

Myotonic Dystrophy and Mental Health Handbook



**Myotonic
Dystrophy**
FOUNDATION



The Myotonic Dystrophy Foundation is the world's largest myotonic dystrophy-only patient advocacy organization. Our programs include funding critical research, providing comprehensive resources and support to affected individuals, and advocating with government agencies to advance the drug development pipeline, increase research funding, and improve patient services.

A publication of the Myotonic Dystrophy Foundation (MDF)

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Welcome to the MDF Mental Health Handbook

This resource was designed for people living with myotonic dystrophy (DM) and their caregivers. Throughout the text, myotonic dystrophy will be abbreviated as “DM”, which stands for the universally used Latin name for the disease: dystrophia myotonica. Myotonic dystrophy type 1 will be abbreviated DM1 and myotonic dystrophy type 2 will be abbreviated DM2. Although DM has the potential to impact cognitive health and development, this resource emphasizes the social and emotional impact of the disease. We hope to give the reader an overview of possible mental health issues that may affect people living with DM and potential resources.

Just like the physical symptoms of DM, the mental symptoms are highly varied and can affect people in many different ways. Therefore, it’s important to keep in mind not every section of this document will be relevant to your experience or the experience of your loved one. Additionally, while this handbook was written by experts in the field, it does not replace individual assessment and consultation with a mental health professional or medical doctor.

This handbook aims to provide information on many of the ways mental health can be impacted by DM; however, because there is still so much we do not understand about DM, some of the content in this handbook may be speculative (educated guesses). For example, some sections may reference research on similar diseases, such as other neuromuscular conditions, when research specific to DM is unavailable. The hope is that in coming years, additional research into DM will teach us more about how mental health is impacted by the disease, and updated versions of this handbook will be created.



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<http://www.myotonic.org/MentalHealth>

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A Note to the Reader



From Handbook Project Manager, Ruth Sheldon, MPH, MSW

As a person with myotonic dystrophy type 1 (DM1), I often find myself wondering about the relationship between my mental health and the disease I live with. I think about how my experience of living in this body changes the way I think, perceive, and interact with the world around me. I think about whether I would still have anxiety and depression if I were born without DM. I also wonder about how my experience of certain mental health issues is different from the experience of my unaffected peers.

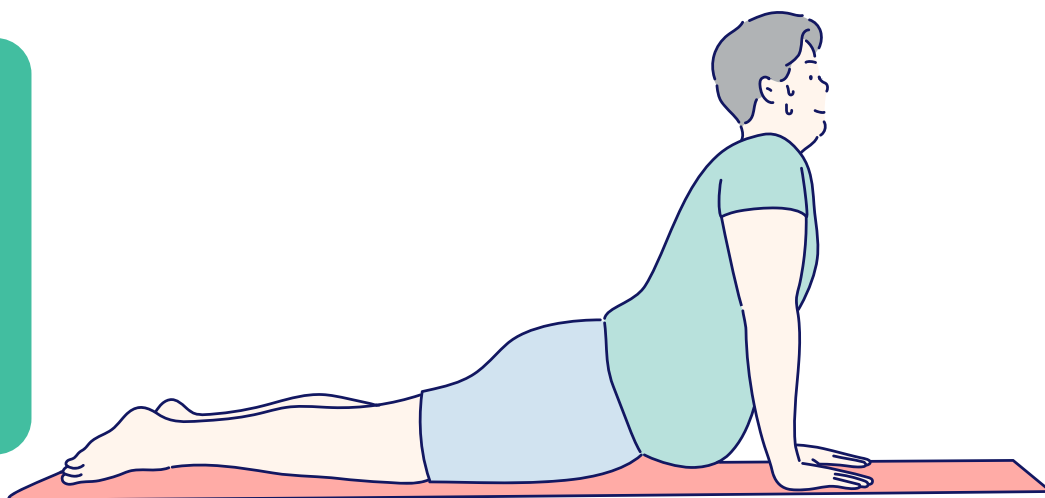
The other day, I was listening to my friend discuss her social anxiety. She described feeling insecure and overwhelmed, and how her face flushed bright red whenever she was asked a question or put in the spotlight. I empathized the best I could, but I was also irritated. I wondered how her social anxiety might be if she had a body like mine. One that needs to have access to a bathroom in case I get an upset stomach; one that carries a tackle box of pills wherever I go; one that has to teach my own doctors about living with DM. Both of our experiences are incredibly valid, but both experiences are incredibly different, and should be treated as such.

I was extremely excited to begin working on this resource because I felt like I was finally learning about mental health in the context of my physical health as they are intrinsically linked. In other words, it is difficult to separate the social and emotional experience from the experience of living as a chronically ill person because they are so interconnected.

Today, I can sit back and smile knowing this handbook was designed and written collaboratively by mental health experts and people within the DM community, for the DM community. I hope this handbook answers some questions and provides useful resources but, more than anything, I hope it makes the reader feel less alone. Whatever brings the reader to this handbook, whatever challenges are experienced, the reader can know there are people out there who know what they are going through. And beyond that, there are people working tirelessly towards a cure for DM.



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Types of DM and Mental Health Concerns

This section will explore the way DM impacts the brain's structure and function, as well as mental health concerns relating to specific types of DM.

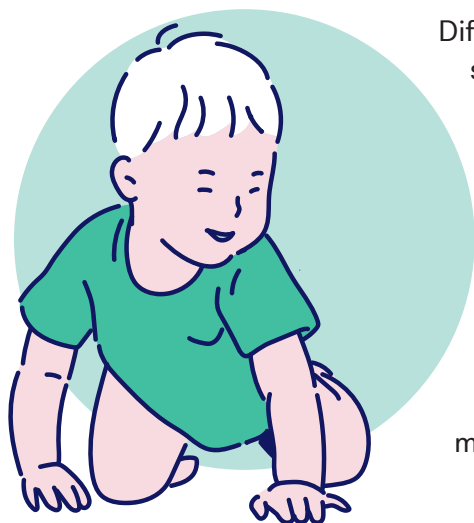
DM & BRAIN STRUCTURE

Myotonic dystrophy is an inherited disease that is passed from one generation to the next through a faulty gene. This faulty gene causes what is known as “repeats” in RNA, which is genetic material that contains instructions for cells. These repeats become trapped in cells, affecting proteins, various molecular processes in cells, tissues, and even organs. Simply stated, the cellular instructions for people living with DM are incorrect, and this causes the body to develop cells that don't function properly. This problem negatively impacts most body systems, including central nervous system (CNS) function in people with DM (Gourdon & Meola, 2017). Despite significant knowledge gaps, we know there is a link between brain structure and mental and cognitive symptoms in people living with DM. However, these symptoms are different, depending both on the disease type (DM1 or DM2) and the specific DM1 phenotypes (Congenital DM, Juvenile Onset Adults, or Adult-Onset).



CONGENITAL MYOTONIC DYSTROPHY (CDM)

Congenital means “present at birth,” and congenital myotonic dystrophy (CDM) means life threatening issues related to DM are seen at birth. Individuals with congenital myotonic dystrophy may experience a variety of symptoms that could affect their mental health. Researchers have observed several cognitive symptoms among individuals with CDM. These include developmental delay, moderate to severe intellectual disabilities, speech and language delay, and deficit in visuospatial (the ability to understand what we see around us and understand the size and location of our surroundings) and/or visuo-constructive skills (the ability to see an object or picture as a set of parts and then construct a replica of the original from these parts). These cognitive symptoms exist along a spectrum and show up in a variety of ways. Discussing developmental milestones at well-child visits and doctors' appointments is one way caregivers can track the progress of their loved one.



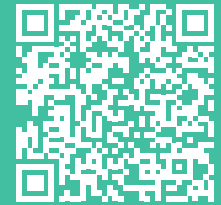
Difficulties with communication and socialization may accompany cognitive symptoms and have been reported among children with DM1 (Angeard et al., 2007, 2011; Ekström et al., 2008, 2009; Douniol et al., 2009, 2012). Communication challenges can impact the way a child is socialized and can make it difficult to adapt to school settings. Children may require academic accommodations, or special assistance, throughout the day. For example, some children benefit from special learning technology, extended time for transitions, or noise-canceling headphones. Children with CDM may also benefit from working with a psychologist or mental health professional. Being able to process their emotions with a trusted adult (who is not a parent or caregiver) can help a child learn new methods to cope with stress and anxiety and increase their self-esteem.

Congenital myotonic dystrophy has been associated with attention deficit/hyperactivity disorder (ADHD) and autism spectrum disorder (ASD). ADHD affects an individual's ability to pay attention, sit still, or control impulsive behaviors. ASD occurs across a spectrum but often presents challenges in the areas of social skills, speech, nonverbal communication, relationships, and self-regulation. Professionals can provide a screening evaluation to help with diagnosing and initiating appropriate treatment.

Resource Feature: Education Accommodations

For more information about academic accommodations, check out MDF's "Going to School with Myotonic Dystrophy: A Guide to Understanding Special Education and IDEA." This comprehensive resource helps parents and family members take advantage of the Individuals with Disabilities Act (IDEA) that governs programs and services for children living with disorders like myotonic dystrophy. The Guide covers services and mandates for ages newborn through 21, and provides guidance, tips and resources for parents and caregivers of children living with congenital and childhood-onset myotonic dystrophy.

https://www.myotonic.org/sites/default/files/pages/files/MDF_IDEA_1_21.pdf



Scan to learn more

JUVENILE ONSET ADULT MYOTONIC DYSTROPHY (JOA)

For childhood/juvenile onset adults, the first signs of DM are usually intellectual disability and learning disabilities; these signs can present during childhood or adolescence (before age 21). People with juvenile onset adult (JOA) myotonic dystrophy might encounter cognitive symptoms, including visuo-spatial deficits (the ability to understand what we see around us and to understand the size and location of our surroundings), learning difficulties, and executive function deficits (Gourdon & Meola, 2017).

Executive functioning refers to the set of skills and processes that enable us to plan ahead, follow multi-step directions, transition from one task to another, and maintain focus in the presence of distractions. These skills rely on working memory, mental flexibility, and self-control (Executive Function & Self-Regulation, 2020). Experiencing executive function deficits can make it extremely difficult to complete some of the important daily tasks required to live independently. Difficulty organizing, making decisions, and planning ahead may mean that a person requires assistance. As a result, adults who are considered JOAs may be more reliant or dependent on their caregivers to assist with certain daily life activities like preparing meals, telephoning for information, or managing finances (Muslemanni et al., 2022).

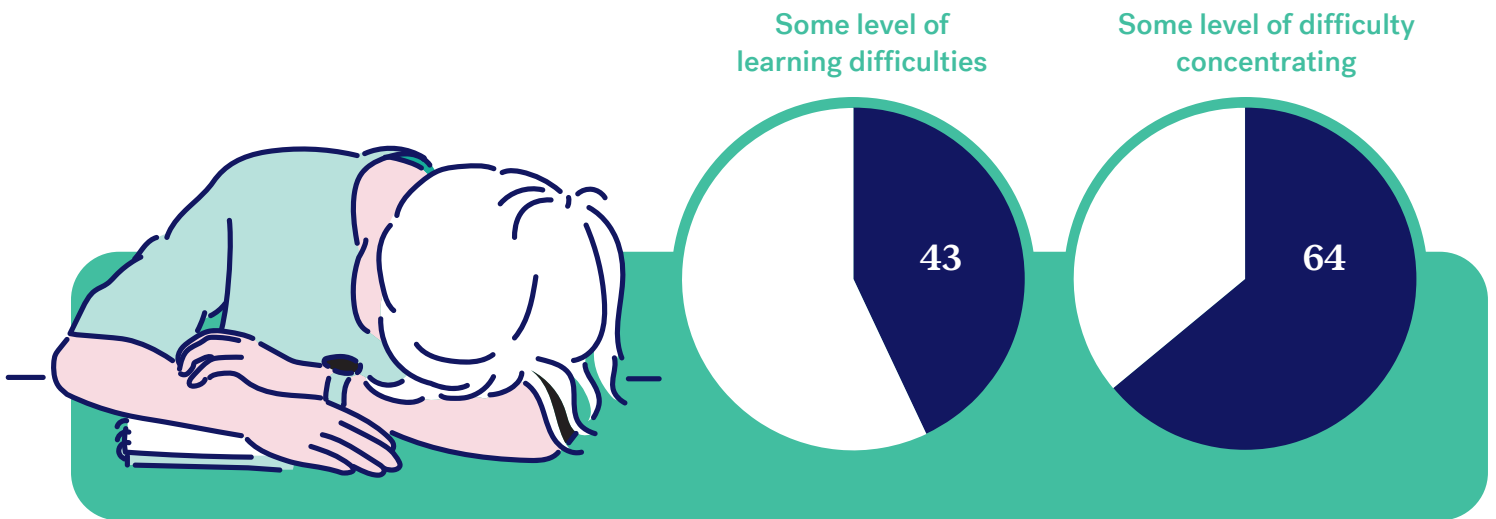


For more information, see page 11 to read the section on function deficits.

ADULT ONSET DM1 & DM2

For Adult Onset DM1 and DM2, the first signs of the disease may vary. However, diagnosis comes after age 21. Adults living with DM1 and DM2 may experience deficits in executive functioning (the set of skills and processes that enable us to plan ahead, follow multi-step directions, transition from one task to another, and maintain focus in the presence of distractions) which have the potential to affect their mental health (Meola et al., 2003; Gallais et al., 2015). These challenges exist along a spectrum and, as a result, affect adults living with DM differently. Individuals living with DM may experience various degrees of impairments in verbal and nonverbal memories of events, spatial abilities (understanding the size and location of our surroundings), and visuo-constructive abilities (the ability to see an object or picture as a set of parts and then to construct a replica of the original from these parts) (Meola et al., 2003).

Research has also suggested that adults with DM1 specifically may have difficulty recognizing different facial expressions (Kobayakawa et al., 2010; Labayru et al., 2018). The inability to recognize certain expressions may lead to difficulty in understanding others' mental states and emotions (Gourdon & Meola, 2017), which has the potential to impact social interactions and relationships.



According to *The Christopher Project*, 43% of respondents with DM2 reported having some level of learning difficulties and 64% of respondents reported some level of difficulty concentrating (Hagerman et al., 2019).

Personality disorders are defined as a pattern of typical and problematic behaviors that is remarkably different from cultural norms and appears distinctly in cognition, emotion, relationships and self-control (American Psychiatric Association, 2013). People living with DM1 can have increased traits of several cognitive and personality disorders: avoidant, obsessive-compulsive, schizotypal, paranoid, passive-aggressive, narcissistic, and antisocial (Minier et al, 2018).

The Lived Experience: Symptoms

DM can have far reaching mental health effects on an individual. In addition to cognitive symptoms, living with DM has the potential to impact an individual's emotional experience and social interactions. The following section contains some of the most common mental health symptoms experienced among people living with DM and recommendations for addressing those symptoms.

ADAPTIVE BEHAVIOR DEFICITS

Adaptive behaviors are behaviors that help individuals participate in daily life (Adaptive Behavior, 2023). Adaptive behaviors can include things like following directions, engaging appropriately in social settings, maintaining one's own safety, carrying on a conversation, grooming, and going to the grocery store. These adaptive behaviors, or adaptive skills, are important to an individual's ability to live independently. Having limited physical mobility due to a chronic illness like DM or pain can reduce a person's ability to use adaptive behaviors as they desire. Similarly, it can impact nutrition and hydration, physical activity level, sleep hygiene, socialization, and interpersonal relationships, as well as social participation in academic and professional settings.

As individuals with DM age, it is common to see a general increase in symptoms, including mental health symptoms.

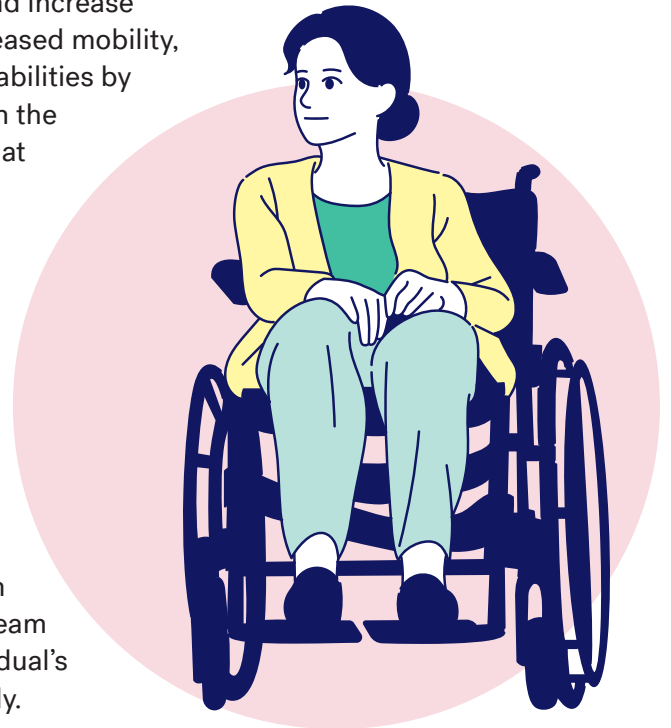
Mobility:

A person's limited mobility can lead to decreased autonomy (independence) thereby impacting a person's sense of self-worth and mood and increase sense of worry. To address a loss of autonomy related to decreased mobility, professionals may recommend the assessment of abilities/disabilities by an occupational therapist. It may be possible to be assessed in the comfort of your own home to get a better idea of difficulties that may be impacting daily life. Check with your, or your loved one's, doctor to request an assessment of this type.

Mental and Cognitive Health:

Many people experience some amount of cognitive decline (gradual loss of thinking abilities such as learning, remembering, paying attention, reasoning) as they age. However, those affected by DM1 may experience this at a faster rate than unaffected peers (Winblad et al., 2016; Gallais et al., 2017; Labayru et al., 2020). Cognitive decline does not always mean an individual is no longer able to make decisions for themselves, however. It is important to work with your, or your loved one's, healthcare team and mental health team to determine when or if the decline is detrimental to the individual's ability to make decisions for themselves and live independently.

More research is needed to determine the rate and effect of cognitive decline for those affected by DM2.



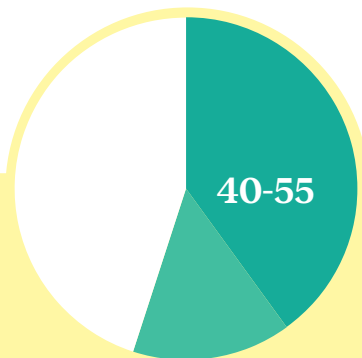
APATHY

Apathy can be defined as a lack of emotion, interest, or concern. From time to time, many people experience apathy. However, when feelings are excessive or interfere with daily living activities, it may be an indicator of an underlying mental health concern. When a person is so apathetic that they neglect their personal hygiene (e.g., brushing teeth, bathing, washing) and health (e.g., eating nutritious meals, exercising, etc.), they likely need to visit a healthcare professional to be individually assessed and treated for any potential underlying mental health issue.

In many cases, people experiencing apathy are not aware of it. Because apathy presents at different levels, or severities, it has the potential to go unnoticed or become a significant problem. In some relationships, apathy can pose a problem because it prevents an individual from engaging in activities they are expected to participate in. In this way, apathy can negatively impact an individual's social, professional, and/or academic life.

Individuals experiencing apathy can do several things to help combat those feelings. Healthcare professionals can help to assess and treat potential mental health issues, such as depression that may be contributing to feelings of apathy. Individuals with more mild apathy can try to incorporate things they enjoy into their day-to-day routine. They might consider signing up for a music or art class at a local community center. Joining a support group (see page 18 for more information) can also be a significant help.

People with DM1
affected by apathy



One review of studies suggests that apathy occurs in 40-55% of people affected with DM1. However this varies among phenotypes (e.g., CDM, JOA, Adult Onset DM1) (Gallais et al., 2015; Van der Velden et al., 2019; Muslemani et al., 2022). More research is needed to better understand the rates of apathy among those affected by DM2.

DIFFICULTY CONCENTRATING

Loss of concentration may be defined as not being able to think clearly, focus on a task, or maintain one's attention. Some people with DM experience an inability to concentrate which can be incredibly discouraging. Being unable to read the newspaper or watch a television program without becoming distracted can mean a person is missing out on the things they enjoy. Difficulty concentrating might look like a person having trouble getting a project started or having challenges getting through tasks at work. Making careless mistakes, losing things, and a lack of mental energy can also be signs of inattention. A person's inattention may be a result of exhaustion or a lack of sleep, stress, or being overworked. Sometimes, however, difficulty concentrating and inattention can be a sign of something more significant (e.g., attention deficit/hyperactivity disorder).

If someone is experiencing these symptoms and cannot otherwise point to a source (stress, lack of sleep), contact a healthcare provider for further assessment.



HYPERACTIVITY & IMPULSIVITY

Hyperactivity and impulsivity are also common symptoms of neurodevelopmental disorders (e.g., attention deficit/hyperactivity disorder) associated with DM.

Hyperactivity is the state of being overly energetic or extremely active and sometimes engaging in disorderly behavior. Hyperactivity, particularly among children, can be disruptive. Though having excessive amounts of energy is not in and of itself a bad thing, it has the potential to interfere with an individual's ability to participate in school or work the way they would like.

Impulsivity is the tendency to act without thinking something through. A person acting impulsively may act rashly when a situation requires more careful thought. Impulsivity may happen alongside, or coexist, with hyperactivity.

Difficulty concentrating, hyperactivity, and impulsivity can be signs of attention deficit/hyperactivity disorder (ADHD). ADHD can impact functioning at home, school/work, and in relationships. Professionals can help with diagnosing ADHD and finding treatment options, such as behavior therapy and/or medication.

To learn more about understanding therapy, see page 21.



EXECUTIVE FUNCTION DEFICITS

Executive function is a general term that refers to the set of skills that help a person plan ahead, follow directions, prioritize and transition between tasks, and maintain focus in the presence of distractions. These skills rely on working memory, mental flexibility, and self-control (Executive Function & Self-Regulation, 2020). Executive function deficits may look like impulsivity or poor self-awareness, difficulty prioritizing, and having a hard time keeping track of things physically or mentally. Without these skills, it can be difficult for an individual to work, perform household tasks on their own, or sometimes even live independently. Therefore, executive functioning is important to an individual's participation in daily living activities.

Executive functioning skills can be learned and, with practice, maintained throughout a person's life. Individuals can try making schedules, using tools like time organizers and calendars, breaking big tasks into chunks, and/or using checklists.

FATIGUE

Fatigue is a constant feeling of drowsiness, exhaustion, and physical or mental tiredness. According to one study, adults with DM1 rated fatigue as the second most experienced symptom and the symptom with the greatest impact on people's lives along with mobility limitations (Heatwole et al., 2012). According to The Christopher Project, fatigue was the second most experienced symptom in individuals affected by DM2 (Hagerman et al., 2019). Individuals with DM1 and DM2 may experience decreased stamina and energy levels. This can lead to reduced participation in social activities and limitations in engaging in extended social interactions or outings (Laberge et al., 2009; Gagnon et al., 2008; Fujino et al., 2017).

Because fatigue is often a big part of living with DM, it is important to prioritize one's activities to conserve energy. "Working smarter, not harder" is a phrase often used by occupational therapists and other clinicians. It means that a person should figure out ways to participate in daily life that are not physically exhausting. One example of this idea is using a handicap parking sticker to park closer to the store so as not to get exhausted getting around inside the store.



Mindfulness and meditation, and cognitive behavioral therapy can both be effective tools for decreasing fatigue (see pages 17 and 22 for more information).

“The fatigue and daytime sleepiness really impact my ability to do the things I love, like painting. The lack of stamina hinders creativity and therefore I try to do things around the house, chores, things that I see the end results, instead of staring at a blank canvas that stresses me out.”

— Sarah Berman, Living with DM1

GRIEF & LOSS

Feelings of grief and loss are common among individuals with chronic illnesses, including DM. The degenerative nature of the disease can cause an individual to lose function and mobility over time. This loss of ability can impact a person's autonomy and sense of independence, particularly if they are unable to engage in certain activities of daily living once thought to be simple (e.g., bathing, dressing, eating, etc.), or cannot participate in social activities the way they would like. Lost function can result in mourning the loss of formerly enjoyable activities. For example, a person who uses a wheelchair to get around may feel a sense of loss over their inability to hike like they once did. A person may feel disillusioned or grieve the ability that they once had. Feeling loss for a life, or person, that "could have been" is not uncommon.

Because these feelings are so common, there are resources available for people who feel grief and loss, or who are in mourning. Talking with a therapist (see page 21 for more information on therapy) provides a way for individuals to express and work through their emotions. Support groups are another resource for individuals experiencing grief and loss (see page 18 for more information about support groups).

SADNESS

“When your loved ones are diagnosed with a progressive neuromuscular disease, it is normal to feel scared and alone. What I have learned as a caregiver is to give yourself and loved ones time to acknowledge and process this rollercoaster of emotion. But, most importantly, find the right emotional support to help you navigate through this new diagnosis.”

— Julie LeBoeuf, Caregiver

Sadness is an emotional pain associated with feelings of disadvantage, loss, despair, grief, helplessness, disappointment, or sorrow. Some people with DM experience sadness. Everyone experiences these feelings from time to time, and they are a very normal part of life. Sometimes, however, these feelings can be difficult to get rid of, or make a person feel stuck. Living with a chronic health condition can mean that an individual has physical and emotional experiences that most people do not experience. Because of this, living with DM may sometimes give an individual feelings of helplessness, and/or loneliness. The good news is many great resources exist to help people cope with some of those difficult feelings. The Myotonic Dystrophy Foundation provides support groups and online resources to help those who may be experiencing feelings of sadness find support through community (see page 18 for more information).

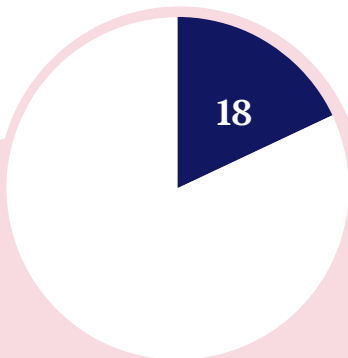


DEPRESSION

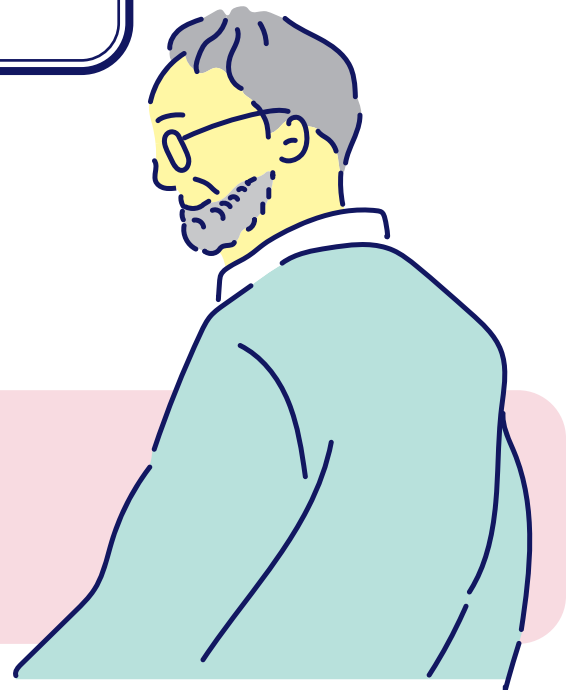
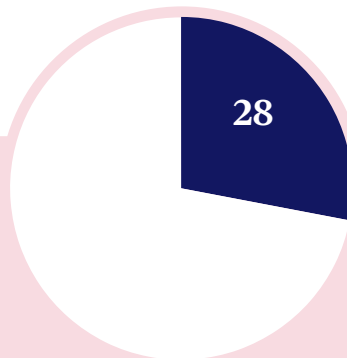
Depression can be described as persistent sadness and lack of interest or pleasure in previously rewarding or enjoyable activities. While it is normal to experience feelings of sadness, severe and/or sustained feelings of sadness may indicate the presence of depression. Seeking assistance from a doctor or mental health professional can be the best way to connect an individual with the care and treatments they need (see page 21 for information about understanding therapy and page 16 for information on autogenic training).

If an individual is experiencing feelings of wanting to harm themselves or others, it is important to seek immediate support through a healthcare provider, emergency department, therapist, dialing the National Suicide and Crisis Hotline, 988, or by dialing 911.

Adults with DM1 feeling sad or depressed



People with DM2 impacted by depression



One study identified that 18% of adults with DM1 reported feeling sad or depressed (Van der Velden et al., 2019). Research suggests, however, that the reported intensity or severity of depression is generally not very high (Minier et al., 2018). According to the Christopher Project report, 28% of people with DM2 reported having depression with major or moderate impact (Hagerman et al., 2019).

“It can be easy to get depressed. I try not to focus on the disease, but instead on combatting the effects of the disease, day by day.”

— Jay Jones, Living with DM1

SOCIAL ISOLATION & WITHDRAWAL

Social withdrawal is when someone begins avoiding people and activities they would usually enjoy. For some people, this can progress to a point of social isolation, where they may even want to avoid contact with family and close friends and be by themselves most of the time. Individuals with DM may experience loneliness, social isolation, or tend to withdraw from social activities. This can be due to a variety of different reasons, including difficulties with physical mobility, speech limitations, or a fear of being misunderstood or judged by others. An individual's ability to participate in certain activities may be diminished because of symptoms. For example, being physically exhausted may cause an individual to retreat from social experiences they would have otherwise enjoyed. As such, a person with DM may avoid a nature hike with friends because they are concerned about a lack of places to sit and rest. Concern and worry about the accessibility of various environments (e.g., parking, elevator, bathroom, etc.) may also prevent a person from participating in or seeking out social experiences.

Mental exhaustion can also influence someone's willingness to engage in social situations. Because DM is not a particularly well-known disease, an individual living with DM may be required to explain themselves or their experience to others (e.g., friends, family, doctors, care team, etc.). When an individual is responsible for educating their teachers, employers, and/or care team about their disease experience, it can feel like no one cares. Bearing the weight of the educational burden can lead to exhaustion, and cause someone to avoid engaging with others.

Additionally, DM can sometimes look invisible to others (e.g., anxiety, fatigue, pain, sleepiness, etc.). This can be discouraging, frustrating, and isolating, and impact interpersonal relationships. For example, excessive fatigue might be interpreted by relatives or neighbors as laziness, and lead to emotional reactions from others like irritability, frustration, and anger, which in turn impacts the person living with DM in a negative way. This may cause the individual living with DM to avoid spending time with relatives or friends.



Learning coping skills can help individuals to manage fears and worries related to social isolation and withdrawal (see pages 16, 17, and 19 for information about Breathing Techniques, Meditation and Mindfulness, and Education and Skill Building).

“I have seen that the mental challenges can completely hinder the individual from having a typical life.... [Being] unable to ‘read’ people causes a lot of embarrassing episodes. Forgetfulness is common, because ‘out of sight is out of mind’... All these challenges lead to depression, sadness, and anxiety. These mental challenges have isolated my daughter from friends and family.”

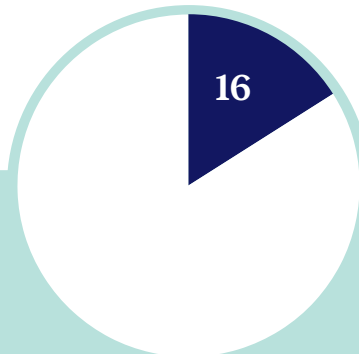
— Loraine Dressler, Living with DM1

WORRY & ANXIETY

Anxiety is a type of mental health condition that causes an individual to have excessive and persistent fear and worry about situations in everyday life. While not everyone with DM experiences anxiety, some individuals may have concerns and worries that grow and take the form of anxiety. Common sources of concern may include the progression of one's own disease, or that of a relative. Worry might appear as passing over challenging opportunities, underestimating one's abilities, fixating obsessively on routines to help manage one's affairs, thinking poorly of oneself (low self-esteem), or feeling ashamed of oneself. These feelings can be particularly difficult when one feels guilty for mistakenly forgetting important appointments, failing to participate as fully as one would like, or not being able to participate in activities that could be done previously. It is not uncommon for individuals with DM to be hypervigilant (unusually cautious) about preparing for potential issues. For example, a person may worry about falling, mobility, getting around, and accessing bathrooms.

Note that some people with DM1 may not recognize the progression of their own disease (Baldanzi et al., 2016). It is not yet well understood how this may or may not affect mental health.

Individuals with DM1 experience anxiety



Research studies estimate that about 16% of people living with DM1 may experience current clinical anxiety (Van der Velden et al., 2019). More research is needed to understand the impact of anxiety on those living with DM2.

Anxiety can be a normal part of life, but when it begins to affect a person's everyday life by taking up significant time, or preventing social engagement, it is important for them to seek support from a doctor or mental health professional (see page 21 for information on understanding therapy). Individuals can also employ different techniques to help them cope with anxiety (see page 16 and 17 for information about breathing techniques, meditation and mindfulness, and progressive muscle relaxation).

Resources and Support

This section contains a wide variety of recommendations for both individuals living with DM and their caregivers. These recommendations were compiled by mental health professionals and experts in the field of neuropsychology. They focus primarily on resources that strengthen emotional resilience and interpersonal relationships. While some resources require clinical or professional assistance, many can be practiced at home. Because everyone experiences DM a little bit differently, not all the resources provided in this section will be right for everyone. Finding out what resources are best for an individual requires patience, an open mind, and sometimes trial and error. However, once useful options have been found, a person's lived experience can improve dramatically.

A Note About Caregivers: Caregivers can take on multiple roles (appointment schedulers, drivers, home health aides, etc.), leading to high stress levels due to the significant responsibility of maintaining their loved one's health and wellbeing. As a result, caregivers may neglect their own health and therefore need supports in place to help manage stress and build resilience. Support groups, mindfulness and meditation, as well as respite care are all effective options for caregivers to receive support (see pages 17 and 18 for more information).

AUTOGENIC TRAINING

Autogenic training is based on repetitions of a set of bodily visualizations (e.g., heaviness and warmth of arms, legs, etc.) that create a state of relaxation. Studies show this method may have positive effects on numerous conditions (e.g., anxiety, mild-to-moderate depression, functional sleep disorder) (Breznoscakova et al., 2023). This can provide a greater feeling of control during panic attacks and help individuals to cope with high levels of stress during specific anxiety inducing situations.

Individuals can learn to use autogenic training through several different means. They can work with a mental health professional trained in hypnotherapy in both individual and group sessions. Individuals can also find resources online and through smartphone apps.

BREATHING TECHNIQUES

Deep breathing is a technique where individuals are trained to contract the diaphragm (stomach muscles) instead of intercostal muscles (rib cage muscles), with a focus on the different sensations felt during the process (e.g., the air flowing through the nose and getting out of the mouth). When part of a regular or daily practice, it has been known to have great effects on stress and anxiety.

One way to practice breathwork involves an individual slowly counting to 5 while breathing in through the nose, holding for 5 seconds, and then breathing out slowly for 5 seconds. Continue this rhythmic breathing practice for 2-3 minutes to enhance the benefit of relaxation and stress reduction. Individuals can also find resources online and through smartphone apps.



MEDITATION & MINDFULNESS

Meditation is a practice in which an individual uses techniques to train attention and awareness and achieve a mentally clear and emotionally calm and stable state. In one study among people with cancer, a 7-week facilitated meditation practice resulted in decreases of stress, emotional irritability and depression, as well as cardiopulmonary (heart and lung) and gastrointestinal symptoms (Specia et al., 2000).

Practicing mindfulness, or simply being aware of one's feelings, thoughts, and immediate sensations in a nonjudgmental manner, for a few minutes per day can also have profound impacts on interactions between caregivers and loved ones. Regular mindfulness practice during caregiving tasks has been shown to have a significant connection with increased happiness on the part of profoundly disabled individuals (Singh et al, 2004).

Individuals who want to practice mindfulness can use smartphone apps (such as Aura Meditation and Sleep, Aura CBT, Calm, Balance: Meditation and Sleep, Headspace: Sleep and Meditation, and Clarity CBT Thought Diary*), watch online videos, or even look for classes at their local community centers, gyms, or healthcare/hospital systems.

**Note, MDF does not endorse specific apps. The list above provides examples based on community member experiences.*



PROGRESSIVE MUSCLE RELAXATION (PMR)

Progressive muscle relaxation focuses on relaxing specific muscular groups; attention is then directed towards sensations felt when muscle is released (Jacobson, 1930). This tactic may have positive effects on stress reduction, enhanced relaxation states, insomnia, pain management, anxiety, and overall well-being. The benefits of PMR may be experienced with one session; however, one may experience greater overall benefit with continued and consistent practice (e.g., 2 – 3 times per week, daily practice, etc.).

You can do PMR at home by using guided audio recordings that can be found online or via smartphone apps, or on your own. This technique involves tensing each muscle group individually, holding for 5 seconds, then relaxing your muscles as you exhale for 10 to 20 seconds.

RESPIRE CARE

Respite care is temporary (often professional) care of a sick, elderly, or disabled person, providing relief for their usual caregiver. You or your support system might consider arranging for temporary relief or respite care to give caregivers much-needed breaks from their caregiving responsibilities. This can involve assisting or temporarily taking over caregiving tasks.

To find care in your area you can utilize several different resources. Some organizations that can connect individuals to local respite services include Area Agency on Aging, the ARCH National Respite Network, and the National Adult Day Services Association.

“I have found it very important throughout my husband’s journey with the disease, and my own journey as caregiver, to focus on my own self-care. My own mental health and self-care is vitally important in caring for my husband as his disease progresses.”

— Samantha Welsh, Caregiver

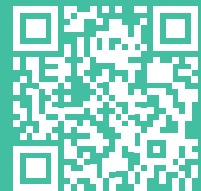
SUPPORT GROUPS

A support group is a group of people with common experiences or concerns who provide each other encouragement, comfort, and advice. Support groups are a great option for individuals seeking emotional support. Individuals with DM might benefit from engaging with support groups specifically for people living with the disease. Support groups may improve quality of life by decreasing levels of anxiety and depression (Pistrang, 2008). Other benefits of support group participation can include improving skills to cope with challenges, learning about a condition and new ways to manage it, and increasing empowerment and sense of autonomy or sense of independence (Mayo Clinic, 2023).

Caregivers can also connect with local support groups, organizations, or online communities specifically for caregivers of individuals with myotonic dystrophy. Peer support can provide a sense of belonging, validation, and shared experiences.

Resource Feature: MDF Support Groups

The Myotonic Dystrophy Foundation (MDF) provides both virtual and local support groups for individuals living with DM and caregivers. MDF support programs are led by trained volunteer community members. Volunteers respect the privacy and confidentiality of anything shared in these programs. Find a support group near you at <https://www.myotonic.org/find-support>



Scan to find an MDF support group

“When I was first diagnosed at the age of 11, my only wish was to meet someone like me. The Myotonic Dystrophy Foundation has created opportunities for me to connect with other young adults my age who can understand and relate to my personal story. Connecting with others has been key for me.”

—Alex LeBoeuf, Living with DM1

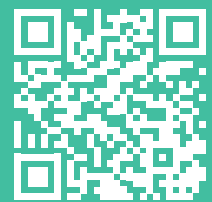
EDUCATION & SKILL BUILDING

Education can be an incredible tool for both caregivers and people living with DM. Access to accurate and up-to-date information about DM (symptoms, progression, available and reliable resources, etc.) can empower individuals and caregivers to anticipate future needs, and advocate for them. For example, knowing the risk of losing physical mobility in older age may motivate a person to plan for the possibility of needing a wheelchair in the future by saving money in advance to prevent financial strain should the need for a wheelchair present itself.



Resource Feature: Educational Videos

View hours of educational and inspirational videos by DM experts whenever you would like through MDF's Digital Academy. Videos are categorized by areas of interest, for example, clinical trials and drug approval, DM2, congenital and childhood onset, genetics, and more! www.myotonic.org/digital-academy



Scan to visit MDF's digital academy

Resource Feature: DM Specific Resources

Check out MDF's Toolkits and Publications page to discover published resources for people living with myotonic dystrophy (DM), their families, their providers, and others involved in their care or concerned with their safety, health, and happiness. <https://www.myotonic.org/toolkits-publications>



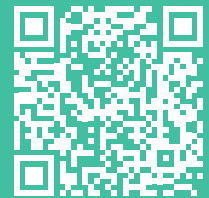
Scan to review MDF's
Toolkits & Publications

FINANCIAL & LEGAL GUIDANCE

Community organizations that assist with navigating financial and legal matters related to chronic health conditions and caregiving can be very useful to individuals with DM and caregivers. Many legal matters arise when accessing insurance benefits, understanding disability benefits, or exploring legal options for long-term care planning, which can be confusing and frustrating. There are also trained advocates who specialize in providing financial advice to people who may have high costs associated with healthcare. In many cases, individuals are employed by the state to assist in these matters and are available at low or no cost to community members.

Resource Feature: Financial Resources Webpage

For more information on financial guidance, check out MDF's Financial Resources webpage which aims to provide U.S.-based families with financial resources that are available on a federal/national level, and state-specific level. The types of resources included are financial, autism-related, caregivers/respite, employment, exercise and outdoors, housing, healthcare and medication, scholarships and education, transportation and equipment, and more. Not every state-specific list will include all categories, and the resources available will vary from state-to-state. <https://www.myotonic.org/financial-resources-0>



Scan to view MDF's
Financial Resource
webpage



Understanding Therapy

This section of the handbook provides information on finding the right fit for a therapist, as well as an overview on Cognitive Behavioral Therapy (CBT) and Acceptance and Commitment Therapy (ACT): two methods of therapy often practiced by mental health clinicians.

KNOW YOUR MENTAL HEALTH PROFESSIONAL

Part of making an informed decision about mental health treatment is knowing your therapist's qualifications and area of expertise. Therapists have different levels of education, training, and licenses, as well as different job titles. Therapists can be psychologists, psychiatrists, licensed professional counselors, licensed marriage and family therapists, licensed clinical social workers, psychiatric nurses, or other licensed professionals with mental health training. Before seeing a therapist, you should ask about several important things:



- **Educational Background:** Therapists undergo various levels of education, which can determine their job titles and roles. Typically, they hold a master's or doctoral degree and receive specialized training in psychological counseling. Psychiatrists, who are medical doctors specializing in mental health, can prescribe medications in addition to providing therapy.
- **Certification & Licensing:** It is important to ensure that the therapist you select meets the certification and licensing requirements mandated by your local or regional jurisdiction for their specific discipline. For example, in the United States, each US state has a Department of Occupational Licensing; you can visit your state's website to verify therapists' licenses.
- **Area of Expertise:** Inquire whether the therapist possesses expertise and experience in treating the specific symptoms or area of concern that you are seeking help for, such as anxiety or depression, and inquire if they have experience working with individuals with physical and/or cognitive disabilities.
- **Feeling Comfortable:** It is important to feel comfortable with your therapist. Many offer free or low-cost initial consultations to see if they are a good match for your needs. If you don't feel great about the first therapist you try, keep looking. Most people would not stop looking for a medical doctor if the first doctor they saw was not a good fit. Even though it can be discouraging, try not to disengage from finding a therapist, even if the second or third person wasn't right for you. You may also ask a therapist to recommend someone else they feel might be a good match for your concerns or needs.

COGNITIVE BEHAVIORAL THERAPY (CBT)

For individuals facing mental health challenges, cognitive behavioral therapy (CBT) can be a helpful tool. CBT is a widely used form of psychotherapy, also known as talk therapy. It involves collaborating with a psychologist or mental health counselor in a structured manner over a set number of sessions. CBT focuses on a person's current problems. It aims to empower individuals to overcome avoiding activities and people they enjoy, develop effective interpersonal skills, and promote overall emotional well-being by incorporating specific behavioral strategies:



- Utilizing problem-solving skills to effectively cope with challenging situations
- Cultivating a stronger sense of self-confidence and belief in one's own capabilities
- Encouraging individuals to confront their fears rather than avoiding them
- Learning to recognize one's distortions in thinking that contribute to problems and reevaluating them based on objective reality
- Utilizing role-playing techniques to prepare for potentially challenging interactions with others
- Learning relaxation and mindfulness techniques to calm the mind and relax the body
- Goal setting
- Self-monitoring
- Using mental distractions and counter stimulation

Not every instance of CBT will incorporate all these strategies. If you choose to explore CBT, you can work with your mental health provider to develop a treatment approach that is tailored to your specific situation and needs. By engaging in exercises during therapy sessions and undertaking "homework" assignments between sessions, clients are guided in developing coping skills that enable them to proactively change their thinking patterns, manage troublesome emotions, and modify their behavior.

CBT is an effective treatment for various issues such as anxiety disorders, depression, sleep problems, mental illnesses, and certain neurodevelopmental symptoms, and can be an incredibly valuable tool for anyone seeking to enhance their ability to cope with stressful life situations (American Psychological Association, 2017). In DM1 specifically, CBT has been shown to be efficient to reduce fatigue and enhance level of activity (Okkersen et al., 2018).

Generally, CBT carries minimal risks as the process mostly involves developing coping skills to enhance management of stress, mood, and worry, and learning strategies to promote relaxation. However, you may experience emotional discomfort at times because CBT can involve delving into painful feelings, emotions, and experiences. Additionally, you may feel physically drained as you engage in the therapeutic process. It is crucial to work with a skilled therapist who will guide and support you, minimizing any potential risks. The coping skills you learn throughout CBT can be invaluable in managing and overcoming negative emotions and fears, leading to personal growth and improved well-being.

CBT Advantages

Development of healthier thought patterns: By identifying and challenging negative and unrealistic thoughts that negatively impact emotions and moods, CBT helps individuals cultivate more positive and realistic thinking patterns.

Short-term effectiveness: CBT is recognized as a time-limited treatment, often producing noticeable improvements within 5 to 20 sessions.

Versatility: CBT is effective in addressing a wide range of maladaptive behaviors and psychological challenges.

Affordability: Compared to certain other therapeutic approaches, CBT tends to be a more cost-effective option.

Flexibility: CBT can be done successfully in both online and face-to-face formats.

Medication treatment alternative: CBT can be utilized as a standalone treatment for those who do not require psychotropic medication.



ACCEPTANCE & COMMITMENT THERAPY (ACT)

Acceptance and Commitment Therapy (ACT), a type of CBT, can be an excellent option for individuals seeking help for mental challenges. ACT acknowledges the relationships between people and settings and assists individuals in tolerating things that are uncomfortable and adapting in new ways to challenging situations.

ACT has three pillars:



These pillars teach the individual that they are capable of doing difficult things and can demonstrate resilience against setbacks. This can be incredibly important when coping with the difficulties of living with a chronic health condition. By helping individuals to approach life challenges flexibly and resiliently, ACT can assist individuals in setting valued goals and living as fully as they are able. This may help them better take advantage of available opportunities while accepting limitations.

Common risks associated with talk therapy, such as ACT, include heightened emotions and the possibility of feeling worse before feeling better. Because ACT is focused on the present, it may not be useful for individuals hoping to process past traumas. Additionally, ACT therapy uses metaphors, so individuals who may have difficulty understanding metaphors, or who think in very literal terms, may have difficulties using this method of therapy.

A Thank You to the Reader

Thank you for engaging with this Mental Health Handbook. Your commitment to understanding the complexities of DM and mental well-being affirms your understanding of the importance of mental health. Remember that, just as DM can be unique to each person, so too can the path to improved mental health and resilience. Your mental health matters, and with the right support, you can face the challenges of DM with greater resilience and hope.



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The mission of the Myotonic Dystrophy
Foundation is Community, Care, and a Cure.

We support and connect the myotonic dystrophy community.

We provide resources and advocate for care.

We accelerate research toward treatments and a cure.

MDF wants to hear from you! To provide feedback on this
resource, or any of our other resources, scan the QR code below.



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