Use your journal, worksheets, work history, and medical records to fully explain your personal circumstances.
- Use details to describe how your DM symptoms and/or other conditions prevent you from working. Refer to Worksheet 2 for examples.
- Ask for your SSA interviewer's contact information so you can follow up later. The general phone number for SSA often is busy.
- It is important to get the SSA interviewer's extension or direct number, or you might have difficulty reaching him/her.
- Ask for a copy of the application and a detailed history of your work wages. The report is free at the interview, but you might have to pay for it if requested at a later date.
- If you are too tired to continue at any point, ask to pick up the conversation later the same day, the next day, or by phone.
- After meeting with SSA, call your doctor(s) and make sure your records have been prepared for SSA and DDS, and make sure the doctor(s) has written the MSS or letter. Keep copies for your file.

What Happens to Your Submitted Application

Your application will go through a three-step process. Keep track of the dates. That way you can remember when you need to contact SSA and DDS to check on your application.

First Step, the Local SSA Office, or “Field Office”:

SSA, the federal agency, has field offices in every state and territory. The field offices accept applications, interview applicants, and make administrative decisions. They determine whether you have worked enough to be entitled to SSDI benefits and other initial evaluations other than the disability decision. If those administrative requirements are met, the application is sent to DDS. On average, this takes about **seven days**.

Second Step, DDS:

DDS (Department of Developmental Services) is a state agency in charge of making the SSA medical decision as to whether you are entitled to SSDI benefits. **Disability Examiners** and **Medical Consultants** who work at DDS determine whether you are “disabled” under SSA’s rules. DDS uses the contact information for your doctor(s), healthcare provider(s), and other sources that you provided when you applied to gather copies of your medical records, reports, and other evidence they need to make a disability determination.

If you submitted medical and other records at the time of your application, DDS will also consider that information. If DDS decides that there still is not enough information to make a decision, it might ask you to have an additional physical or mental exam, called a **Consultative Examination (CE)**, to help verify your claim. DDS then submits a decision to SSA. On average, this takes **90–120 days**.

Third Step, the Determination:

SSA will send its disability determination to you to tell you whether you are entitled to SSDI and what happens next. If you are approved, it will tell when you can expect to begin receiving benefits, any back benefits SSA owes you, and other important information. If you are denied or are not satisfied with the determination, it will tell you how to appeal.

SSDI Application Timeline

	Application Route	Time Frame and Next Steps
1 ↓	Local SSA Field Office	<p>On average, this takes about seven days.</p> <p>Next Step: Make sure SSA has all the information it needs to make a quick determination and to send your application to DDS without delay.</p>
2 ↓	DDS Disability Examiner and Medical Consultant	<p>On average, this takes 90–120 days.</p> <p>Next Step: If you do not hear from DDS by this time, you should contact your assigned Disability Examiner.</p>
3	Determination	<p>If DDS decides you are eligible for benefits, you will be notified by the SSA per the information above. The letter will tell you when to expect to begin receiving benefits, about any back benefits SSA owes you, and other important information.</p> <p>If you are denied disability benefits or are not satisfied with the determination, you have only 60 days from the date of the letter to appeal.</p> <p>For more information on the appeals process, see page 26 of this guidebook or call SSA.</p> <p>It is important to meet this deadline. The reconsideration claim will go to a different Disability Examiner and a different Medical Consultant. If you miss it, you'll have to file a new claim.</p>

Step 4 — Managing Your Application During the Review Process

This section provides information for after you have submitted your

SSDI application, including:

- How to follow up on your application with SSA
 - Tips for communicating with SSA regarding delays
 - What happens if your application is approved
 - How to appeal if your application is denied
 - Upcoming changes to the application process
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Following Up on Your Application

Approximately 45–60 days after you submit your application, you can begin your follow-up process. Mark this in your calendar or journal.

Make Calls:

- If you have not already heard from DDS, call your local SSA field office representative to inquire about the status of your application:
 - Ask if you can provide any additional information or be of any assistance
 - Get the phone number of the Disability Examiner who has your application if you haven't already
 - If you move or get a new phone number, provide updated contact information

Quick Tip

SSA's decision about your application is made by a state-run office called a **Disability Determination Services (DDS)** unit. Call DDS to find out who will be reviewing your application. You can get the phone number from SSA after your case is assigned to DDS. This can take several weeks after you apply for benefits.

- Call the Disability Examiner to ask if he or she needs more information for the application or other help
- Consider checking back every 15 days or so to ask questions while DDS is reviewing your application
- For each call, make notes in your journal:
 - Date and time of conversation
 - Who you spoke with and his or her contact information
 - Detailed notes on his or her responses to your questions

Tips for Communicating with SSA on Delays

Below are some tips to manage your application should the process take longer than the SSDI Application Timeline.

Keep Good Records:

Continue to keep copies of all materials on hand. If SSA requests any additional information, you will need to follow through quickly. Consider sending any follow-up materials by certified mail so you will know when the document is received.

Be Patient, Persistent, and Punctual:

- The person who looks at your application is reviewing hundreds of other applications.
- You might have to explain many times why your DM symptoms and/or other conditions prevent you from working. Know your history and personal information well and be prepared to repeat it consistently.
- If SSA requests an additional physical or mental exam called a Consultative Examination (CE) or

Quick Tip

Follow the Three Ps:

Patience — Stay calm and friendly!

Persistence — Don't give up!

Punctuality — Go to all meetings prepared and on time!

other additional information, follow through quickly. The faster you can respond to SSA requests, the faster your disability claim will be processed.

Have a Consultative Examination:

Your medical records or your doctor's **MSS** could be inadequate to determine whether you are disabled. Before you receive a final notice of SSA's decision, you might receive a notice asking for at least one additional physical or mental exam, called a **Consultative Examination (CE)**.

- Call your Disability Examiner to find out why more medical information or another physical examination is needed. If it is because your doctor's office hasn't sent your medical records, call the doctor's office. Get the fax number for DDS and ask your doctor(s) to fax your records. Call your Disability Examiner to follow up.
- Your **treating source** or doctor might be able to perform the CE, but SSA could ask you to visit another doctor for the exam. SSA pays for the CE.
- If you cannot go to the CE on the day it's scheduled, be sure to follow the instructions on the letter DDS will send you in order to reschedule your examination.

Handle Significant Delays:

If you are unable to get in touch with your local SSA field office or Disability Examiner, if they are unable to explain the delays, or if your application review period exceeds the average time, you might need professional assistance to navigate the issues. Professionals (paid or unpaid) are called SSDI Claimant Representatives. Representatives are usually attorneys but they don't have to be. You can find a representative by:

- **Contacting the National Organization for Social Security Claimants Representatives** at: www.nosscr.org or call 1-800-431-2804.
- **Contacting the National Association of Disability Representatives** at: www.nadr.org.
- **Securing paid professional assistance from an individual attorney.** Paid representation could be expensive, however SSA must approve the fee and there are limits on the fees that representatives can charge. Contact the Myotonic Dystrophy Foundation for information on finding professionals or your local SSA

field office for a list of representatives. Your first visit should be free, but ask for a complete written explanation of fees and rates before agreeing to any meetings or signing any documents. Fees are deducted from benefits, not requested up front. For more information about representatives and fees, visit: www.ssa.gov/pubs/EN-05-10075.pdf.

If Your Application is Approved

If your application is approved, you will receive a letter notifying you. It will tell you when you can expect to begin receiving benefits, about any back benefits SSA owes you, and other important information. Keep all notices mailed to you by SSA and DDS.

Benefits for Family:

When you start receiving disability benefits, certain members of your family also might qualify for benefits, including:

- Your spouse
- Your divorced spouse
- Your children
- Your disabled children

Each family member might be eligible for a monthly benefit of up to 50% of your disability rate. However, there is a limit to the total amount of money that can be paid to a family on your disability benefits. The limit varies, but it is between 50 and 80% of your disability benefits.

If the sum of the benefits payable to your account is greater than the family limit, the benefits to the family members will be reduced proportionately. Your benefit will not be impacted.

If any of your qualified family members apply for benefits with you, SSA will ask you for their Social Security numbers and their birth certificates. If your spouse is applying for benefits, SSA also might ask for proof of marriage, and dates of prior marriages, if applicable.

Benefits for Widows or Widowers Who Are Disabled:

Benefits might be payable to widows or widowers who have a disability if the following conditions are met:

- Are between ages 50 and 60
- The widow or widower meets the definition of disability for adults
- The disability started before the spouse's death or within seven years after the spouse's death

SSA uses the same definition of disability for widows and widowers as it does for workers. For more information regarding disabled widows or widowers benefits, call SSA or visit: www.socialsecurity.gov/dibplan/dqualify9.html.

If Your Application is Denied

You have the right to appeal if your application is denied or you are not satisfied with the determination SSA makes on whether you are entitled to Social Security disability benefits. Keep all notices mailed to you by SSA and DDS. Generally, you only have **60 days** after you receive the notice of SSA's decision to ask for any type of appeal.

- If you do not file an appeal within that deadline, you'll have to file a new claim. SSA also might dismiss your appeal. That means you might not be eligible for the next step in the appeal process and that you might also lose your right to any further review.
- If you file an appeal after the deadline, you must explain the reason you are late and request that SSA extend the time limit. SSA can explain further and help you file a written request for an extension.

The first step in the appeals process, in most states, is called a Reconsideration Determination. A reconsideration is a complete review of your claim by someone who did not take part in the first decision. SSA and DDS will look at all the evidence submitted when the original decision was made, plus any new evidence. Most reconsiderations involve a review of your files without the need for you to be present.

If you disagree with the Reconsideration Decision, you can ask for a hearing. The hearing will be conducted by an **Administrative Law Judge (ALJ)** who had no part

in the first decision or the reconsideration of your case. The hearing is usually held within 75 miles of your home. The judge will notify you of the time and place of the hearing.

What Happens During a Hearing with a Judge

Before the hearing:

- You and your authorized representative, if you have one, can look at the evidence in your case file and submit new evidence.
- **It is very important that you submit any additional evidence you want the judge to consider as soon as possible.** If you do not have it when you request a hearing, send it to the judge as soon as you can.

At the hearing:

- The judge explains the issues in your case and might question you and any witnesses you bring to the hearing.
- The judge might ask other witnesses, such as a doctor or vocational expert, to come to the hearing.
- You and the witnesses answer questions under oath. The hearing is informal but is recorded.
- You and your representative, if you have one, may question any witnesses and submit evidence.
- After the hearing, the judge issues a written decision upon studying all the evidence, then sends you a copy of the decision or dismissal order.

It is very important that you attend the hearing scheduled by the judge. If for any reason you cannot attend, contact the judge as soon as possible before the hearing and state the reason. The judge will reschedule the hearing if you have provided a good reason. If you do not go to a scheduled hearing and the judge decides that you do not have a good reason for not going, your request for a hearing might be dismissed.

Help Process Your Hearing as Quickly as Possible

There are a number of things you can do to speed up the processing of your request for a hearing. You should be aware that the hearing process is a rather lengthy one, so

it is best to help any way you can to speed it up.

- If you wish to appoint a representative, do so as early as possible. Your representative will want time to review your file and prepare for the hearing. If you wait until the date of the hearing or shortly before, your hearing might have to be postponed to provide the representative with the necessary preparation time.
- Make sure that any new or updated medical evidence you want considered has been submitted before the date of the hearing by either you or your representative (the earlier the better). It could result in an early favorable decision for you, eliminating the need for a hearing. If a hearing is necessary, it will eliminate the delays caused because additional evidence has not yet been received.
- Don't cancel a hearing unless absolutely necessary. Again, rescheduling your hearing will delay the decision-making process in your case.
- Notify SSA of any changes to your address immediately.

Appeals Council

If you disagree with the hearing decision, you can ask for a review by Social Security's Appeals Council. The Appeals Council looks at all requests for review, but it might deny a request if it believes the hearing decision was correct. If the Appeals Council decides to review your case, it will either decide your case itself or return it to a judge for further review.

If the Appeals Council denies your request for review, SSA will send you a letter explaining the denial. If the Appeals Council reviews your case and makes a decision itself, SSA will send you a copy of the decision. If the Appeals Council returns your case to a judge, SSA will send you a letter and a copy of the order.

Federal Court

If you disagree with the Appeals Council's decision or if the Appeals Council decides not to review your case, you can file a lawsuit in a federal district court. If you have new evidence or new symptoms, you also can consider filing a new claim. For more information on the appeals process, call SSA or visit: www.socialsecurity.gov/appeals.

Step 5 — Getting Help with Your Application

The SSDI application can sometimes seem complex and overwhelming. If you need help from someone else, this section will guide them through the necessary steps.

- If you have a friend, family member, or caregiver assisting with limited parts of your application, he or she can assist with any part of the process.
 - If you have an authorized representative who will be acting on your behalf or in your absence to complete the entire application, he or she must submit a form to SSA to gain permission to help.
-

Help from Friends and Family Members

There are several ways a friend, family member, or other representative can help you apply for and manage your disability benefits:

- They can assist with part of the application process, such as gathering and organizing all the necessary work and medical records into a folder or keeping a journal. They can accompany you on visits to your doctor(s) and SSA, sit beside you, and help answer any tough questions. They also can help fill out the worksheets in this guidebook.
- If you cannot manage any part of the application process yourself, or if you want or need someone to act on your behalf or in your absence with SSA, you can appoint an authorized representative.
- An attorney or non-attorney representative who specializes in Social Security, friend, or family member can serve as your authorized representative. That person will need to develop a telephone relationship with your healthcare provider(s) and become familiar with all the documentation required to submit a successful application. **Both you and the person representing you must complete and sign Form SSA-1696 (Appointment of Representative). Download and complete at: www.socialsecurity.gov/representation.**
- If you want a representative but don't know how to find one, ask your local SSA

field office. Some representatives charge fees. Others do not. To understand how representatives can charge fees and how SSA approves fees see: www.ssa.gov/pubs/EN-05-10075.pdf.

- Once you are approved for benefits, you also might want help managing your disability benefits. A representative payee receives and manages the cash benefits if you cannot manage them on your own. He or she cannot collect a fee from you unless SSA authorizes the payee to collect a fee for providing services or unless the person is your legal guardian authorized by a court to charge a guardian fee.
- For more information on representative payees and related forms, go to: www.socialsecurity.gov/pubs/10076.html.

Note: SSA does not recognize powers of attorney or award them any special status. That means individuals with power of attorney over some affairs cannot act as your representative with the SSA unless they follow the steps outlined above.

Duties of an Authorized Representative or Representative Payee

An authorized representative or representative payee can help with several activities, including:

- Attending (with or without the applicant) all SSA or DDS interviews and conferences.
- Helping to obtain medical records from your healthcare provider(s) or hospital(s) and information from the SSA file.
- Making formal requests for reconsiderations, hearings, or appeals reviews.
- Preparing for administrative hearings and presenting your case at a hearing.

An authorized representative or representative payee must read and sign a form that documents his or her agreement to follow SSA Rules of Conduct and Standards of Responsibility for Representatives. Find the rules at: www.socialsecurity.gov/representation/conduct_standards.htm.

Some rules include:

- Act with reasonable promptness
- Help the applicant comply with SSA requests for information or evidence
- Bring to SSA's attention everything that shows that the applicant is disabled
- Do not coerce, threaten, intimidate, or deceive the applicant
- Do not charge, collect, or retain any fee in violation of SSA regulations or unless SSA has approved the fee agreement (if the representative is being paid)

Once your representative has read these rules and completed the form, he or she should mail it to your local SSA field office.

APPENDIX A: Glossary

Activities of Daily Living (ADL): Normal day-to-day activities such as walking, going to the bathroom, eating, dressing, bathing, etc.

Administrative Law Judge (ALJ): A federal judge who makes administrative legal decisions. This is the person who hears the case at the second level of appeal for initial claims.

Appeal: A process by which a claimant who is dissatisfied with his or her disability determination can contest it. All decision notices clearly state the rights of appeal available to the claimant. It is, therefore, very important to read any notices or mail received, and if not understood, to get help. The notices include telephone numbers to call for information.

Claimant: Applicants who apply for disability are referred to as claimants by the Social Security Administration (SSA) and the Disability Determination Service (DDS).

Claims Representative: The federal employee at the local Social Security Administration field office who takes the disability application and determines whether all administrative requirements have been met.

Consultative Examination (CE): A medical or psychological examination ordered by the Disability Determination Service (DDS) or another adjudicator due to insufficient or conflicting evidence in the claimant's medical records. CEs might include specialty exams or laboratory tests.

Disability: The inability to engage in any substantial gainful activity (SGA) due to any medically determinable physical or mental impairment. The impairment must be expected to result in death or have lasted or be expected to last for a continuous period of at least 12 months. A person must be unable to do his or her previous work **and** be unable to engage in any other kind of work that exists in the national economy considering his or her medical condition, age, education, and work experience.

The worker's medical impairment(s) must be the primary reason for his or her inability to engage in SGA.

Disability Determination Services (DDS): The state agency authorized by the Social Security Administration (SSA) to make the medical determination regarding whether or not a claimant is disabled according to SSA regulations and standards.

Disability Examiner: The state employee who is a member of a team (with a medical doctor, licensed psychologist, or other medical professional) that makes the medical determination as to whether a claimant meets the Social Security Administration (SSA) standard for disability.

Field Office: The local Social Security Administration office. The Claims Representative works at this office.

Impairment: A physical or mental condition that can be proven by medically acceptable evidence — medical signs, symptoms, and laboratory findings. Impairment can never be proven only by symptoms.

Initial Claim: A claim that is based on a new application, regardless of the level of appeal. This is contrasted with a “continuing disability review” (CDR). CDRs are reviews that the Social Security Administration (SSA) conducts from time to time to determine whether individuals who have already qualified for disability benefits still are disabled.

Listings: A list of impairments with specific severity criteria maintained by SSA that are so severe that SSA disability status is assumed. The Listings describe, for each major body system, impairments that are considered severe enough to prevent a person from doing any substantial gainful activity. If an individual has an impairment on this Listing that meets the criteria shown, or several symptoms that equal in severity to an impairment on this list, then the individual is considered disabled.

Medical Source Statement (MSS): The opinion of a licensed medical practitioner that describes what, if any, limitations the claimant’s impairments impose on his or her ability to perform work or major life activities; or, stated positively, what the claimant is able to do despite his or her impairments. For example, “My patient is able to stand and walk a total of three hours out of an eight-hour day, sit a total of three hours out of an eight-hour day, and carry five pounds occasionally.”

Residual Functional Capacity (RFC): What an individual can still do physically and mentally in a work setting despite his or her medical impairments. When a person has a severe medical impairment(s) that does not meet or equal the requirements of a Listing, SSA must go on to consider whether the person meets the complete definition of disability.

First, SSA considers whether the person has the RFC to do work that he or she has done in the past 15 years. If the person does, he or she is not disabled. If the person

does not, SSA considers whether he or she can do other work, considering the person's RFC and his or her age, education, and work experience. At this last step, it is harder for younger people to qualify than for older people. Likewise, it is harder for people with useful skills and advanced education to qualify than for people with no useful skills and less education.

Social Security Disability Insurance (SSDI): A federal insurance program that provides cash assistance for individuals who have worked under Social Security long enough to have "insured status" and who are disabled. SSDI also includes disability benefits and other kinds of benefits for some family members of individuals who are insured and who have died, retired, or become disabled. Most individuals who qualify for SSDI also qualify for Medicare after they have been entitled to benefits for two years. For more information, visit: www.socialsecurity.gov/disability.

Substantial Gainful Activity (SGA): A measurement of work and wages. If you are working and engaging in SGA when you apply for benefits you cannot be found to be disabled. (If you already qualify for benefits, you might be able to return to work without losing benefits, at least for a time. See: www.socialsecurity.gov/work.)

In 2016, for an individual who is not blind, the SGA wages amount to \$1,130 per month. If an individual has wages \$1,130/month or more, he or she is deemed capable of performing SGA and SSA will deny the application (by law, this amount is \$1,820 for someone who is statutorily blind). SSA does not always count all of a person's wages when they determine whether wages are above the SGA level. For example, SSA will deduct the cost of impairment-related work expenses before determining whether a person is earning at least \$1,130 in a month. (Examples of impairment-related work expenses that people with DM might have include assistance traveling to and from work, assistance at work with personal functions, or assistance with work-related functions.)

Supplemental Security Income (SSI): Supplemental Security Income (SSI) is a cash benefit for people who are elderly, blind, and/or disabled and who have very limited income and assets. Unlike Social Security Disability Insurance (SSDI), individuals do not need to have any work history to qualify for SSI assistance. SSI payments do not come from Social Security taxes and there is no insured status requirement as in SSDI.

While SSI and SSDI provide different benefits, SSA uses the same definition of disability for adults and the same medical requirements in their disability

determination process for both SSI and SSDI. You can even qualify for both at the same time. In many (but not all) states, individuals who qualify for SSI also qualify for Medicaid.

If you think you might be eligible for SSI benefits, you should contact SSA right away. The earliest you can receive cash benefits is the month after the filing date of your application, or the month after you first meet all the eligibility requirements, whichever is later. If you do not have all of the documents that SSA needs, you can get them later. For more information or to start the application process call SSA or visit: www.ssa.gov/disabilityssi/ssi.html.

Treating Source: A treating source is any doctor or medical professional who has or had an ongoing treatment relationship with you. For example, your doctor whom you see regularly for examinations and treatment of your DM symptoms is a treating source. Under SSA's rules, a doctor who treated you once in the hospital is not considered a treating source.

APPENDIX B: Worksheets

Worksheet 1: Applicant Medical History

This worksheet will help gather the medical information you need to complete your SSDI or SSI application.

Worksheet 2: How DM Impacts Your Functioning and Ability to Work

This worksheet will help describe your DM symptoms and how they impact your functioning on the job.

Worksheet 3: Physician Medical Information

This worksheet will help your doctor(s) document your symptoms related to DM and/or other health conditions.

Worksheet 4: Applicant Work History

This worksheet will help gather the work, personal, and income history you need to complete your SSDI or SSI application.

Worksheet 1: Applicant Medical History

FOR PERSONAL USE

The purpose of this worksheet is to help gather all the medical information related to your disability(ies) that you need for your Social Security Disability Insurance application. To use this worksheet, collect for yourself as much of the following information as possible and fill out each section below.

Bring a copy of this worksheet to the appointments with your doctor(s) to remind him or her of what information to collect and to double check for any missing information. **Bring a copy of this worksheet to your SSA interview** as well and attach any copies of the relevant information you have gathered for the checklist. **KEEP YOUR ORIGINALS.**

- A. List all illnesses, injuries, or conditions that prevent you from working. This should include all symptoms, whether or not they are related to DM.

- B. Date you became unable to work in any substantial gainful activity (SGA) because of your medical condition (MM/DD/YY).

- C. If you are receiving Medicaid, write your Medicaid ID number in the space. Include a copy of your Medicaid benefit card.

- D. List the names of your doctor(s), therapist(s), and other healthcare provider(s) who have treated or examined you for your disability-related illnesses, injuries, or conditions in the past and who you expect to treat you in the future. Also include medical professionals who know about the effects of your DM symptoms even if

they didn't treat or examine you for it.

For each practitioner treating your symptoms, please include the following: Name, Specialization, Address, Phone, Reason for Visit, Date First Seen, Date Last Seen.

1. Healthcare Providers Treating Motor or Physical Symptoms:

2. Healthcare Providers Treating Vision Symptoms:

3. Healthcare Providers Treating Cognitive or Mental Health Problems:

4. Healthcare Providers Treating Fatigue Symptoms:

E. Hospitals, clinics, neurology clinics, rehabilitation facilities, or emergency rooms you visited. If you have a hospital number and you know it, include that too. For each visit, please include the following: Name, Address, Phone, Reason for Visit, Date of Admission, Date of Discharge.

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F. All medications you take and why you take them — not only those used to treat your DM symptoms. Include whether you have any side effects from a medication. Also include medications you have tried before and why they did not work and/or you stopped taking them. For each medication, please include the following: Name of Medication, Dosage (if known), Length of Prescription, Reason for Taking Medication, Prescribing Physician.

This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and extend across the width of the page. There are no margins, text, or other markings on the paper.

G. Medical tests you have had or are going to have related to your DM symptoms and/or other conditions. For each test, please include the following: Name of Test, Place of Test, Reasons for Test, Name of Healthcare Provider(s) Who Ordered Test, Test Date(s) (MM/DD/YY), Test Results.

[illegible]

Worksheet 2: How DM Impacts Your Functioning and Ability to Work

FOR PERSONAL USE

The purpose of this worksheet is to help describe how your DM symptoms and/or other conditions impact your ability to do work activities, under each section below. For each, include how your symptoms have changed your ability to work over time.

Think about activities you did at work before your disability and what activities you can no longer do since your DM diagnosis or symptom onset. Think about activities that are too difficult or painful to perform for very long, activities for which you need assistance to complete, and activities that you can no longer perform at all. Use the examples that follow to think about your own situation.

Be thorough. If you do not have room to write in the space provided, use notebook paper or cut and paste into a word processing program. **Use the information you include here to talk with your doctor(s) and SSA representative. Give your doctor(s) copies of this worksheet** so he or she can use the sheet when drafting your Medical Source Statement (MSS). **KEEP YOUR ORIGINALS.**

1. Physical or Other Work Activities

How have your DM symptoms and/or other conditions impacted the following physical or other work activities? Use these examples to describe your circumstances in your own words in the space provided.

- Sitting still at your workstation or keeping your balance in one place. **Describe any assistance or accommodations you receive at work.**
- Standing, walking to work, walking around your workplace, or requiring an assistive device to walk.
- Grocery shopping, including length of time to buy five bags of groceries and how you feel when you're finished.
- Activities that use your hands, such as typing.
- Preparing breakfast or lunch at work. Cleaning the kitchen or dishes.
- Carrying or lifting things, including weights of items lifted.
- Using public transportation or driving to work.
- Speaking clearly.
- Dressing yourself or other self-grooming activities.
- Controlling your bladder and bowel.
- Vacuuming, sweeping, or mopping, including length of time. **Describe any assistance you might receive at home.**
- Mowing the lawn of an average home, including length of time.
- Repairing computer problems or balancing a checkbook, including length of time.
- Walking 100 yards (or one football field), including length of time.
- Showering or bathing.

[illegible]

2. Visual Work Activities

How have your DM symptoms and/or other conditions impacted the following visual work activities? Use these examples to describe your circumstances in your own words below.

- Writing paperwork.
- Reading, even in large type or font.
- Using a computer screen or other electronic screen.
- Seeing materials presented at work-related meetings.
- Using or operating work-related equipment.

Describe your visual limitations related to your work and other daily activities:

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

3. Thinking and Concentrating at Work (Cognitive Activities)

How have your DM symptoms and/or other conditions impacted the following cognitive activities at work? Use these examples to describe your circumstances in your own words below.

- Following and participating in workplace discussions or interacting with others at work.
- Working longer hours to catch up (because your work is slower or inferior) or not meeting deadlines or quotas.
- Memory. Remembering to perform all of your duties.
- Reasoning, concentration, and understanding your work functions.
- Concentrating on one task for longer than a few minutes. Organizing tasks, working with numbers or calculations, and remembering instructions.
- Tolerating stress or anxiety you feel at work.
- Losing focus at work because of depression, interruptions or distractions, or background noise.
- Becoming upset because of distractions or interruptions. Controlling your emotions.

Describe your cognitive limitations related to your work and other daily activities:

4. Extreme Feelings of Tiredness or Fatigue at Work

How have your DM symptoms and/or other conditions impacted your feelings of tiredness and fatigue at work? Use these examples to describe your circumstances in

your own words below.

- Completing a full workday, including travel to and from work.
- Staying awake at work.
- Engaging in any activity for more than an hour.
- Walking, tripping, falling, and/or requiring an assistive device, like a wheelchair.
- Getting dressed or any other activity of daily living.
- Keeping up with the pace of activity at your workplace.
- Participating in evening activities away from home.
- Needing to rest on the weekends in order to be able to work the next week.
- Using vacation days when you are out of paid sick days.

Describe your limitations caused by tiredness and fatigue, related to your work and other daily activities:

Worksheet 3: Physician Medical Information

FOR PHYSICIAN USE

The purpose of this worksheet is to assist you in supporting your patient's Social Security Disability Insurance application, in compiling medical records, and in writing the Medical Source Statement (MSS). Below are possible medical tests you might give your patient to support his/her claim. All tests might not be necessary. Please consult with your patient regarding insurance coverage before conducting tests.

Complete these worksheets using patient medical records and case notes. You might need to hold a clinical consultation to assess interactive symptoms, such as fatigue and physical limitations.

Attach copies of these worksheets and the MSS to the package of medical records and other documents you will send to the state Disability Determination Services (DDS). Keep copies of this in patient records and share the complete copy of this package of information with the patient.

SSA Criteria: Disorganization of Motor Function

Documentation Included in Record:

- | | |
|---|------------------|
| <input type="checkbox"/> EDSS | Test date: _____ |
| Physician Comments: _____ | |
| <input type="checkbox"/> MRI () with Contrast () without Contrast | Test date: _____ |
| Physician Comments: _____ | |
| <input type="checkbox"/> CT Scan | Test date: _____ |
| Physician Comments: _____ | |
| <input type="checkbox"/> Other Laboratory Testing | Test date: _____ |
| Physician Comments: _____ | |

SSA Criteria: Visual Documentation Included in Record:

- ☐ Vision Test date: _____
Physician Comments: _____
- ☐ Acuity, Visual Fields, Visual Evoked Potentials, Nystagmus, Etc. Tests Test date: _____
Physician Comments: _____
- ☐ Other Vision Testing: Test date: _____
Physician Comments: _____

SSA Criteria: Mental Impairments Documentation Included in Record:

- ☐ Neuropsychological Tests Test date: _____
Physician Comments: _____
- ☐ Memory Test Test date: _____
Physician Comments: _____
- ☐ DSM-IV Diagnosis Test date: _____
Physician Comments: _____
- ☐ Depression or Anxiety Tests or Scales: Test date: _____
Physician Comments: _____
- ☐ Other Cognitive Tests: Test date: _____
Physician Comments: _____
- ☐ Mental: Test date: _____
Physician Comments: _____

SSA Criteria: Fatigue of Motor Function

Documentation Included in Record:

- ☐ Modified Fatigue Impact Scale Test date: _____
Physician Comments: _____
- ☐ Fatigue Questionnaire Test date: _____
Physician Comments: _____
- ☐ Sleep Questionnaire Test date: _____
Physician Comments: _____
- ☐ Other Exercise Protocols to Measure Motor Fatigue (e.g., work simulation):
Test date: _____
Physician Comments: _____
- ☐ Complete Blood Count Test date: _____
Physician Comments: _____
- ☐ Hematocrit Test date: _____
Physician Comments: _____
- ☐ Thyroid Function Test date: _____
Physician Comments: _____
- ☐ Liver Function Test date: _____
Physician Comments: _____
- ☐ Other Laboratory Testing: Test date: _____
Physician Comments: _____

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Date: _____

Official SSA Listings Criteria for Neurological Disorders Relevant to DM (Worksheet 3 continued)

FOR PHYSICIAN USE

Disorganization of Motor Function:

A. Disorganization of motor function means interference, due to the patient's neurological disorder, with movement of two extremities; i.e., the lower extremities, or upper extremities (including fingers, wrists, hands, arms, and shoulders). By two extremities, they're referring to both lower extremities, or both upper extremities, or one upper extremity and one lower extremity. The relevant listings for DM all include criteria for disorganization of motor function that results in an extreme limitation (see below) in the patient's ability to:

- ☐ Stand up from a seated position; or
- ☐ Balance while standing or walking; or
- ☐ Use the upper extremities (including fingers, wrists, hands, arms, and shoulders).

B. Extreme limitation means the inability to stand up from a seated position, maintain balance in a standing position and while walking, or use upper extremities to independently initiate, sustain, and complete work-related activities. The assessment of motor function depends on the degree of interference with standing up; balancing while standing or walking; or using the upper extremities (including fingers, hands, arms, and shoulders).

- ☐ Inability to stand up from a seated position means that once seated, the patient is unable to stand and maintain an upright position without the assistance of another person or the use of an assistive device, such as a walker, two crutches, or two canes.
- ☐ Inability to maintain balance in a standing position means that the patient is unable to maintain an upright position while standing or walking without the assistance of another person or an assistive device, such as a walker, two crutches, or two canes.
- ☐ Inability to use the upper extremities means that the patient has a loss of

function of both upper extremities (including fingers, wrists, hands, arms, and shoulders) that very seriously limits his/her ability to independently initiate, sustain, and complete work-related activities involving fine and gross motor movements. Inability to perform fine and gross motor movements could include not being able to pinch, manipulate, and use the fingers; or not being able to use the hands, arms, and shoulders to perform gross motor movements, such as handling, gripping, grasping, holding, turning, and reaching; or not being able to engage in exertional movements such as lifting, carrying, pushing, and pulling.

Marked Limitation in Physical and Mental Functioning

- A. Marked limitation: Although the SSA does not require the use of such a scale, “marked” would be the fourth point on a five-point scale consisting of no limitation, mild limitation, moderate limitation, marked limitation, and extreme limitation. SSA considers the nature and overall degree of interference in the patient's functioning. The term “marked” does not require that the patient must be confined to bed, hospitalized, or in a nursing home.
- B. Physical functioning: Examples of this criterion include specific motor abilities, such as independently initiating, sustaining, and completing the following activities: Standing up from a seated position, balancing while standing or walking, or using both the upper extremities for fine and gross movements. Physical functioning may also include functions of the body that support motor abilities, such as the abilities to see, breathe, and swallow. It also includes symptoms such as pain or fatigue, as documented in the medical record, and caused by the neurological disorder or its treatment, that seriously limit the ability to independently initiate, sustain, and complete these work-related motor functions, or the other physical functions or physiological processes that support those motor functions.
- C. Mental functioning must be present in at least one of the four areas:
- ☐ Understanding, remembering, or applying information (see Blue Book 11.00G3b(i)); or
 - ☐ Interacting with others (see Blue Book 11.00G3b(ii)); or
 - ☐ Concentrating, persisting, or maintaining pace (see Blue Book 11.00G3b(iii)); or
 - ☐ Adapting or managing oneself (see Blue Book 11.00G3b(iv)).

Respiratory Impairment:

3.10 Sleep-related breathing disorders with clinical evidence of the following:

- ☐ Mean pulmonary artery pressure greater than 40 mm Hg; or
- ☐ Arterial hypoxemia, measured by arterial blood gas values of PO₂ and simultaneously determined PCO₂ measured while at rest (breathing room air, awake and sitting or standing) in a clinically stable condition on at least two occasions, three or more weeks apart within a 6-month period. See tables in SSA Blue Book for reference. <https://www.ssa.gov/disability/professionals/bluebook/3.00-Respiratory-Adult.htm>.

Cardiovascular:

4.05 Recurrent arrhythmias, not related to reversible causes, such as electrolyte abnormalities or digitalis glycoside or antiarrhythmic drug toxicity, resulting in uncontrolled, recurrent episodes of cardiac syncope or near syncope, despite prescribed treatment (see 4.00B3 if there is no prescribed treatment), and documented by resting or ambulatory (Holter) electrocardiography, or by other appropriate medically acceptable testing, coincident with the occurrence of syncope or near syncope.

Digestive Tract:

5.06 Inflammatory bowel disease (IBD) documented by endoscopy, biopsy, appropriate medically acceptable imaging, or operative findings with:

- A. Obstruction of stenotic areas (not adhesions) in the small intestine or colon with proximal dilatation, confirmed by appropriate medically acceptable imaging or in surgery, requiring hospitalization for intestinal decompression or for surgery, and occurring on at least two occasions at least 60 days apart within a consecutive 6-month period.

OR

- B. Two of the following despite continuing treatment as prescribed and occurring within the same consecutive 6-month period:

- ☐ Anemia with hemoglobin of less than 10.0 g/dL, present on at least two evaluations at least 60 days apart; or

- ☐ Serum albumin of 3.0 g/dL or less, present on at least two evaluations at least 60 days apart; or
- ☐ Clinically documented tender abdominal mass palpable on physical examination with abdominal pain or cramping that is not completely controlled by prescribed narcotic medication, present on at least two evaluations at least 60 days apart; or
- ☐ Perineal disease with a draining abscess or fistula, with pain that is not completely controlled by prescribed narcotic medication, present on at least two evaluations at least 60 days apart; or
- ☐ Involuntary weight loss of at least 10 percent from baseline, as computed in pounds, kilograms, or BMI, present on at least two evaluations at least 60 days apart; or
- ☐ Need for supplemental daily enteral nutrition via a gastrostomy or daily parenteral nutrition via a central venous catheter.

5.08 Weight loss due to any digestive disorder despite continuing treatment as prescribed, with BMI of less than 17.50 calculated on at least two evaluations at least 60 days apart within a consecutive 6-month period.

Mental Impairment:

12.02 Organic Mental Disorders: Psychological or behavioral abnormalities associated with a dysfunction of the brain. History and physical examination or laboratory tests demonstrate the presence of a specific organic factor judged to be etiologically related to the abnormal mental state and loss of previously acquired functional abilities.

The required level of severity for these disorders is met when both A and B are satisfied, or when C is satisfied.

A. Demonstration of a loss of specific cognitive abilities or affective changes and the medically documented persistence of at least one of the following:

- ☐ Disorientation to time and place; or
- ☐ Memory impairment, either short-term (inability to learn new information), intermediate, or long-term (inability to remember information that was known sometime in the past); or

- ☐ Perceptual or thinking disturbances (e.g., hallucinations, delusions); or
- ☐ Change in personality; or
- ☐ Disturbance in mood; or
- ☐ Emotional ability (e.g., explosive temper outbursts, sudden crying, etc.) and impairment in impulse control; or
- ☐ Loss of measured intellectual ability of at least 15 I.Q. points from premorbid levels or overall impairment index clearly within the severely impaired range on neuropsychological testing, e.g., Luria-Nebraska, Halstead-Reitan, etc;

AND

B. Resulting in at least two of the following:

- ☐ Marked restriction of activities of daily living; or
- ☐ Marked difficulties in maintaining social functioning; or
- ☐ Marked difficulties in maintaining concentration, persistence, or pace; or
- ☐ Repeated episodes of decompensation, each of extended duration;

OR

C. Medically documented history of a chronic organic mental disorder of at least two years' duration that has caused more than a minimal limitation of ability to do basic work activities, with symptoms or signs currently attenuated by medication or psychosocial support, and one below:

- ☐ Repeated episodes of decompensation, each of extended duration; or
- ☐ A residual disease process that has resulted in such marginal adjustment that even a minimal increase in mental demands or change in the environment would be predicted to cause the individual to decompensate; or
- ☐ Current history of one or more years' inability to function outside a highly supportive living arrangement, with an indication of continued need for such an arrangement.

Worksheet 4: Applicant Work History

FOR PERSONAL USE

The purpose of this worksheet is to help gather all of the personal, income, and work history information you need for your application. To use this worksheet, collect all of the documents and information on the list. Include a description of the type of work you performed and the length of time you held that type of job. Attach all separate documents to this worksheet. Remember that SSA has access to employer and wage information and can help collect any missing information. Do not delay your application while gathering this information.

Personal Information

- Original or certified copy of your birth certificate. If you weren't born in the United States, you need proof of U.S. citizenship or legal residency.
- Your checking or savings account number, if you have one.
- Social Security Number(s) for yourself, your spouse, and your minor children.
- Name, address, and phone number of a person who SSA can contact if they are unable to get in touch with you.

Work History Information

- If you were in the military service, the original or certified copy of military discharge papers (Form DD 214) for all periods of active duty.
- If you worked last year, include your W-2 Form from last year. Or if you were self-employed, your federal tax return (IRS 1040: Schedules C and SE).
- Workers' compensation information, including date of injury, claim number, and proof of payment amounts.
- Job descriptions and dates you worked in the past 15 years.

APPENDIX C: Sample Physician-to-SSA Letter

This is a sample letter and is meant as a guide to help clinicians draft a personalized Medical Source Statement. Each case is unique, and this letter should reflect your patient's individual circumstances.

[Doctor's Name] [Street Address] [City, ST ZIP] [DATE]

[Recipient Name] [Title] [Company Name] [Street Address] [City, ST ZIP]

Re: [Patient Name; Date of Birth; SSN]

To Whom It May Concern:

I have examined [NAME] and in my opinion, there is no doubt that due to the scope and complexity of [NAME]'s condition, [HE or SHE] is unable to resume any type of gainful employment in the near or foreseeable future. [NAME] has [DM DIAGNOSIS AND RELEVANT CONDITIONS] that will last more than 12 months that is confirmed through physical examination, medical history, magnetic resonance imaging, and standard neurological examination, including evaluations of strength, spasticity, coordination, gait, sensation, vision, and mental status. [NAME's] symptoms include [FULL LIST OF SYMPTOMS AND ANY ASSISTANCE DEVICES]. [GUIDE FOR BODY OF LETTER:]

- Include details of all impairments related to DM, the progression and severity of symptoms, and all other conditions. Refer to the SSA Blue Book (www.socialsecurity.gov/disability/professionals/bluebook) or the criteria listed in the Myotonic Dystrophy Foundation's *Applying for Social Security Benefits Toolkit* (<http://myotonic.org/resources/toolkits-guidelines>).
- Include details of all lesser functional limitations that might not be DM related. Include clinical and laboratory findings and a detailed opinion about the claimant's ability to function.

- Describe the medical history, the specific tests used, lab results, and the relevant clinical findings. Include that the individual is compliant with prescribed medical treatments. If possible, avoid using the fatigue criterion alone because it is difficult to measure objectively.
- Include details of how physical, visual, and cognitive impairments render the patient unable to work for a sustainable amount of time and explain the basis for your opinion.

Myotonic dystrophy is a progressive neurological disorder, and while some disability can be delayed with treatment, there is not a cure. My expectation is that [NAME] will see a continued decline in function over time.

Sincerely,

APPENDIX D:

Additional DM and Disability Resources and Contacts

Social Security Administration (SSA)

You can find additional information on Social Security Disability Insurance at the SSA website:

www.socialsecurity.gov/disability

SSA also has a toll-free number that operates from 7 a.m. to 7 p.m. ET, Monday through Friday: 1-800-772-1213.

If you have a touch-tone phone, recorded information and services are available 24 hours a day, including weekends and holidays.

If you are deaf or hard of hearing, you may call the toll-free TTY number, 1-800-325-0778, between 7 a.m. and 7 p.m. ET, Monday through Friday. Remember to have your Social Security Number ready when you call.

Disability Law Center Contact Information

Disability Law Center at the Community Legal Center

205 North 400 West

Salt Lake City, Utah 84103

Phone: 1-800-662-9080

TTY: 1-800-550-4182

Fax: 801-363-1437

info@disabilitylawcenter.org

Disability Evaluation Under Social Security (The Blue Book)

A guide for physicians and other health professionals with an understanding of the disability programs administered by SSA. Explains how each program works and the kinds of information that health professional(s) can furnish to help ensure sound and prompt decisions on disability claims. Also includes a copy of the adult and childhood Listing of Impairments. For more information, visit:

www.socialsecurity.gov/disability/professionals/bluebook

The Social Security Redbook

A summary guide to employment support for individuals with disabilities under the Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) programs. For more information, visit: www.socialsecurity.gov/redbook/eng/main.htm

National Organization of Social Security Claimants' Representatives (NOSSCR)

NOSSCR

560 Sylvan Avenue
Englewood Cliffs, NJ 07632
Phone: 1-800-431-2804
Fax: 201-567-1542
Nancy Shor, Executive Director
nosscr@nosscr.org

NOSSCR Government Affairs Office

1025 Connecticut Ave, NW
Suite 709
Washington, DC 20036
Phone: 202-457-7775
Fax: 202-457-7773
Lisa Ekman, Director

Call NOSSCR at 1-800-431-2804 for a referral to a private attorney in your area. You can contact the attorney about representing you in your claim for Social Security or SSI benefits.

Myotonic Dystrophy Foundation

Phone: 1-866-968-6642, 1-415-800-7777
www.myotonic.org

APPENDIX E:

SSA Muscular Dystrophy Listing and Criteria Reference Sheet

SSA's Listing of Impairments for Muscular Dystrophy, In Easy-to-Understand Terms

While myotonic dystrophy isn't specifically mentioned in the SSA's Listings, muscular dystrophy as a whole is one of the impairments that SSA recognizes as likely to cause disability severe enough to prevent you from working and entitle you to disability benefits. SSA's Listing of Impairments for DM is grouped into two criteria:

- Disorganization of motor function.
- Marked limitation in physical functioning and mental functioning.

The text below describes each of these criteria in more detail and in easy-to-understand terms. For the official criteria, see the SSA DM Relevant Listings Criteria (pages 50-54). Use the information here as a reference:

- To write in your journal about your DM symptoms and how they impact your ability to work.
- To complete the SSA Adult Disability Starter Kit.
- To complete the worksheets in this guidebook.
- To use the official language to help describe your symptoms and circumstances in your own words.

You can also **give a copy of this reference sheet to your doctor(s) and your authorized representative if you have one** to help them understand how SSA views DM-related impairments.

Disorganization of Motor Function

Definition: Disorganization of motor function means problems with movement or other physical activities.

SSA considers disorganization of motor functioning as the presence of problems with your ability to use your extremities (your arms, hands, and legs). Problems must be “significant and persistent,” and they must impact at least two of your arms and/or legs. Problems must seriously limit your ability to move, stand, walk, or use your hands and arms.

SSA also considers disorganization of motor function as the presence of neurological impairments including: full or partial paralysis, tremors or involuntary movements, problems with muscle coordination, and sensory problems. You might have one of these problems or a combination of several problems. SSA considers the extent to which these problems make it difficult for you to walk, stand, maintain balance, and move your fingers, hands, or arms.

Examples might include:

- You find it difficult to walk or use stairs.
- You experience weakness or lack of control in muscles.
- Your arms or legs move when you don’t want them to move, or you experience shaking, tremors, or muscle spasms.
- You lose balance when walking or standing still, or bump into walls.
- You do not have good hand-eye coordination.
- You lose control of one or more of your limbs when you are resting or trying to move.
- You experience numbness or stiffness.
- You have difficulty speaking and/or slur your speech.

For more information, visit the Myotonic Dystrophy Foundation website at:

<http://myotonic.org/what-dm/how-dm-affects-your-body/skeletal-muscles66>

Mental Impairment

Definition: Mental impairment means a psychological, emotional, or behavioral problem, associated with a brain disorder that interferes with your ability to carry out activities of daily living or perform work-related activities. The problem must be described in your medical history, and must be related to your loss of mental function. If you feel you have significant cognitive impairments, you can have a neuropsychological test performed to support your claim. This is normally covered by insurance.

You could meet the SSA criteria for mental impairment in one of two ways:

First, SSA considers whether you have lost cognitive abilities or experienced changes in your behavior, including disorientation to time and place; problems with short-term memory that make it difficult for you to learn new information; problems with long-term memory that cause you to forget things you once knew; problems such as hallucinations or delusions; personality changes; mood changes; sudden emotional outbursts; difficulty controlling impulses; or loss of intellectual ability.

Second:

1. The changes must seriously restrict your ability to carry out activities of daily living, cause problems maintaining social relationships, cause problems maintaining concentration, or cause repeated long-term periods where you are incapacitated, or
2. If you have a medical history of a chronic mental disorder that has lasted at least two years that limits your ability to do basic work activities and that is currently controlled by medications or counseling, SSA can consider whether the disorder has caused any of the following: repeated periods where you are incapacitated, situations where a minimal increase in mental demands or a change in your environment are predicted to cause you to become incapacitated, or needing a highly supportive living arrangement for at least one year and expecting a continued need for that support.

Examples might include:

- You have trouble remembering names, times, and dates.
- You cannot remember how to complete everyday activities or you feel confused when attempting to complete everyday activities.

- You cannot concentrate on a task or have trouble processing information, planning and prioritizing, multi-tasking, or problem-solving.
- You have trouble controlling your emotions.
- You have mood swings or panic attacks, making interacting with others difficult.
- You cannot remember words or feel like they are stuck on the tip of your tongue.

For more information, visit the MDF website at: <http://myotonic.org/what-dm/how-dm-affects-your-body/central-nervous-system>

APPENDIX F:

Considerations for Those Newly-Diagnosed with DM

If you or someone close to you has recently been diagnosed with DM, you probably have a lot of questions and concerns. You also could be feeling so overwhelmed by the diagnosis that you aren't sure of the kinds of questions to ask. MDF has developed programs to give you information and support. To review these materials, go to: <http://myotonic.org/what-dm/start-here/>

Be Informed:

Other information available on the MDF website includes:

- **Digital Academy** — Videos and webinars for people with DM.
- **Body Systems Tool** — An interactive overview of the disease and its impacts.
- **Treatment Information** — Descriptions of various treatments available to help reduce and/or manage symptoms. Talk to your doctor(s) about what's right for you. Enter "treatment" in the search bar.
- **Financial Resources** — Programs, organizations, and materials that can assist with various forms of financial assistance.
- **Warmline** — A professionally-staffed warmline for people living with DM, their caregivers, medical professionals and others to ask questions.
- **Email Newsletter** — The *Dispatch*, a monthly newsletter with the latest in DM research and care.

Begin Keeping Records Immediately:

Some day you might need to apply for Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), or other types of cash benefits. Medical records will be critical to a SSDI, SSI, or similar application. Be sure to have your doctor(s) regularly document in the record how DM is impacting your functioning, ability to do work and daily activities, and the changes over time.

You should begin a journal and DM information folder that includes materials from your doctor(s) on: (a) your diagnosis; (b) the progression of your DM symptoms, including the appearance and worsening of your symptoms; and (c) any impact on your work.

To Work or Not to Work:

Your decision to continue working if or when DM significantly impacts your job responsibilities, or to explore an alternative income source such as SSDI, is complex. Some jobs are compromised by DM symptoms much more quickly or directly than others.

Key topics for you to consider include:

- What the Americans with Disabilities Act means in employment.
- Employment strategies and options, including training, transportation, special equipment, and more.
- Talking to your employer's human resources staff.
- Changing your job to accommodate your DM symptoms by using flextime, working at home, or working part-time.

If work is no longer possible for you, knowledge of the Social Security disability benefits and application process will assist in accessing benefits more quickly.

Ask the Myotonic Dystrophy Foundation for assistance.

Call 1-866-968-6642 or visit www.myotonic.org

Acknowledgements

MDF sincerely thanks the **National MS Society** for generously allowing the Foundation to adapt its SSA Guidebook for people living with MS to DM and the myotonic dystrophy community. Adapted/ excerpted from SSDI Guidebook for People Living with MS with permission from the National Multiple Sclerosis Society. The National Multiple Sclerosis Society is proud to be a source of information on multiple sclerosis related topics.

The information provided is based on professional advice, published experience, and expert opinion, but does not constitute medical or legal advice. For specific medical advice, consult a qualified physician. For specific legal advice, consult a qualified attorney.



MYOTONIC
DYSTROPHY
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Care and a Cure

The Myotonic Dystrophy Foundation's mission, "Care and a Cure," is to enhance the quality of life of people living with myotonic dystrophy and advance research focused on treatments and a cure.

Myotonic.org