Myotonic Dystrophy FOUNDATION

Guide for Adults Affected by Juvenile-onset Myotonic Dystrophy and Their Caregivers

The Myotonic Dystrophy Foundation (Myotonic) 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, advocating with government agencies to enhance the drug development pipeline, increase research funding, and improve patient services.

Disclaimer: This Guide was created to educate and help adults affected by juvenile-onset myotonic dystrophy and their caregivers. The information in this document is the opinion of the authors and should not be treated as legal advice. If you have legal questions, please consult the resources in the appendix. Medical information available in this Guide is designed as general information only. Individuals should consult a physician or other qualified medical professional for advice on medical treatment.

A publication of the Myotonic Dystrophy Foundation (Myotonic)

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Guide for Adults Affected by Juvenile-onset Myotonic Dystrophy and Their Caregivers

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REMINDER

You will find a list of key terms and abbreviations in the Glossary. All blue bolded words and phrases have definitions listed there.

INTRODUCTION TO THE GUIDE

The Guide for Adults Affected by Juvenile-onset Myotonic Dystrophy and their Caregivers was developed as part of the comprehensive Juvenile-onset Adult (JOA) Program launched in 2019 to help improve the quality of life of those affected by juvenile-onset myotonic dystrophy (DM) and their caregivers. Before the start of this program, there were no specific resources developed to serve this population, nor formalized programs to help families with juvenile-onset myotonic dystrophy understand the specific nature of JOA related symptoms and disease burden, navigate care, resources, socialization, employment, etc. People living with juvenile-onset Adult myotonic dystrophy can often feel isolated, may have trouble finding a supportive friend group, and struggle to build what they feel are meaningful lives. Other family members living with JOA's are often life-long caregivers for these individuals, confronting a care and support burden that changes over time, and often in need of support and resources for their own mental, physical, and emotional health.

To begin to address this deficit and help improve the quality of life of individuals and families living with juvenile-onset DM, Myotonic created the JOA Program and this Guide. Both are meant to help improve the quality of life for JOAs and their caregivers, through access to resources such as social programs, employment, training, and more. This Guide is specifically designed to help families of individuals affected by juvenile-onset DM understand how to manage their lives, especially at transition points in development and education. The Guide will help JOAs and their caregivers get started, understand the essentials and find support.

The Guide provides information on:

- The basics of how myotonic dystrophy affects the body
- How to manage medical care
- How to find a caregiver
- Benefits programs and insurance
- Employment resources and tips for accessing the right supports and services
- Vocational training and educational programs
- Social programs and supports
- Housing options

NOTE: Bolded terms in blue will be used throughout the text and indicate that an explanation of the term is available in the Glossary.

The full list of Resources (with hyperlinks) can be found in the Appendix.

If you do not have internet access, check your local public library, with family and friends, or contact Myotonic for more help. You can reach Myotonic at 415-800-7777 or info@myotonic.org

SECTION

1

UNDERSTANDING MYOTONIC DYSTROPHY

Myotonic dystrophy (DM) is a genetic disorder that affects many parts of the body. There are different types of DM and some types cause more serious problems than others. There is currently no cure for myotonic dystrophy and for the most part, DM is not well understood by the general medical community, but there is a lot that can be done to improve quality of life. It is important to learn as much as possible about DM in order to talk to doctors easily and educate the people around you.

How Myotonic Dystrophy Affects the Body

Myotonic dystrophy is a very complicated condition. The symptoms and disease progression can vary widely. The affects can be quite different even among members of the same family, so it is difficult to predict how the disorder will affect an individual. One person with DM may have only mild muscle pain or cataracts that develop in later years, while someone else with DM may be born with serious breathing problems. The most common effects of myotonic dystrophy are muscle problems, including muscle weakness (myopathy), trouble relaxing a muscle (myotonia), and muscle wasting that becomes worse over time (atrophy). However, it is misleading to think of DM as only a muscle disorder because it also affects other body systems, including the heart, lungs, and gastrointestinal (GI) system. DM can also cause problems with cognitive function, personality, and vision. Not everyone with myotonic dystrophy will have all or even most of the possible symptoms.

DM1 is the most common form of myotonic dystrophy and the one with the most severe effects. At least one in 2,100 people worldwide have DM1, although the number may be far greater. There are three categories of DM1, categorized by when symptoms of the disease first appear. Note that juvenile-onset myotonic dystrophy is a form of DM1.

- Congenital: Presents life-threatening issues at birth
- Childhood/juvenile-onset: First signs are usually intellectual disability and learning disabilities; can present during childhood or adolescence (before age 21)
- Adult-onset: First presents after the age of 21; characterized by distal muscle weakness, wasting, and stiffness

Table 1: Treatment options for symptoms of myotonic dystrophy

Symptom	Treatment
Mild diabetes symptoms	Anti-diabetic medications
Myotonia that impairs normal activities	Anti-myotonic medications (such as mexiletine)
Muscle pain	Nonsteroidal anti-inflammatory medications
Excessive daytime sleepiness	Wakefulness-promoting agents
Muscle weakness, myotonia and contractures	Physiotherapy
Swallowing and pronunciation issues	Speech therapy
Behavioral and psychological issues, such as attention deficit, depression, and anxiety disorders.	Psychiatric therapy
Learning disabilities and cognitive delays	Individualized support
Safe navigation	Assistive devices (braces, canes, walkers, scooters, wheelchairs)
Droopy eyelids (ptosis)	Eye crutches
Irregular heartbeat issues	Pacemaker or implantable cardioverter defibrator (ICD)
Improve respiratory function	Incentive spirometry and cough assist devices
Ensure respiratory sufficiency	Continuous Positive Airway Pressure (CPAP) or Bilevel Positive Airway Pressure (BiPAP) device
Gait issues and contractures	Orthopedic surgery
Vision	Cataract removal
Droopy eyelids	Eyelid surgery



RESOURCE

To learn more about how to manage DM1, please review Consensus-based Care Recommendations for Adults with Myotonic Dystrophy Type 1: https://www.myotonic.org/sites/default/files/pages/files/Myotonic-ClinicalCareRecs-AdultsDM1-English-2019-11-05.pdf

Managing Myotonic Dystrophy

While no treatment currently exists that slows down the progression of myotonic dystrophy, symptom management can improve quality of life. Taking early steps to prevent or treat problems as they appear can help avert complications. DM is a progressive or degenerative disease, meaning that symptoms tend to worsen gradually over several decades. DM1 is a variable diagnosis and the prognosis for an affected individual is difficult to predict. Some people may experience only mild stiffness or cataracts in later life. In the most severe cases, respiratory and cardiac complications can be life threatening even at an early age. In general, the younger an individual is when symptoms first appear, the more severe symptoms are likely to be. However, prognosis is as variable as the symptoms of this disease. How DM affects one individual can be completely different from how it manifests in another, even for members of the same family. It is impossible to predict how the disease will affect any one individual. Table 1 reviews treatment options for symptoms of myotonic dystrophy.

Genetics of Myotonic Dystrophy

DNA is the genetic material found in the nucleus of nearly every cell. A gene is a stretch of DNA that carries a set of instructions on how a protein should be made. These proteins carry out the functions of the body. Scientists estimate that humans have about 25,000 different genes. For example, there are genes that control eye color, genes that make proteins to break down food in the stomach, and genes that encode enzymes that regulate how cells grow.

When the DNA of a gene is altered, a mutation is said to have occurred. Some mutations have little effect on how the body functions. Others are more serious, causing the production of defective proteins that result in disease symptoms.

How Myotonic Dystrophy is Inherited

Myotonic dystrophy is passed from parent to child by autosomal dominant mutations. This means that the faulty gene is located on one of the chromosomes that does not determine sex (autosome) and that one copy of the mutated gene is enough to cause the disease (dominant). Because the gene is not located on the X or Y sex chromosomes, it can be passed to male and female children with equal frequency.

In nearly all cases, people affected by myotonic dystrophy have one normal copy of the DM gene and one copy with the mutation. This means that an affected parent has a 50% chance of passing on the mutated gene to an offspring. Individuals who receive the mutated gene will have the disease, although they may not show symptoms for many years. Children that do not inherit the mutated gene will never develop myotonic dystrophy.

Causes of Myotonic Dystrophy

In people affected by myotonic dystrophy, there is a problem with a particular gene that causes it to convey faulty instructions. This mistake results in the symptoms of DM. The gene responsible for DM1 is found on chromosome 19. Each chromosome consists of a long chain of chemicals that form the units of DNA. These units are called nucleotide bases. The disease is characterized by stretches of DNA (abbreviated CTG) on the DMPK (dystrophia-myotonic protein kinase) gene that are repeated several times. DM1 is sometimes referred to as a trinucleotide repeat disease because of the repetition of these three DNA base pairs. In healthy people, there are between 5 and 37 repeats of the CTG sequence. People with DM1 have expanded repeats which can contain anywhere from 50 to more than 4,000 repeats of the CTG sequence.

Distinctive Genetic Mechanisms in Myotonic Dystrophy

Myotonic dystrophy is one of the most complex disorders known. In addition to the incredible variability of clinical symptoms, the disease also has several unique features:

- Autosomal dominant inheritance: The genes for DM1 are dominant, meaning that a person can inherit the disease even if only one parent carries the gene. A child has the same risk of inheriting DM regardless of whether it is the father or the mother who carries the gene.
- Variable penetrance: The number and severity of DM symptoms varies widely among people with the disease. This is true even among people with the same type of DM and among individuals in the same family.
- Somatic mosaicism: A key characteristic of DM is that different cells in different tissue types will show varying numbers of genetic repeats. This is due in part to the number of repeat changes in different cells and increases in number throughout the lifetime of the individual. Thus, the number of repeats reported in a diagnostic test will depend on how old the individual was when sampled and which tissue was tested.
- Anticipation: The number of repeats in the DM genes tends to increase with each affected generation. As a result, the symptoms of the DM1 appear earlier in life and are more severe in each successive generation. These changes are often dramatic, for example, a person whose only symptom was cataracts that appeared later in life can have a child with life-threatening symptoms present at birth. This effect indicates that the number of times the gene sequence is repeated influences the severity of disease symptoms.
- Transmission of the congenital form through the mother: The most severe form of DM1 (congenital) is almost always passed to the child from an affected mother. Scientists think that this occurs because the number of repeated sequences expands greatly during the process when the egg cells are created.

Reproduction and Family Planning

Individuals with myotonic dystrophy may have concerns about starting a family because of the risks of passing the disease onto their children. Discussing family planning issues in genetic counseling with a medical professional can help individuals make informed decisions. There should be a discussion between the parent and JOA regarding the choice of having children or not. If the JOA plans to have children, a plan should be discussed about who will support and care for the child when/if the JOA or their parent can't continue care. If the JOA does not plan to have children, contraception should be discussed.

Multiple diagnostic options exist for individuals who are considering having children, including:

- Preimplantation Genetic Diagnosis (PGD): This is the diagnosis of a genetic condition before pregnancy. This form of testing is done on a woman's eggs using In vitro fertilization (IVF). Unfertilized eggs are taken from the woman by a doctor and fertilized outside the womb in a laboratory. The embryos are tested for myotonic dystrophy at the 6 and 8 cell stages. Only non-DM affected fertilized eggs are implanted into the uterus.

- Prenatal diagnosis: Parents wishing to find out during pregnancy whether their fetus has inherited the myotonic dystrophy gene can undergo prenatal testing. Two types of tests are available:

  1. Amniocentesis: This procedure involves removing a sample of fluid from the womb that contains skin cells shed by the fetus. The cells are then grown in the lab to provide DNA for testing. The test is typically done 15 weeks into the pregnancy and can take 2-3 weeks for results to become available.

  2. Chronic Villus Sampling (CVS): The doctor removes a piece of tissue from the edge of the placenta using a needle inserted through the abdomen or vagina. The sampled tissue contains the same genetic information as the fetus. The DNA is isolated and tested for the presence of the myotonic dystrophy mutation. The test can be done in the first trimester (generally around 10 weeks into the pregnancy) and results are typically available within 1-2 weeks

Mothers who have DM1 should be closely monitored during pregnancy because they have a higher risk of having a child with congenital DM1. In these cases, excessive amniotic fluid (hydramnios) can accumulate, which can usually be seen during ultrasound examination. Decreased fetal movement is frequently noted. Also, breech presentation and weak uterine contractions can cause long or difficult deliveries, often resulting in Caesarean births.

Newborns with congenital myotonic dystrophy require immediate intensive medical support. Delivery at a medical center with high-risk neonatal support may be recommended. Regardless of whether or not testing is done, individuals with a family history or symptoms of DM should inform their obstetrician so the medical team can prepare for the possible complications seen in these children.

Caregivers of individuals with DM should be aware that pregnancy can sometimes enhance the symptoms of DM in females. While it is possible for an affected parent to deliver a child without DM, DM can progress and accelerate in the affected parent, which may then require the caregiver to take over the care and upbringing of the child. While PGD can determine a DM diagnosis, there is still a possibility that the child will be born with another condition. All of these possibilities can put

added effort on the person with DM and the caretaker, thus adoption and birth control are options that should be strongly considered. Many JOAs do not have the maturity level to raise a child, especially one with special needs that are often present in DM. A child with DM requires special commitment and effort that go beyond normal parenting, which is often very difficult for a JOA and their family to manage.

Frequently Asked Questions about Myotonic Dystrophy

1. *What are other names for myotonic dystrophy?*
   - Myotonic Muscular Dystrophy (MMD)
   - Dystrophia Myotonica: Latin name used by many doctors, often abbreviated as DM. The different types of DM are typically referred to as DM1 or DM2.
   - Steinert's Disease: Named for the German doctor who first identified DM1 in 1909.

2. *What are the types of myotonic dystrophy?*
   - There are two well-defined types of the disease (DM1, DM2) which have distinct but overlapping symptoms. Both DM1 and DM2 are characterized by muscle weakness and myotonia, heart abnormalities, cataracts and insulin resistance. In general, DM2 is less severe than DM1; fewer systems are affected, individuals develop the disease only as adults, and the disorder's impact on everyday life is relatively less disruptive. DM1 can occur from birth to old age; symptoms vary greatly among individuals, from minor muscle pain to serious respiratory and cardiac issues. The congenital form of DM1 is the most severe version and has distinct symptoms that can be life-threatening.

3. *How do people get myotonic dystrophy?*
   - Myotonic dystrophy type 1 (DM1) is an inherited genetic disease caused by a change in a gene called DMPK. In people with DM1, a small section of DNA within this gene is repeated over and over, many more times than usual. Because the disease is caused by this abnormal increase in the number of repeated DNA sequences, DM1 is also referred to as a repeat expansion disease.

     The expanded repeat causes abnormal RNA to build up inside cells and interfere with the way other genes are processed. As a result, cells—especially muscle cells—do not function normally. These changes can affect muscles as well as many other parts of the body, leading to the wide range of symptoms seen in DM1.

4. *How is myotonic dystrophy diagnosed?*
   - A complete diagnostic evaluation, which includes family history, physical examination, and medical tests, is typically required for a presumptive diagnosis of myotonic dystrophy. The presence of the disorder can then be confirmed by genetic testing. The genetic test requires a sample of blood from the patient. The DNA is then extracted from the blood

and analyzed to see if that person has the mutation that causes DM. Prenatal testing, where the DNA of the fetus is checked for the presence of the DM mutation, is also available. Diagnosis of DM is not difficult once the disorder is suspected, however, delays in diagnosis are common. More common diseases with symptoms that mimic DM must typically first be ruled out. Physicians may see only one or two individuals with DM in their entire practice and may not be familiar with the range of ways this disease can present.

5. *What is the prognosis for myotonic dystrophy type 1?*
   - The prognosis for DM1 is variable and difficult to predict. Some people may experience only mild stiffness or cataracts in later life while in most severe cases, respiratory and cardiac complications can be life-threatening even at an early age. In general, the younger an individual is when symptoms first appear, the more severe symptoms are likely to be. However, prognosis is as variable as the symptoms of this disease. How myotonic dystrophy affects one individual can be completely different from how it affects another, even for members of the same family. It is impossible to predict how the disease will affect any single individual.

6. *What DM treatment or therapies are available?*
   - No treatments currently exist that slow the progression of myotonic dystrophy, but symptomatic treatments are available. Managing the symptoms of this disease can reduce suffering and improve quality of life. Ongoing monitoring can reduce the complications seen at critical times.
   - For more in-depth information about symptom management and DM treatments, view the Myotonic toolkit: https://www.myotonic.org/sites/default/files/pages/files/Myotonic-Toolkit-2019.pdf

7. *Regarding anesthetic risks, what specifically should people with myotonic dystrophy tell an anesthesiologist before surgery?*
   - Perioperative complication is increased in individuals with DM. All medications, including sedatives, induction medications, anesthetics, neuromuscular junction blockers, and opiates must be carefully chosen, and doses must be carefully determined. In particular, anticholinesterases (e.g. neostigmine), depolarizing neuromuscular blocking agents (e.g., suxamethonium) and inhalational anesthetics should be avoided. Cardiac problems should be alerted to the anesthesiologist, who should also be aware that hyperkalemia, hyperthermia shivering, mechanical or electrical muscle stimulation can cause myotonia, which may interfere with the surgery. Perioperative aspiration is a risk due to bulbar weakness.
   - For more anesthesia information, view the Anesthesia Guidelines: https://www.myotonic.org/sites/default/files/pages/files/Myotonic-Anesthesia-DM1-2019-11-05.pdf



RESOURCE

To learn more about more about genetic testing and diagnosis, visit www.myotonic.org/living-dm/testing-and-diagnosis

8. *If two siblings have the disease, will they have similar organ issues over time?*
    - Not always, as their genetic background is different although many genes are shared. Genomic background is likely to play an important role in organ-specific phenotype expression.

9. *Is there always gene **expansion** at every generation? Is it larger with maternal transmissions or is there an identical distribution between men and women?*
    - About 6% of paternal transmissions result in contraction of the repeat in the offspring. Expansion is more prominent with paternal transmissions when the repeat is small (37-100) while it is much larger with maternal transmissions when the repeat is over a few hundred.

Further information about these topic areas can be found at the following links:

- https://www.myotonic.org/what-dm/faqs
- https://www.myotonic.org/what-dm/medical-glossary
- https://www.myotonic.org/digital-academy/dm-anticipation-part-1
- https://www.myotonic.org/toolkits-publications

SECTION

2

MANAGING YOUR MEDICAL CARE

Finding a Care Team

Because of the range of systems affected in juvenile-onset myotonic dystrophy, affected individuals may see multiple specialists who are unaware of the full spectrum of issues that can be experienced. Informed individuals with DM often know more about the various aspects of DM than any single specialist that they see. It is important for the family to identify who is going to be your primary physician, meaning the doctor that should be called if you are in the emergency room, if you need a dental procedure, a routine surgery, or if another doctor prescribes you a medication. You need a doctor who is experienced in DM and can answer these questions for your other providers. You may have 6 or 7 different doctors, all of whom are experts in their specific field, but may not be an expert in DM. If you don't live near a center where active DM research is taking place, you can still assemble a skilled team to take care of you.

The variability in symptoms presents unique challenges in both the diagnosis and management of myotonic dystrophy. Therefore, it is important for you to learn as much as possible about the disease and its symptoms. Multi-disciplinary teams are often needed to provide comprehensive and coordinated clinical care. By taking an active role in care, you can help this process and make sure that potential complications are detected and managed at the earliest stages.

Table 2 on the following page lists types of specialists who are commonly a part of the myotonic dystrophy care team and their role in symptom management. A more comprehensive list can be found here: https://www.myotonic.org/working-your-myotonic-dystrophy-care-team

Your Understanding of your Disease

You may come into contact with providers throughout the medical system who may not know what myotonic dystrophy is nor how it affects you. They may ask you questions about yourself and your medical condition, so it is good to be prepared with what you will say to them. Below are sample questions that you may be asked by members of a medical team. While there are many other questions that your medical team could ask you, think about how you would answer these questions as preparation for upcoming appointments.



QUICK TIP

For more information about creating your care team, watch this video: https://www.myotonic.org/digital-academy/creating-medical-team-dm-care

For help with finding a provider in your area, please call 415-800-7777 or visit: https://www.myotonic.org/find-a-doctor

Table 1: Specialists who may be part of the DM care team and their role in symptom management

Specialists	Symptom Management Role
Neurologist	Weakness, stiffness, and chronic muscle pain, cognitive development delays, reduced executive function.
Primary Care Physician (PCP)	Exhaustion, inability to sleep well, excessive daytime sleepiness, feeling faint.
Cardiologist	Abnormal heartbeat, heart damage (cardiomyopathy), fainting spells.
Gastroenterologist (GI)	Chronic diarrhea, constipation, unexplained stomach pain, gallstones, swallowing problems
Geneticist/Genetic Counselor	Inheritance patterns of genetic conditions, genetic counselling, family members at risk.
Pulmonologist	Chronic respiratory problems, sleep apnea, frequent chest colds that do not go away, aspiration pneumonia caused by swallowing issues.
Ophthalmologist	Blurry or dimmed vision (possible cataracts), eye muscle weakness, droopy eyelids (ptosis).
Occupational Therapist (OT)	Problems managing daily living activities, assessment for equipment and housing adaptations.
Physical Therapist (PT)	Gait irregularities and muscle weakness.
Speech/Language Therapist (SLP)	Delayed or impaired speech, swallowing difficulties.
Dietician/Nutritionist	Weight control, special diets, alternative feeding methods and nutrition.
Social Worker/Case Manager	Social care needs, personal and respite care, social support.
Educational Psychologist	Special educational needs, additional support required.

General medical questions:

- What is your diagnosis? How do you explain it if someone asks?
- Do you take any medications? Which ones and why?
- Have you had any surgeries? If so, for what?

Questions about specialists:

- Has a pulmonary doctor (a doctor who specializes in lungs) spoken with you about ways of improving your breathing?
- Has a cardiologist (a doctor who specializes in the heart) spoken with you about your heart?

Other questions about yourself:

- What are you doing to stay healthy?
- Would you like to speak with someone about nutrition and exercise?
- Have you learned how to drive or how to use transportation services to get around your community?
- You may have learned about topics like relationships, parenting, sex and reproduction. What questions do you have that we can answer?
- Are you currently involved in any social activities?

Talking to Healthcare Professionals

You can play an active role in your health care by talking to your doctor. Clear and honest communication between you and your doctor can help you both make smart choices about your health. It's important to be honest and upfront about your symptoms even if you feel embarrassed or shy. Have an open dialogue with your doctor; ask questions to make sure you understand your diagnosis, treatment, and recovery. Many JOAs will need a caregiver to go with them to appointments to be an advocate and make sure all questions are answered. Some JOAs may present themselves to their doctors as committed and capable adults, but their caregivers see a different side at home, often of someone who is not capable of managing appointments on their own. The following tips can help you talk to your doctor and make the most of your appointments:

- Write down a list of questions and concerns before your appointment.
- Consider bringing a close friend or family member with you to your appointment.
- Take notes about what the doctor says or ask a friend/family member to take notes.



REMINDER

You will find a list of key terms and abbreviations in the Glossary. All blue bolded words and phrases have definitions listed there.

- Learn how to access your electronic medical records so you can keep track of test results, diagnoses, treatments plans, and medications.
- Ask for your doctor's contact information (email, phone) and their preferred method of communication.
- If you are having troubling understanding your doctors' responses, ask them to speak slowly and repeat themselves. Have a pen and paper handy to write down their answers.
- At the end of your appointment, repeat back to the doctor what you heard and what you need to do next; this makes sure you are understood.
- Other clinic staff such as nurses and pharmacists are good sources of information.

Transitioning Towards Age-appropriate Care and Increasing Care Needs

To ensure a smooth transition from pediatric to adult healthcare, parents and caregivers of juvenile-onset Adults with myotonic dystrophy need to consider all care options in advance, including the best care model for their family member. Some clinics begin at age 12 to 14 to prepare for the change from a "pediatric" model of care, where parents make most decisions, to an "adult" model of care, where youth take full responsibility for decision-making. At age 18, youth legally become adults. At that time, consent from the young adult will be required to discuss any personal health information with family members. If the young adult has a condition that prevents health care decision-making, then the parents/caregivers need to consider legal options that are required to become responsible for decision-making, such as conservatorship. This process should be accomplished before the youth turns 18. The following 'Self Care Assessment Form for Young Adults with Neurological Disorders' may help determine if your young adult family member with DM is capable of managing their own healthcare decision making after they turn 18 years old. https://www.childneurologyfoundation.org/wp-content/uploads/2017/08/C_SelfCareAssessmentParents.pdf

If your family decides that your JOA is competent to make healthcare decisions once they turn 18, review the below documents to prepare for the transition of care between pediatric and adult neurological care.

Transitions Checklist: https://www.childneurologyfoundation.org/wp-content/uploads/2017/08/B_TransitionChecklist.pdf

Plan of Care: https://www.childneurologyfoundation.org/wp-content/uploads/2017/08/E2_PlanofCare.pdf

The transition from pediatric to adult care can look very different for each JOA. Given the complexity of the diagnosis, some JOAs may

need to remain under the care of a pediatric team for longer than normal and gradually transition to adult care. The medical system doesn't formally recognize the juvenile adult stage in the same way that it recognizes the pediatric and adult stages. Many financial supports and programs that are available to children are discontinued at age 18 or 21, while some programs will switch from federal to state funded. While the JOA might remain in pediatric care until after age of 18 or 21, their social programs may be discontinued or changed. Once the JOA turns 18, it is important to work with the social worker and medical team at the clinic to access social services and programs that are available to adults.

Staying Organized

Keeping your medical information, appointments and tasks organized is vital to managing your medical care. Consider creating a three-ring binder that includes information on your upcoming appointments, general health (medical records), names and contact information for everyone on your care team, your health insurance information, prescriptions, and a copy of the clinic visit planner. The clinic visit planner helps organize information for upcoming clinic visits and provides a place to write questions to share with providers. https://www.myotonic.org/sites/default/files/pages/files/Myotonic-MyClinicVisitPlanner-2019.pdf

Transportation

Planning transportation ahead of time to get to medical appointments is necessary. Communication amongst family members regarding medical appointments is vital so the appointment can be put on the family calendar and transportation can be arranged. If you drive to appointments, consider obtaining a DMV disabled parking permit, which allows you to park in spots that are often closer to the office. More information about DMV placards can be found at the following link, or ask your doctor for a form: https://www.dmv.org/

Alternatives to driving to medical appointments include public transportation (bus, train), ride-sharing applications (Uber, Lyft), and county-based transportation programs (Paratransit). Each county in the United States has special transportation services for people with disabilities, often provided as a supplement to fixed-route bus and rail systems by public transit agencies. Call 211 or visit http://www.211.org/ to find your local Paratransit provider.



QUICK TIP

Consider keeping your medical information organized in a list like the following:

- Your name:
- Your address:
- Your phone number:
- Your E-mail address:
- Your diagnosis:
- Primary Care Physician (PCP) name and number:
- Neurologist name and number:
- Cardiologist name and number:
- Pulmonologist name and number:
- Other doctors names and numbers:
- Your insurance company, policy number, group number:
- Your parent/guardian/ caregiver name(s) and phone number(s):

SECTION

3

CAREGIVING 101

Barry M Cohen, Ph.D.

Mostly everyone I know who is a caregiver in the myotonic dystrophy (DM) community has not elected to take the 'job,' rather they became a caregiver because of illness, circumstance, and need. That is what happened to me. I had a large, active management consulting company, but my wife needed me. She grew progressively worse with DM1, struggling with balance issues and progressive weakness. I arranged my work schedule to care for her and keep her company. Her friends had pretty much abandoned her, which further aggravated her feelings of isolation and frustration. Fighting depression and loneliness further complicated her physical symptoms. I knew if the roles were reversed, my wife (an RN) would have cared for me. I naively stepped into the job; I thought it would be a "piece of cake." I can tell you now, years later, that caregiving was about the hardest thing I ever did. It takes an enormous physical and mental toll. If the person you are caring for is a young child, parent, or in my case my wife of almost 40 years, your time can become consumed by caregiving, even if that is not the intent.

The AARP Bulletin (2018) recently published a study tracking the longevity of family caregivers. The role of caregiver took years off their lives compared to a match sample of non-caregivers. I present this study not to scare you, or discourage you from becoming a caregiver, but rather to impress on you to prepare yourself for the role, and never forget that you must care for yourself all along your caregiving journey. You never know what will unexpectedly come your way. For example, my wife's mother was in an assisted care facility when I started caregiving for my wife. She suffered from Alzheimer's Disease; at first the symptoms were gradual and manageable, but as she got worse, I got emergency calls from medical facilities to come to her aid. Even when she was stable, I had to take her to doctors' appointments and consult with specialists on her medications and care. I had my hands full.

I have a son who has DM inherited from my wife. We had no idea that she had the disease and passed it on to my son. She was a healthy parent at the time. Fortunately, my son did not have debilitating symptoms when I began caregiving. He was the least of my challenges. I have known caregivers who have two and three children with DM as well as a spouse who has the disease. Hats off to them for all that they do.

It is important to understand caregiving responsibilities and the varied tasks that a caregiver will encounter. The following is a list of possible physical (P) and mental (M) demands that can come with caregiving.

- Establish a helping and trusting relationship (M). Don't underestimate this task! If your loved one is suffering, they may rebuff you, act out with anger, present impatience, and worse.
- Caregiving means providing companionship and fighting loneliness (M). People who have relationship building skills are at an advantage. I spent many hours reminiscing with my wife about our early marriage and raising our children. I made a special effort to keep her updated on world events and family happenings, and indulged her hobbies, such as scrabble and crossword puzzles.
- Toileting, including occasionally cleaning up accidents, helping with walking and getting up from seated positions (P). We got it down to a routine and I had guidance from hospital experts in how to most keep my wife as safe as possible.
- Falling is an ever-present threat; it can happen at any time. A person's leg can give out, trip over something they did not see (due to droopy eyes from muscle weakness) or fail to attend to something in their path (lack of focus or poor attention). Walking with the aid of a walker can help, but there is no substitute for an attentive caregiver (M). It was up to me to help her get up, even when she was emotionally upset and felt helpless on the floor. I had to calm and comfort her first and then lift her onto a couch or hassock nearby. I was trained by a physical therapist on lifting (P). When I couldn't lift her without hurting myself, I asked for help from neighbors and friends.
- I learned to keep a bedside commode by our bedside. It minimized falling at night, but I had to get up in the middle of the night and sometimes lost sleep (P).
- There are a myriad of tasks caregivers provide, such as contacting pharmacies, making physician appointments, dispensing pills, assisting with physical therapy exercises, buying aids, etc. I researched ways I could help my wife make her life easier. I often contacted other DM families about tips to make life easier (M). For example, my wife and I were on a helpline with our Myotonic Dystrophy Community and we learned about a simple plastic device popular in Europe called 'Acapella.' This device helps bring up phlegm, similar to the electronic device 'Cough Assist.'
- Parents of DM children are well aware that the disease can cause learning disabilities. About one half of all teens with myotonic dystrophy that I work with have these disabilities. Parents and caregivers often consult with educators, school psychologists, guidance counselors, speech therapists, and more (M). My son had learning disabilities and needed special tutors and special needs schools. The Myotonic Dystrophy Foundation published an excellent toolkit for parents, school specialists and teachers, called Going to School with Myotonic Dystrophy: A Guide to Understanding Special Education and IDEA. Caregivers of school age children can learn a lot from this toolkit about best ways to teach young people affected by the disease. https://www.myotonic.org/sites/default/files/pages/files/Myotonic-GoingToSchoolWithMyotonicDystrophy-2019.pdf

RESOURCE



Going to School with Myotonic Dystrophy: A Guide to Understanding Special Education and IDEA

Add subtitle "Finding a Caregiver"?

There are critical abilities and personality attributes that caregivers need to be successful. If you can afford caregivers part-time or full-time, select your caregiver carefully. You will need to first outline the particular tasks required for your situation. You can use my tasks above to start your list but make your own list to "fit" your unique situation. Once you have your list, decide if you will hire an agency or provide your own help. Ideally, a combination of both roles is needed to provide some relief from caregiving.

No matter what strategy you take, start with "pre-screening telephone interviews". This requires a resume, but do not make the assumption that someone with caregiving experience can do the work. In your pre-screening interviews, look for people who are willing to assume responsibility, show compassion for others, have a consistent work history, are willing to take initiative when the caregiving job requires it, and work in partnership with others. Listen carefully and ask good questions to learn about the candidates. It is often better to turn down candidates if you have any doubts about them. Telephone interviews can be short if it is apparent that the applicant is not a good fit for the position. Interviews should last about an hour for desirable candidates. It is important to do a background check before you offer the position to anyone.

Based on my own caregiving experiences and the experiences of other caregivers in the DM community, I have identified the "Success Factors" below that I believe are a part of exceptional caregivers. Applicants may not present all of these factors but be careful about candidates that you believe are going to have difficulty with any of these factors.

Maturity

A mature person makes considered decisions, balancing one's own needs with the interests of others, and is self-aware. Mature caregivers are not reactive; they consider circumstances when taking action, perform with a goal or purpose in mind, and consider what people around them need from them.

Sensitivity

A sensitive person has the ability to recognize other's feelings and be responsive to others. Sensitive caregivers are diplomatic and considerate; they genuinely care about the well-being of others and do not put their own needs ahead of others.

Partnership Skills

A person who accepts responsibility and steps up to one's commitments without making excuses or blaming others. Caregivers with exceptional partnership skills will take initiative to improve things and won't blame others for things that go wrong. For example, if a medication delivery is very late and medications are needed, a responsible caregiver will make arrangements to pick up the medications at the pharmacy.

Compatibility

A compatible caregiver has common interests with the client and enjoys common interests. Exceptional caregivers learn the interests of their clients

and will learn from them. A caregiver who learns how to play a game that the client enjoys or reads a book that the client finds enjoyable goes beyond the call of duty.

Listening

A person who has the ability to hear what is said even if the message is incomplete or implied. Individuals with DM can suffer from a lack of focus. As a result, they can omit or disconnect from their thoughts. A sensitive caregiver will gently ask for clarity or even restate certain words to help the client reach an understanding of what is meant.

Stress Tolerance

A person with good stress tolerance maintains a steady and consistent response even under stress, over-reaction, or emotional distress from the client. Caregiving can quickly change from being calm and predictable to feelings of frustration, outbursts, or anger. Caregivers need to keep a steady disposition even when things get tough and they can't drop out or withdraw even if they are feeling confused or conflicted as the client depends on them.

In summary, here are my wisdoms about caregiving. Good luck on your caregiving journey!

- Take care of yourself. Sleep, take respite, rest, eat well, deal with your own stress, laugh, and find joy in caregiving. It is a noble job - you can make a difference!
- You will be humbled by caregiving. It can take a lot out of you, but if you get back as much as you put in, you will find solace and compassion in the job.
- You may meet people in circles that you have never met before. While the list of health practitioners can get very long, do not forget the DM community and the Myotonic Dystrophy Foundation. Both are huge resources for you!
- Caregiving will try you physically and mentally. Examine your own readiness to step into the job. No one is perfect; we all have our strengths and weaknesses. Be prepared to learn about yourself. Caregiving is a life journey, not a short stint. Keep learning and enjoying the support of loved ones and caregivers in the community.
- Caregiving can give you great joy, despite its demands. It is an opportunity to develop a new relationship or renew an old one. Caregiving is relationship building; you can find joy from laughter, humor, new insights, and old insights renewed. Caregiving can be discovery as you seek new solutions to support your loved one. Look for happiness opportunities, such as telling stories or taking a journey down memory lane. Be creative; there are obstacles that can lead to solutions.
- Step away from caregiving; take a break, go to your favorite restaurant, visit with friends, enjoy time away, and treat yourself well. ***You deserve it!***



QUICK TIP

Want more information about caregiving? Contact the Family Caregiver Alliance at 800-445-8106, or visit https://www.caregiver.org/national-center-caregiving

SECTION

4

UNDERSTANDING YOUR BENEFITS, RESOURCES AND ENTITLEMENTS

There are various income and insurance programs that are important to know about if you are affected by myotonic dystrophy. This section will review Social Security Disability (SSDI), Medicare, Medicaid, private health insurance, and other state and federal benefit programs. If you need help navigating insurance and income programs, please contact the Myotonic Dystrophy Foundation at 415-800-7777 to speak with staff who can guide you in this process.

Social Security

The Social Security Administration offers two types of benefits for disabled workers, Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). While SSDI is funded by Social Security deductions from paychecks and serves individuals who have paid into the system, SSI is for low-income people, the blind, and children.

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

SSI is a cash benefit for people who:

- Have income and assets under the SSI program's strict limits, see here: https://www.disabilitysecrets.com/topics/financial-eligibility-ssi.htm

There are two ways that you can apply for SSI or SSDI benefits. You can:

- Apply online at https://www.ssa.gov/
- Call the toll-free number, 1-800-772-1213, to make an appointment to file a disability claim at your local Social Security office or to set up an appointment for someone to take your claim over the telephone. The disability claims interview lasts about one hour. If you're deaf or hard of hearing, you may call the tollfree TTY number, 1-800-325-0778, between 7 a.m. and 7 p.m. on business days. If you schedule an appointment, you will be sent a disability Starter Kit to help you get ready for your disability claims interview. The Disability Starter Kit also is available online at www.socialsecurity.gov/disability

RESOURCES

For more information on disability benefits, review: https://www.ssa.gov/pubs/EN-05-10029.pdf

Call Myotonic at 415-800-7777 to request a copy of the Applying for Social Security Disability Benefits Toolkit. Or you can download a copy of the guide at this link: https://www.myotonic.org/sites/default/files/pages/program/IDEAv26b.pdf

Medical Insurance

Medicare is the federal health insurance program for the elderly and disabled, comprised of Part A for hospital care, Part B for medical services, and Part D for prescriptions. It is run by the Centers for Medicare and Medicaid Services. Individuals (or their spouses) who have paid into the Social Security system for a total of 10 years, qualify for Medicare if they are:

- Aged sixty-five and older; or
- Disabled and eligible for Social Security benefits or have ESRD (permanent kidney failure requiring dialysis or transplant)

Medicare has three major components:

1. Part A (Hospital Insurance):

- Enrollment occurs automatically at age 65 with no premium charges, except for those individuals who did not pay Medicare taxes while employed. They can receive Part A by paying premiums.
- Part A provides coverage for care in hospitals as an inpatient, critical access hospitals, skilled nursing facilities, hospice care, and some home health care.
- It does not require periodic re-enrollment.

2. Part B (Medical Insurance):

- Part A beneficiaries may enroll and may sign up anytime during a seven month period beginning three months before turning 65.
- Enrollees pay premiums of $202.90 a month for calendar year 2026.
- Part B covers physician and outpatient services, including the services of physical and occupational therapists, and some home health care.

3. Part D (Prescription Medication Coverage):

- Part D pays for your prescription medications. You can purchase a Part D plan through a private insurer.
- Each plan generally has some premiums and out-of-pocket costs, either flat copays for each medication or a percentage of the prescription costs. They also may have an annual deductible.
- Check https://www.medicare.gov/ to determine if the plan you're considering has your medications on their covered list, called formularies. Formularies change from year to year, so it's important to recheck your plan every year at open enrollment time, from October 15 to December 7.

REMINDER

You will find a list of key terms and abbreviations in Glossary and Abbreviations on page 62. All blue bolded words and phrases have definitions listed there.

For more information on Medicare and to enroll, visit https://www.medicare.gov/index or call 1-877-486-2048.

The Health Insurance Counseling and Advocacy Program (HICAP) can guide you through the process of enrolling in Medicare. Find your local HICAP branch here: https://www.seniorsresourceguide.com/directories/National/SHIP/

Medicaid is the largest program providing medical and health-related services to America's poorest people. Medicaid was designed as a federal–state partnership to provide public funding of health care for low-income children and adults. States set income standards for adults without children, while parents of children are categorically eligible if they meet income and asset tests. Medicaid provides benefits that are not typically covered (or covered to a lesser extent) by other insurers, including caregiving, long-term care services and supports. It also pays for Medicare premiums and cost sharing.

Medicaid eligibility is based on categorical eligibility, meaning that people must fit into a pre-defined group of individuals:

- Children
- Parents
- Pregnant women
- Seniors
- People with disabilities
- Childless, non-elderly, adults (Affordable Care Act expansion)

Eligibility is based on the person, so some people in a family may be covered but some may not be (sometimes, kids are covered but parents are not). Income must be below defined limits, usually set by the Federal Poverty Level (FPL): https://www.healthcare.gov/glossary/federal-poverty-level-fpl/

The following services must be provided to individuals who are enrolled in Medicaid:

- Inpatient and outpatient hospital services
- Physician services
- Early/periodic screening, diagnostic, and treatment services for individuals under 21
- Nursing facility services for individuals ages 21 years and older
- Home health care for people eligible for nursing home services
- Family planning services and supplies
- Rural and federally qualified health clinic services

- Laboratory and X-ray services
- Pediatric and family nurse practitioner services
- Nurse midwife services

More information on Medicaid can be found here: https://www.hhs.gov/answers/medicare-and-medicaid/who-is-eligible-for-medicaid/index.html

To enroll in Medicaid, visit this link to find your local office: https://www.medicaid.gov/medicaid/eligibility/index.html

Private insurance plans are obtained through employment or can be bought through a broker or your states healthcare exchange. There are various types of private health insurance plans to choose from, depending on your age, finances, and health status. When choosing a health plan, consider the following questions:

Do you have any pre-existing conditions?

Pre-existing conditions are no longer an issue in terms of coverage availability as the Affordable Care Act (ACA) banned medical underwriting as of 2014, but this can be a factor in terms of picking a plan because benefits, out-of-pocket expenses, covered medications (formulary), and provider networks vary considerably from one plan to another. If one member of your family has pre-existing conditions or is anticipating significant medical expenses in the coming year, you may want to consider enrolling the family in separate plans, with more robust coverage for the family member who's expected to need more healthcare during the year.

Do you take any prescription medications?

Check the formularies of the health plans you're considering. You may find that one plan covers your medications in a lower-cost tier than another or that some plans don't cover your medications at all. Health plans divide covered medications into categories, generally labeled Tier 1, Tier 2, Tier 3, and Tier 4. Medications in Tier 1 are the least expensive, while those in Tier 4 are mostly specialty medications. Medications in Tier 4 are generally covered with coinsurance as opposed to a flat-rate copay.

Are you currently receiving medical care from a particular physician or hospital?

Provider networks vary from one carrier to another, so compare the provider lists for the plans that you are considering. If your provider isn't in-network, you may still be able to use that provider but with a higher out-of-pocket cost, or you may not have coverage outside the network at all. In some cases, you'll need to decide whether keeping your current provider is worth paying higher health insurance premiums. If you don't have a particularly well-established relationship with a specific doctor, you may find that selecting a plan with a narrow network could result in lower premiums.

Are you anticipating any expensive medical care in the coming year?

If you know that you have an upcoming surgery, for example, it will likely make sense to pay higher premiums for a plan with a lower out-of-pocket limit. You may get better value from a plan with a lower total out-of-pocket limit, regardless of how much the plan requires you to pay for individual services prior to meeting that out-of-pocket limit. For example, if you know that you're going to need a knee replacement, a plan with a total out-of-pocket limit of $3,000 might be a better value than a plan with a $5,000 out-of-pocket limit. Even if the latter plan requires copays for doctor visits, the former plan counts your doctor visits towards the deductible. It would ultimately be a better deal to pay the full cost of your doctor visits if you know that all of your healthcare spending on covered services will cease once you hit $3,000 for the year. Getting to pay a copay, instead of the full cost, for a doctor's visit is advantageous in the short-term. But for people who are going to need extensive medical care, the total cap on out-of-pocket spending may be a more important factor.

Private health insurance can be acquired in several ways.

- Group health insurance is the most common and is usually obtained through packages offered by employers.
- Individual health insurance is health coverage that is purchased by an individual or a family that is not tied to a job or a group of policyholders.
- The health insurance marketplace allows individuals to purchase private health insurance plans. The marketplace allows for direct comparisons of private health insurance options on the basis of price, quality and other factors, and coordinates eligibility for premium tax credits and other affordability programs. Find your states health insurance marketplace here: https://www.healthcare.gov/

More information about health insurance can be found in the Guide: Health Insurance Considerations for People Living with Myotonic Dystrophy in the United States: https://www.myotonic.org/sites/default/files/pages/files/Myotonic-InsuranceConsiderations-4-2020.pdf

Other State and Federal Benefit Programs

General Assistance (GA): GA is a welfare program that benefit adults without dependents (single persons or childless married couples). The General Assistance or General Relief (GA/GR) Program is designed to provide relief and support to indigent adults who are not supported by their own means, other public funds, or assistance programs. In some states, General Assistance programs are not universal and the policies of different counties or cities therein may differ widely. Find out if your state has GA here: https://www.usa.gov/benefits

Unemployment: Unemployment benefits are funded by the government for those who are registered as unemployed, often on conditions ensuring that they seek work, and are validated as being laid off and not fired for cause. Apply for unemployment benefits in your state here: https://www.careeronestop.org/LocalHelp/UnemploymentBenefits/unemployment-benefits.aspx

Family Medical Leave: The Family and Medical Leave Act of 1993 (FMLA) is a United States labor law requiring covered employers to provide employees with job-protected and unpaid leave for qualified medical and family reasons. Paid Family Leave (PFL) provides benefits to individuals who need to take time off work to care for a seriously ill child, parent, parent-in-law, grandparent, grandchild, sibling, spouse, or registered domestic partner. Benefits are also available to new parents to bond with a new child entering their life either by birth, adoption, or foster care placement. Find out if your state has PFL benefits here: https://www.dol.gov/general/topic/benefits-leave/fmla

State Disability Insurance (SDI): SDI is a partial wage-replacement insurance plan that is state-mandated and funded through employee payroll deductions. Five states (California, Hawaii, New Jersey, New York, Rhode Island) and Puerto Rico have State Disability Insurance. Note that some states require that you apply for and collect SDI before you can apply for SSDI. More information here: https://eligibility.com/state-disability-insurance

SNAP: Previously known as Food Stamps, this federal nutrition program provides food benefits on a monthly basis for those with qualifying income. Learn more about SNAP and how to apply at this site: https://www.usa.gov/benefits

SECTION

5

PSYCHOLOGICAL AND SOCIAL CONSIDERATIONS

By Missy Dixon, PhD, The University of Utah

Cognitive and psychological dysfunction, hallmarks of the central nervous system (CNS) alterations in childhood and juvenile-onset forms of DM1, are clinical characteristics to be considered in the care management of adults with juvenile-onset myotonic dystrophy (DM) given their impact on quality of life.[1-4] A wide range of neuropsychiatric symptoms and comorbidities reported in adolescents and adults with juvenile-onset DM include intellectual disability, age-related cognitive decline, speech and language delay, executive function deficits including working memory, inattention, processing speed, and visuospatial function, and autism spectrum disorder.[3,5-12] Additionally, characteristics of psychiatric disorders such as paranoid, dependent and aggressive personality patterns have been reported in the DM1 adult population,[13-15] as well as traits associated with internalizing disorders including apathy, low self-esteem, anxiety, and depression.[13,16-18] A progression of cognitive and psychological impairment may be observed with age and disease duration in the JOA population. As such, cognitive and adaptive abilities, level of impairment, mental/emotional age and maturity should be considered when caring for a JOA.

There are core cognitive control processes that are responsible for the direct management of cognitive, emotional, and behavioral functions that are necessary for problem solving. These core processes include19:

should these be capped?

- Response Inhibition: The ability to control impulses and behavior; appropriately stop and modulate ones own behavior at the proper time or in the proper context (e.g., ability to stay on task and not respond to distractions).
- Mental Flexibility and Control: The ability to change what you are thinking about, how you think about it, and what you think about it. We are required to exercise this process regularly when we change our minds about something or our circumstances change.
- Emotional Control: The ability to modulate emotional responses appropriately according to situational demand or context.
- Information Processing Speed: The speed of processing incoming information. It may be difficult to mentally keep pace with others if attention or other core processes are impaired.
- Sustained Attention: The ability to look at, listen to, and think about anything over a period of time. Without attention, learning does not occur, and issues of understanding and memory are affected.

- Working Memory: The ability to keep information in mind long enough to complete tasks or make an appropriate response (e.g., remembering instructions in order to complete an assignment).
- Multiple Simultaneous Attention: The ability to multitask with success by moving attention back and forth between two or more tasks at the same time. This process makes demands on sustained attention, response inhibition, and processing speed, and it requires organization and planning strategies, which are higher level skills.
- Category Formation: The ability to organize information, concepts and skills into categories, which forms the cognitive basis for higher level abilities such as applying, analyzing, and evaluating those concepts and skills. Category formation is the foundation of language formation and organization of the world.
- Pattern Recognition and Inductive Thinking: The ability to identify patterns and to figure out in a logical way what those patterns suggest about what will happen next. When this process is impaired, learning from past experiences does not occur, which can be potentially harmful, particularly when someone does not recognize unsafe situations and engages in unsafe behaviors.
- Plan/Organize: The ability to anticipate future events or consequences using goals or instructions to guide behavior. Developing or implementing steps in advance to complete a task or action.

Impairment in cognitive capacities can impact attention, anticipation, judgment, self-awareness, emotional development, and decision making. JOAs may experience deficits in one or more of the core capacities due to brain changes associated with DM1. It may be helpful for a JOA to work with a therapist to learn cognitive strategies to help improve or maintain their cognitive abilities.

How can Parents and Caregivers help JOAs with Cognitive Impairment(s)?

Below are strategies, based on the above core cognitive control processes, for parents and caregivers to consider using with JOAs who have cognitive deficits.

Response Inhibition:

- Provide a quiet and stable learning environment.
- Use instructional strategies to avoid distracting surprises.
- Teach and model strategies for self-regulation including breathing techniques, taking turns and waiting to provide a response.
- Answer questions about tasks before getting started.

- Gather materials that are necessary to complete tasks before starting, to reduce potential to be distracted.
- Write down the steps needed to complete the task.
- Break down steps into bite-size tasks.
- Have written reminders placed all over to help keep the JOA stay on task.
- Explore and discuss appropriate and inappropriate responses and behaviors with the JOA.
- Have written and verbal reminders asking the JOA, "Is my response helpful or hurtful?"

Mental Flexibility and Control:

- Alter everyday routines.
- Seek out new experiences.
- Practice using creative thinking to manage and solve problems.
- Identify multiple ways to solve a problem and chose a different way each time
- Meet new people.
- Use a different learning style.
- Identify several coping strategies to manage in different situations and practice using these strategies.
- Improve nutrition.
- Exercise 30 minutes a day.
- Practice good sleep hygiene (e.g., 7-10 hours of sleep per night).
- Use thought stopping techniques and thought reframes to identify negative thought patterns and use positive reframes.
- Schedule breaks and vacations.
- Try something new (e.g., new foods, new television show, new route to the store).

Emotional Control:

- Practice waiting to respond; don't react right away.
- Identify emotional triggers.
- Do not engage in certain conversations when tired.
- Practice good sleep hygiene.

- Use breathing techniques and relaxation exercises to slow down and improve logical thought.
- Use exercise or physical activity to short-circuit the neural network that reinforces emotional reactions. Being physical can shift your state of mind.
- Use visualization to identify emotional triggers and reframe scenarios in your mind.
- Drink a glass of water slowly to short-circuit typical emotional response pathways and behaviors by forcing you to concentrate on a different task.
- Use thought reframes to change the way you think and emotionally respond.
- Discuss emotions regularly when calm and use phrases such as, "I feel (emotion) when this happens" or "It makes me sad when you tell me that I am not good at math."
- Encourage the JOA to use alarms or reminders to "check in" with themselves or caregivers and identify their emotion. For example, the JOA sets an alarm for twice a day as a reminder to ask themselves "How am I feeling right now and why am I feeling this way?" This strategy aims to improve the JOAs awareness of their feelings and the associated circumstances.

Information Processing Speed:

- Slow down the rate of speech to match the JOAs pace.
- Provide time for the JOA to think over information.
- Invite and answer questions.
- Provide information using visual, auditory/verbal, physical forms/ strategies as ways for the JOA to receive and interact with and process information.
- Set timers to help improve speed and stay on track.
- Use appropriate language and terms when conveying information.
- Practice identifying key words and common phrases to decode information more quickly.

Sustained Attention:

- Chew gum.
- Drink water; maintain prescribed daily hydration.
- Exercise regularly; 30 minutes minimum per day.
- Practice meditation.

- Practice focusing on one task for 5 minutes and pace up in time.
- Use behavioral techniques including using timers, reminders, calendars, chunking information into digestible tasks.
- Schedule regular breaks.
- Remove distractions such as phones, television, email, social media; make your environment as calm as possible.
- Work in a quiet location.
- Do one thing at a time and avoid multitasking.
- Use alarms and reminders to bring your attention back to the task if you are not able to focus.

Working Memory:

- Use visualization and verbal skills repeatedly to improve working memory.
- Ask the JOA to teach you how to do something.
- Play games that use visual and verbal memory such as "telephone."
- Play cards.
- Encourage active reading and request that the JOA tell you what they are reading about (e.g., read the news paper and report on current events).
- Provide information into smaller portions.
- Give one direction at a time. Once mastered, add a second direction, then a third, and so on. Practice this technique regularly.
- Use multiple senses to improve working memory; Ask the JOA to describe something by how it looks, smells, feels, tastes, etc.
- Memorize numbers.
- Play "I spy."
- Use reminders via apps or sticky notes.
- Use calendars to remind of appointments.
- Set timers and alarms as reminders.
- Use checklists for tasks with multiple steps.
- Develop routines and practice them regularly.
- Reduce multitasking.
- Practice mindfulness to minimize distractions.
- Add exercise to daily routine.

Multiple Simultaneous Attention:

- Use a to-do list.
- Prioritize tasks.
- Group similar tasks.
- Reduce distractions.
- Monitor progress.
- Change from multitasking to single tasking.
- Take a brain break; Get up and do something different to give your brain an opportunity to rest and renew.
- Category Formation:
- Present new concepts or skills in more than one way and use repetition.
- Use categorizing, naming, and sorting activities (e.g., name different types of homes that people or animals live in; play "Go Fish" with a regular deck of cards).
- Use metaphors to teach new concepts and identify how they are similar to concepts that that JOA is already aware of.
- Ask the JOA to make connections between different behaviors and link them to potential outcomes.
- Name three people and ask the JOA what those three people have in common or how they are connected.

Pattern Recognition and Inductive Thinking:

- Discuss pattern behaviors and potential outcomes.
- Explore how and why pattern behaviors repeat.
- Break down behaviors into tiny steps and name step(s) that perpetuates the pattern.
- Ask the JOA to identify and explain pattern behaviors to parent/ caregiver.
- Use visual aids such as books and movies to identify patterns of repeated behaviors and consequences. Movies scripts often use behavior formulas for their plot and story development. Discuss similarities in movie character's behaviors as well as story endings. For example, the good characters in scary movies often become separated before walking directly into traps set by the bad characters; they never learn from their previous experiences and harm comes to them. Discuss alternative behaviors that the movie character could engage in to avoid having bad things happen to them.

- Explore how acting on impulses without thinking through things might contribute to pattern development, and discuss potential outcomes.
- Explore appropriate and inappropriate alternative behaviors and potential outcomes.
- Collaboratively explore behavior patterns of the JOA and others (e.g., can be a character from a book or movie, or someone that the JOA knows) and identify which behaviors often lead to unfavorable outcomes that come with negative consequences. For example, a JOA may express their frustration about boundaries and a curfew set by their parents by yelling at others, name calling, stomping around, and throwing objects. These types of behaviors negatively impact the the JOAs relationship with their parents and siblings, resulting in their siblings no longer wanting to go out to dinner with them. This consequence is a source of continued frustration for the JOA and their family.
- Discuss how brain changes may cause the JOA to think and do things differently than others. Validate their experience by recognizing the additional challenges that they may face. Use problem solving and cognitive-behavioral strategies (e.g., thought stopping and reframing techniques) to develop alternative coping strategies and positive reinforcements to establish and practice new behaviors that will lead to positive outcomes in the future.
- Use pacing strategies to practice alternative behaviors and focus on regular practice and consistency related to reinforcement. Allow time for the JOA to be successful in establishing new behaviors and training their brains to do things differently.
- Play pattern recognition games such as "Connect Four" and identify move patterns that contribute to losing the game. This can be done by stopping after each move to identify consequences to each move and alternative strategies, or by retracing moves and naming alternative moves at the end of the game.

Plan/Organize:

- Use checklists. Help the JOA use a list to organize thinking and prioritize tasks.
- Identify the number one thing to do on the list that day.
- Break tasks down into smaller, more manageable steps.
- Make a timeline to complete tasks with due dates.
- Rewrite lists regularly with the JOA to help them remember and prioritize tasks.

- Remind the JOA to read over the list before going to sleep to develop an action plan for the next day.
- Teach/remind the JOA to use a notebook or phone app to keep their list up-to-date and readily available.
- Teach/remind the JOA to take notes and use them as reminders of appointments and things that need follow-up.
- Help the JOA use a planner or calendar app to write down appointments and other important events that are both short and long term.
- Remind the JOA to consult their planner daily to plan and organize their time.
- Help the JOA make a schedule for their time and identify strategies to adhere to scheduling including use of alarms and timers as reminders of appointments.
- Practice breathing exercises and meditation to reduce worry and stress and promote relaxation. It is easier to think, plan and organize when our brains are not occupied with worries.
- Help the JOA organize their physical surroundings by decluttering, categorizing and labeling their things. Do this weekly.
- Help the JOA establish a filing system to categorize their belongings and keep them organized.
- Work with the JOA to designate a specific space to study or work.
- Help the JOA establish a designated study time using reminders and alarms.
- Model organizational skills to the JOA.
- Use a whiteboard and write down reminders, tasks, and to-do items.
- Help the JOA establish a plan of attack by asking them to break tasks into steps, prioritize steps and tasks, and provide a timeline for when the task will be completed.
- Help the JOA reassess timelines and priorities when needed.
- Help the JOA identify alternative strategies for completing tasks and staying organized.
- Provide positive praise and reassurance to the JOA that they are successfully building organization and planning skills with their continued dedication and practice.

Brain research indicates that the brain continues to grow and develop connections throughout life. Developing cognitive skills necessary to learn and improve functioning can happen across the lifespan.



QUICK TIP

For more brain activities that can help develop and improve cognitive skills necessary for learning, go to https://www.learningrx.com/brainbuzz-articles/smart-moms-toy-box/smart-mom-s-toy-box-10-games-under-20/

The learning skills that each activity utilizes are described and related to the cognitive processes mentioned in this section.

Cognitive symptoms may also be attributable to comorbid neurodevelopmental disorders such as autism (ASD) or attention deficit hyperactivity disorder (ADHD). Consistent neuropsychological evaluations are important to identify cognitive strengths and weaknesses, establish baseline level of function, identify appropriate interventions aimed at improving overall functioning in activities of daily living (e.g., participating at home/school/work/community, relationships, eating, sleeping, physical activity, socializing), and track changes in cognitive function with time and disease progression to maintain/improve quality of life. Knowing the etiology of cognitive symptoms and associated behaviors may be useful for parents and caregivers to support psychological health and social well-being in that it can be used to manage expectations related to abilities and changes in daily functioning, and in identifying strategies to address the behaviors. Additionally, services and therapies that address cognitive symptoms and behaviors associated with DM1 that overlap with comorbid neurodevelopmental disorders, such as ASD or ADHD, may be available and helpful for JOAs.

Myotonic Dystrophy Type 1 and Autism Spectrum Disorder

Autism spectrum disorder (ASD) refers to a broad range of developmental disabilities that can cause significant challenges related to social skills, speech and nonverbal communication, relationships, restrictive and repetitive behaviors, and self-regulation. ASD affects each person differently with distinct strengths and challenges associated with learning, thinking and problem solving. ASD symptoms vary widely in range and severity. Common symptoms include communication difficulties, problems with social interactions, sensory sensitivities, obsessive or restricted interests, and repetitive behaviors. Behavioral, developmental, cognitive, and psychological symptoms may be experienced by individuals with ASD and include the following:

- Behavioral: Poor eye contact, inappropriate social interaction, compulsive and impulsive behaviors, repetitive movements, self-harming behaviors, repetitive speech
- Developmental: Speech delay or learning disability
- Cognitive: Restricted interests or problems paying attention
- Psychological: Apathy towards other's emotions, anxiety, or depression
- Other: Sensory sensitivities to sound, touch, taste, smell and/or look

Awareness of potential ASD comorbidity in the JOA population is essential to their care. Studies of children and adolescents with childhood and juvenile-onset DM1 have shown that emotional and behavioral disorders are prominent in the DM1 population, with

ASD and other neuropsychiatric disorders being reported in 36-53% of the childhood DM1 population.[20,21] Difficulties in executive function and social cognition may contribute to the range and severity of symptoms, cognitive abilities and functional adaptations seen in JOAs with ASD comorbidity.[21] Neuropsychiatric symptoms commonly associated with children and adolescents with DM1 and ASD include developmental and language delay, attention deficit, hyperactivity, emotional and affective lability, lowered adaptability, and social withdrawal.[22] Cognitive symptoms and associated learning disabilities typically manifest before the neuromuscular symptoms in juvenile-onset DM1, and may represent diagnostic challenges and delays associated with juvenile-onset DM1.

One of the most important things that a parent or caregiver can do is to learn the signs of autism to know if their JOA is at risk for an ASD. Request a screening evaluation right away if there is concern about the JOAs behaviors and the possibility of him or her having autism. A professional evaluation is the crucial first step in understanding your JOAs world, diagnosis and treatment. Early intervention is key for people with autism and has a positive impact on outcomes later in life.

Genetic and environmental factors likely contribute to autism, but it is not clearly understood what causes ASD in the general population or in the DM1 population. Changes in certain genes may increase the risk that a child will develop autism. There is an increased risk of having autism if there is a family member who has autism. Genetic risk factors combined with environmental risk factors appear to impact early brain development related to how individual cells communicate with each other, as well as how different brain regions communicate with each other. While it is uncertain if the cognitive impairments and associated behaviors are exclusive to the DM1 cognitive phenotype, or if they warrant a comorbid diagnosis of ASD, it is clear that JOAs may experience significant cognitive impairments that can be associated with changes in brain structure and function. The resources below about ASD and DM1 are meant to create awareness of comorbid diagnoses associated with juvenile-onset DM1, and to provide an introduction to behavioral considerations for JOAs and their caregivers. It is imperative to consult your health care team about management of specific comorbidities and behaviors. To learn more about what causes autism, across the spectrum and throughout the lifespan, please refer to the resources at right. The autism community is well-established and has many resources and toolkits available.

To find autism resources in your area related to advocacy, after-school programs and camps, employment and education, evaluation and diagnosis, health and medical, housing and community living, recreation and community activities, safety, schools, state services and entitlements, support, and treatment and therapies, review the resources at right bottom.



RESOURCES

Autism links:

- https://www.autismspeaks.org/what-autism
- https://www.autismspeaks.org/signs-autism
- https://www.cdc.gov/ncbddd/autism/facts.html
- https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml
- https://www.autismspeaks.org/directory

For resources in your area:

- https://www.autismspeaks.org/resource-guide
- https://www.autismspeaks.org/directory

Myotonic Dystrophy Type 1 and Attention Deficit Hyperactivity Disorder

Attention deficit hyperactivity disorder (ADHD) is a common neurodevelopmental disorder that is characterized by differences in brain development and activity that affects one's ability to pay attention, control impulsive behaviors (may act without thinking about what the result will be), or be overly active (making it hard to sit still). ADHD is typically diagnosed in childhood with the symptoms and behaviors continuing throughout the person's adult life. ADHD can impact functioning at home, school, work, and in relationships. Signs that a JOA may have comorbid ADHD include:

- Consistent daydreaming
- Forgetfulness or trouble keeping track of things (e.g., losing things)
- Difficulty sitting still or constant fidgeting
- Talking too much
- Making careless mistakes
- Taking unnecessary risks
- Difficulty resisting temptation
- Difficulty taking turns
- Having a hard time getting along with others

ADHD is categorized into three different types that are based on symptom presence and severity, which can change over time. These include:

- Predominantly Inattentive Presentation
- Predominantly Hyperactive-Impulsive Presentation
- Combinded Presentation

Receving a diagnosis of ADHD is a process that involves several steps to rule out other psychological diagnoses, behavioral disorders, medical conditions, and learning disorders that have similar symptoms. Information about the criteria for diagnosing ADHD can be found through the resources listed below. Treatments typically include a combination of behavior therapy and medication. To learn more about ADHD treatments, review the links below. It is important to establish a healthy lifestyle to effectively manage the symptoms of ADHD. Healthy habits that impact attention functioning in daily life include: maintaining adequate nutrition and eating healthy, participating in daily physical activity that is appropriate for one's age, limiting amount of daily screen time, and establishing proper sleep hygiene and habits based on age. More information about healthy

lifestyle habits that can affect attention can be found in links at right. Additionally, ways that parents and caregivers can help JOAs who have attention and impulsivity problems are described in the previous section related to cognitive capacities and in the following section about the DM1 illness experience.

Attention Deficit Hyperactivity Disorder and Lying

Individuals with ADHD may experience impulse and/or behavioral issues that can result in lying. Similarly, some JOAs lie or offer less than truthful answers that can lead to false impressions related to competency and compliance behavior, mistrust among parents and caregivers, and health and personal safety concerns. In individuals with ADHD, sensory information overloads the prefrontal cortex, and before the brain is able to sort through consequences using empathy and compassion to guide it, the body reacts. The person does not learn from their experiences, which is potentially compounded by issues of executive function. Individuals with ADHD may lie unintentionally. What parents of JOAs construe as a lie may be an organizational or record keeping issue rather than an intentional attempt to deceive. Lying may also be due to impulsivity and used to explain impulsive behavior.

How Can Parents and Caregivers Help JOAs Who Lie or Exhibit Impulsive Behavior?

- Identify if the JOA is lying to get out of unpleasant tasks and use creative problem solving or outside of the box thinking to make tasks more exciting.
- Refrain from labeling the behavior as lying (in the traditional sense) because it is most likely that the behavior is not intentional. The JOA needs your help to develop more appropriate coping strategies to manage their impulsive behavior and cognitive impairments. Reframing lying as a JOA's coping strategy to manage behavior and cognitive impairment rather than deliberate misbehavior may help parents and caregivers of JOAs work together to effectively manage impulsive behavior and cognitive deficits.
- Identify lying as a coping mechanism to defend against vulnerability and avoid interpersonal pain rather than a tool of manipulation aimed at hurting parents and caregivers.
- Increase empathy and compassion to help the JOA understand that you know that they are coping with their DM1 as best as they can and you want to help them.
- Explore alternative coping strategies to manage impulsive and self-defeating behaviors, address cognitive impairment, and interpersonal vulnerabilities.

RESOURCES

ADHD links:

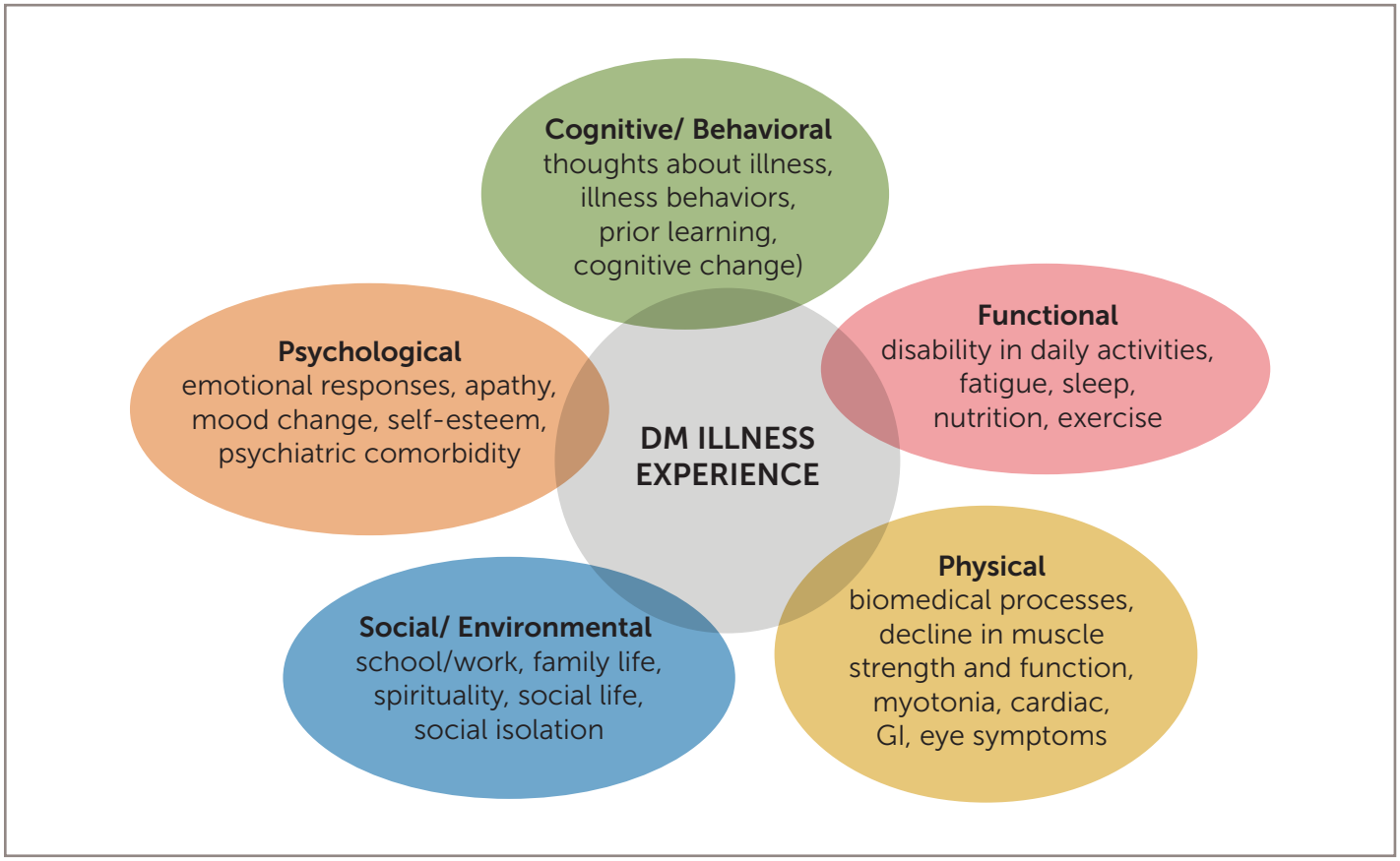
- https://www.cdc.gov/ncbddd/adhd/facts.html
- https://chadd.org/understanding-adhd/
- https://www.parentcenterhub.org/
- https://www.parentcenterhub.org/find-your-center/
- https://www.nimh.nih.gov/health/publications/could-i-have-adhd/index.shtml#pub1
- https://chadd.org/for-adults/overview/

- Practice using alternative coping techniques regularly and role play to increase the JOAs comfort with new strategies and normalize alternative coping so that it becomes the norm.
- Have JOAs use behavioral strategies such as setting reminders or alarms to remind them to ask "Is my behavior helpful or hurtful?" in an effort to increase awareness of impulsive and self-defeating behaviors, and to improve efforts of personal responsibility and behavioral control.
- Don't ask the JOA to retell the details of a lie that was told as this may only lead to additional lies. Let it go and move forward.
- Share your concerns related to the JOAs safety.
- Collaborate with the JOA to identify positive reinforcements that the JOA will work for to reduce the target behavior and improve overall functioning in interpersonal relationships.
- Improve social skills through training described later in this section to reduce the target behavior and improve overall functioning in interpersonal relationships.
- Collaborate with the JOA to identify appropriate consequences for impulsive behaviors or lying and develop an implementation plan. Provide consistent follow through with consequences when appropriate.
- Recognize that impulsive behaviors and lying may be developmental, and the JOA could be hiding incompetency or executive deficits because they do not want to be judged by others and/or they do not know how to describe their specific cognitive needs and ask for help. For example, JOAs may not recognize that they process information more slowly than others, so it may be more difficult for them to ask for help. Parents and caregivers who are aware that processing speed is slowed may ask the JOA if they would like more time to think about things and let them know that they can return to this conversation later.

Myotonic Dystrophy Illness Experience

Supporting the psychological health and social well-being of adults with juvenile-onset myotonic dystrophy requires a biopsychosocial approach to understanding myotonic dystrophy (DM), including the disease experience, effective communication, active listening, and promoting interpersonal skills to navigate relationships and the mental health aspects. The DM disease experience is unique to each individual and their care team insofar as we recognize that every juvenile-onset adult (JOA) is an individual. While JOAs may have symptoms and circumstances similar to other JOAs, their experiences are uniquely their own as a result of complex interactions between biological, psychological and social factors that are individually specific. For

Figure 1: The DM Illness Experience Model



*Adapted from Caplan, D. & Giles, L. (2013), The Illness Experience Diagram.

example, a JOA who experiences fatigue may have difficulties with thinking, communicating and holding a job, whereas another JOA with fatigue symptoms may experience changes in personality and relationship problems.

The DM illness experience includes physical, cognitive/behavioral, psychological, social/environmental and functional aspects of the disease. Some of the different factors that may affect illness experience include emotional symptoms, symptom frequency and severity, level of disability, access to healthcare providers and DM specialists, relationships and social supports, education, employment status, and economic resources. For family members and caregivers, understanding a JOA's symptoms in the context of their illness experience facilitates engagement between caregivers and JOAs, and provides a structure for communication that focuses on the impact that a particular symptom/behavior has on a JOA's daily function. Parents and caregivers can use the "DM Illness Experience Model" (Figure 1) as a communication tool to identify specific areas of concern and to develop a support plan.

For example, a decline in muscle function (physical domain) may contribute to thoughts and fears of falling (cognitive domain), increased disability in daily function (i.e., no longer able to go up and down stairs;

functional domain), which could socially isolate the JOA from family and friends if meet-ups involve stairs (social/environmental domain). An emotional response to this scenario could be changes in mood including symptoms of depression and increased apathy. It is difficult for someone to care about participating in events when there are barriers to participation. Understanding what those barriers may be and how they change as the myotonic dystrophy progresses is helpful when managing care. In the scenario mentioned above, caregivers identify mood changes and social withdrawal in their JOA. Using the DM Illness Experience Model to engage in conversation with the JOA about the relationship between the emotional and physical experiences of living with DM and how that impacts behavior, the parent/caregiver and the JOA can develop a plan to help improve psychosocial function. In this case, removing functional and environmental barriers by moving social gatherings to an accessible area may contribute to increased opportunities for social interaction, which may elevate mood and increase interest in relationships and social activities. Additional support could come in the form of professional counseling with a focus on using cognitive behavioral techniques to decrease target symptoms of internalizing disorders and improve functioning in activities of daily living including physical activity level, social experiences, interpersonal relationships, and work/school participation.

Communication and Social Skills

Communication skills are vital in all aspects of life, from personal relationships to professional life, mental health and everything in between. Effective communication involves accurately relaying information, ideas or opinions in a clear, concise and compelling manner with the emphasis on the receiver. Good listening skills are also essential to effective communication. An active listener is attentive, uses open body language, uses reflection, is non-judgmental, and appropriately responds in conversation. Useful communication techniques include relaxed and attentive body language, kind and concerned facial expressions, and appropriate tone of voice and cadence.

Effective communication is essential to managing the care of JOAs. Establishing consistent and effective communication with JOAs regarding their illness experience is useful when identifying their needs, decreasing feelings of ambiguity and associated frustrations, problem solving, and collaboratively developing plans that fit both JOA and parent/caregiver needs. Further, it conveys mutual respect of both parties and their shared journey in managing DM.

JOAs may experience difficulty communicating with others, miss social cues or appear apathetic to their environment, which can impact current relationships and their ability to form new and healthy relationships. Some JOAs may be autistic and this impacts the way

that they communicate and perceive the world. Social skills, meaning the skills that we use to communicate and interact with others, are the cornerstone of healthy interpersonal relationships, self-advocacy, and positive psychosocial experiences. Parents/caregivers who use effective communication skills and active listening in their interpersonal interactions and relationships model valuable social skills to JOAs. Repeated exposures to good communicators and opportunities to interact with them that commence early in life increases awareness of healthy and unhealthy communications, helps to develop respect for self and others, builds empathy and interpersonal skills, develops problem solving skills and increases accountability awareness for JOAs. Additionally, JOAs with well-developed social skills have an easier time identifying their physical and emotional needs in the context of their illness experience and communicating their needs to parent/caregiver.

How Can Parents and Caregivers Help JOAs Build Social Skills?

- Model effective communication skills including empathic listening, convey messages concisely and clearly, monitor non-verbal behavior and body language, manage your emotions, ask for feedback, think before you speak, be open to different answers and other opinions, provide positive feedback.
- Use appropriate language that the JOA will understand; using advanced vocabulary can lead to disengagement by the JOA because they are unable to organize and process information at an advanced level.
- When speaking, mirror JOA's rate of speech and voice volume to attend to their cognitive processing abilities.
- Allow adequate time for the JOA to organize, process and respond to information.
- Model active listening; hear what is being said so that you may respond with empathy; repeat back what is said so that it is clear that you received the message.
- Paraphrase if needed to clarify.
- Maintain eye contact when communicating and discuss the importance of good eye contact.
- Discuss the importance of body language and facial expressions in communication; ask for clarification if body language or facial expressions are incongruent with the message being communicated or if ambiguous.
- Check-in with the JOA about their feelings and illness experience.
- Ask open-ended questions and encourage JOAs to talk about themselves.

- Provide appropriate and respectful feedback during interpersonal interactions to convey mutual respect.
- Set appropriate expectations regarding verbal and physical behavior in relationships including expectations related to verbal and physical boundaries. Mutually discuss the importance and necessity of verbal and physical boundaries in relationships and what should be done if personal boundaries are not respected.
- Model boundaries in relationships related to communication by listening, making eye contact, attending to the conversation, not walking away, not doing something else at the same time that may look like you are not paying attention, asking questions and engaging in the conversation in a respectful way, and not talking over the other person. Do not dismiss the person's feelings or perception of their experience (children, adolescents and adults want to be heard and respected, too!). Put your phone down when engaging in conversations with others.
- Model physical boundaries in relationships by being respectful of other's physical being. For example, ask if it is okay for you to give them a hug and talk about why it is important to ask for permission to touch someone. This conversation can segue into a discussion about relationship expectations, providing consent, and why consent is important for healthy relationships.
- Express appropriate expectations, needs and wants specific to different types of relationships.
- Use "I feel" statements when providing feedback to increase the JOA's awareness of other's emotional responses to interpersonal interactions, to improve their sense of accountability for their social communications, and to build empathy and rapport skills.
- Model emotions for the JOA and discuss the importance of acknowledging emotions that are present. When emotions are ignored, they usually come out at some other inappropriate time in an inappropriate way.
- Ask regularly how the JOA feels and thinks to develop emotional awareness and to normalize this behavior specific to friendships and close personal relationships.
- Encourage the JOA to use reminders and timers to check in with herself/himself to identify how they feel and why they feel that way. Have the JOA practice this once or twice a day.
- Recognize social strengths in the context of the JOA's emotional age rather than chronological age where they may be seen as deficient at that level. Interact with the JOA on the highest emotional age that they exhibit regularly and show consistent follow-through that is emotional age-appropriate. For example, a JOA who is 23 may have the emotional maturity of a 10-year-old.

Keep this in mind during interactions and social skills training in order to maintain expectations, identify the JOA's strengths, and allow them to be successful.

- Discuss personal hygiene as a self-care behavior that is a social skill, including that maintaining good personal hygiene is important in relationships.
- Use creative problem solving to identify sensitivities related to personal hygiene and potential solutions to improve/manage hygiene. For example, a JOA may be operating on the emotional/mental level of a 11-year-old boy who does not like to shower. It may be that the JOA will shower in a particular bathroom when a certain soap is available. Discuss motivators to changing the JOAs behavior with the JOA and ask what they would like to get out of this if they are working hard to change their behavior. Use positive reinforcement to increase target behaviors (e.g., brush teeth and shower daily) and improve overall functioning in daily activities.
- Offer compliments generously.
- Practice appropriate manners in different situations.
- Enroll JOA in social skills training courses or other programs where social skills are practiced.
- Introduce one social skill at a time; practice using this skill often before layering in new social skills.
- Role-play often to practice and achieve competence in social skills.
- Provide diverse social opportunities for the JOA to practice social skills in the community.
- Practice, practice, practice: developing social skills requires dedication and repetition across a variety of settings.

Practicing social skills in a variety of contexts improves social and emotional competence. It is important to start developing social abilities early in life, as it can take much effort and a lot of time for JOAs to develop the necessary social skills to successfully navigate social interactions and relationships. Approach social skills building and emotional development from an ability frame of reference to understand the JOA abilities and capabilities, and use this information to develop a progress plan and move forward. Using social skills in relationships builds mutual respect, promotes healthy communication, improves psychosocial symptoms and well-being, and increases social connections and inclusion for JOAs.

Social Inclusion and Relationships

Social connectedness is central to a person's physical, psychological and social health. Positive social connections provide a sense of

purpose, offer emotional and social support, and fulfill a natural human need to belong. Physical health benefits associated with social connectedness and relationships include boosted immune system function, decreased inflammation, lower risk of cardiovascular disease, lower blood pressure, and good nutrition. Mental health benefits that have been attributed to strong social connections include lower rates of depression and anxiety, perception of lower level of stress, increased happiness, self-worth and confidence, greater empathy for others, better emotional regulation, a wider range of coping skills, and a decreased risk of suicide.

Making friends, dating, romantic relationships, and developing a sustainable social network requires hobbies and interests. Social inclusion and relationships are important to JOAs, regardless of their level of physical and cognitive disability. A key component of social inclusion for anyone in their social networks is that they perceive themselves, and they are perceived by others, as full participants in their relationships, with a focus on similarities rather than differences.

Friendships develop out of shared interests, experiences, and one's willingness to share in another's interests when they are different. Parents and caregivers can encourage JOAs to seek employment or volunteer opportunities at a place that aligns with their specific interests, or to participate in clubs or activities where people with their shared special interests are likely to gather. To find others with similar interests, a JOA can volunteer at a local animal shelter, become involved in community service projects, attend special events at the local library or community center, or participate in parks and recreational programs. Involvement in classes sponsored by a place of worship provides opportunities for JOAs to build friendships and experience social inclusion. Peer-mentoring programs are another way for parents and caregivers to facilitate the development of friendships.

Finding support online though social networks and special interest sites may be another way for JOAs to develop friendships. While these friends may not live in close proximity, having someone to share ideas with and talk to is another way of experiencing social connection. For example, the Myotonic Dystrophy Foundation offers a Facebook group and Facebook chat for JOAs to connect with each other, as well as a phone-based peer support network. Additionally, there may be a local DM support group that you can attend or a local support group for individuals with similar disabilities.

Some JOAs have sexual and intimacy needs, and some are interested in dating and marriage. It is important to recognize that age appropriate and socially acceptable expression of these feelings is normal. Social and sexual education, specific to the developmental level and intellectual attainment of JOAs, is necessary to promote healthy and positive social and sexual awareness. Effective sex education can empower JOAs to make appropriate decisions that contribute to quality of life, reduce the risk of sexual abuse, avoid sexual misunderstandings, and

prevent unwanted pregnancy and disease transmission. Sex education includes discussions of decision making and consent, cultural norms, peer pressures, relationships, social skills and communication, emotional and physical considerations, sexual promiscuity and values-based expectations, and the spectrum of sexual behavior beyond intercourse. It is necessary to provide JOAs with factual information specific to sexual intercourse, expressions of sexuality and intimacy, birth control/protection use, preventing pregnancy and sexually transmitted infections, and potential consequences of being sexually active including pregnancy and parenting. It is important to stress personal responsibility, values and expectations, and social norms during discussions about sex.

Additionally, teaching JOAs, beginning in childhood, boundaries normal to verbal, physical, and sexual interactions in relationships, and assertiveness skills to protect against verbal, physical, or sexual abuse, will help JOAs to develop positive and healthy behaviors and relationships. It is never too early or too late to start a conversation about personal safety and continuing this conversation into adulthood supports JOA needs related to developing and maintaining healthy relationships.

How Parents and Caregivers Support Social inclusion and Healthy Relationships?

- Be present and available.
- Use communication and social skills to model positive interpersonal interactions.
- Model positive relationships.
- Practice using social skills to promote positive relationships.
- Encourage social connectedness for through active participation in social activities.
- Encourage and help the JOA to develop friendships and a healthy support network. This may mean looking to other communities where cognitive impairment and neurodevelopmental delays are present in order to match the JOAs cognitive and emotional abilities with those of others who have similar strengths and challenges.
- Engage in open discussions of healthy and unhealthy relationships.
- Discuss dating and provide information specific to normal dating behaviors.
- Discuss different types of friendships and associated expectations.
- Discuss touching, kissing, intimacy and sexuality in relationships.

- Share your values.
- Discuss consent and practice providing/not providing consent using role play.
- Discuss peer pressure in relationships.
- Discuss emotional readiness in sexual relationships.
- Provide age-appropriate sexual education.
- Provide age-appropriate information about birth control/ personal protection. including what it is and what it does, why it is important and when to use it, the different forms of birth control/protection by gender and how they are to be used, where and how it can be obtained, and why it is important to ask and confirm that potential partners are using appropriate protection when in a sexual relationship.
- Encourage the JOA to discuss being sexually active with their health care provider and to seek information and advice about health considerations, personal safety concerns, birth control and using protection, sexually transmitted diseases, pregnancy and related issues, parenting and DM1.
- Discuss the outcomes of unprotected sex including pregnancy and acquiring sexually transmitted diseases.
- Engage in open discussions about sexually promiscuous behaviors, name what these behaviors are/look like, and share expectations related to values and sexual behavior.
- Identify safety concerns related to sexually promiscuous behavior and discuss the potentially negative consequences.
- Collaborate with the JOA and use problem solving techniques to identify appropriate actions/solutions to address potential consequences of being sexually active.
- Engage in discussions about pregnancy and raising children and share your expectations.
- Discuss the emotional experiences of relationships, social inclusion and exclusion
- Provide opportunities to meet and socialize with like-minded and diverse people across different social settings.
- Encourage the JOA to use the buddy system and go places with trusted family or friends.
- Discuss potential situations and ways that JOA can be taken advantage of.
- Identify safety concerns in social interactions and relationships including verbal, physical, and sexual abuse.

- Practice safe and unsafe scenarios often.
- Identify someone for the JOA to talk to when their relationship feels unsafe.
- Role play healthy and unhealthy friendships.
- Engage in open discussion of risky/unsafe behaviors and the consequences of engaging in this behavior (e.g., engaging in unprotected sexual intercourse and the potential to become pregnant and/or become infected with a sexually transmitted disease), and have these conversations often.
- Discuss internet safety and participating in social media and networks, establish acceptable and unacceptable behaviors related to internet and social media use.
- Identify unsafe internet behaviors, situations and ways to navigate such situations.
- Use role play regularly to practice with JOA what they would do when safety is at risk while on the internet.
- Explain that you may have to monitor their internet and social media use for safety reasons.
- Use problem solving with the JOA to establish ground rules for monitoring and mutually agreed upon consequences for breaking rules.
- Prepare the JOA for the emotional experience of rejection and normalize the experience.
- Discuss the evolution of friendships and the possibility that a friendship may end.
- Identify potential barriers to positive social relationships and ways to remove barriers.
- Teach and model assertiveness.
- Identify abusive behavior and ways to avoid abuse in relationships.
- Identify cyberbullying behaviors and what to do about it.
- Discuss relationships in the context of JOAs illness experience.
- Practice, practice, practice!

Seeking Social Support with a Mentored Relationship

JOAs, along with parents and caregivers, should determine if the JOA would benefit from having a mentor. Defining the mentor/mentee relationship is important. Identifying the JOAs and parent/caregiver's needs and expectations is essential to selecting the right mentor.

Selecting the right mentor is very important in that the mentor will be an influential person in the JOAs life; someone who will provide emotional and social support and model behavior. JOAs and parents/caregivers should consider the following questions when considering inviting a mentor to participate in the JOAs social network. What is it that the JOA wants from a mentor? How often does the JOA expect to interact with the mentor? Are the JOAs and parent/caregiver goals aligned when it comes to having a mentor? What types of activities would the JOA like to do with the mentor? For example, consider a male JOA who is interested in getting a part-time job in the near future. As such, he would like to develop, practice and improve his social skills across multiple social contexts to prepare for job interviews. The JOA would like to work with someone outside of his family who is male and available when needed.

Sourcing the local community for mentorship programs can be completed with a quick internet search. JOAs and parents/caregivers may also consider identifying a mentor through family, friends, colleagues and/or acquaintances. It is important to identify a mentor who not only has the skills needed to be a successful mentor, but also to take into consideration the person and to evaluate whether this person will be the right mentor for the JOA. Knowing the qualities of a great mentor is important when choosing and evaluating a mentor. Most important, a mentor needs to be a great communicator and teacher.

A great mentor…

- Always challenges the mentee to be better
- Can draw from relevant experience and wisdom
- Shares the mentees vision of success and where the mentee wants to be
- Supports the mentee by picking the mentee up when they stumble
- Is a great listener and is always willing to listen to more than just their own opinion
- Is invested in the mentees success and is happy for the mentee to succeed
- Provides the mentee with the necessary tools to figure out the answers
- Provides constructive feedback to help the mentee identify what went wrong, as well as offers praise when the mentee accomplishes something correctly
- Respects the mentee and sees the mentee as their equal
- Is available to the mentee to provide the help and guidance they are seeking

Managing Mental Health

Finding a Mental Health Professional

Finding the right mental health professional to work with JOAs may be a challenge, especially if the parent/caregiver or JOA has never worked with a mental health provider before. It is important that JOAs and their parents/caregivers trust the mental health provider and find them to be knowledgeable of the psychological complexity of living with a chronic illness. It may take time and persistence to find this ally and/or to build a treatment team. Additionally, the JOA has to feel comfortable working with this person. Working with a mental health professional is similar to dating, if the JOA does not feel safe and supported in this working relationship, find a different provider with whom the JOA will click.

Given the variety of symptoms that JOAs may experience in the context of myotonic dystrophy, you should look for a mental health provider who wants to be educated about DM and is motivated to learn more about the disease. You can let the provider know that DM symptoms include, but are not limited to: confusion or slowed thinking, learning problems, memory problems, changes in executive function (e.g., working memory, planning and organization, monitoring behavior), attention problems, prolonged depression (sadness or irritability), feelings of extreme highs or lows, excessive feelings of anxiety, social withdrawal, apathy, dramatic changes in eating or sleep habits, strong feelings of anger, delusions or hallucinations, low self-esteem, excessive thoughts or behaviors related to chronic medical illness, growing inability to cope with daily problems and activities, suicidal thoughts, denial of obvious problems, lack of insight, numerous unexplained ailments, and substance abuse. Additionally, JOAs may experience problems in their relationships, family situation, job loss, or the death of a loved one.

What type of mental health professional does the JOA need?

There are many reasons why a JOA would want to consult with a mental health provider. Identifying which symptoms or domain(s) of the DM illness experience (i.e., cognitive/behavioral, psychological, social, functional, physical) are driving their decision to seek help will aid in determining what type of mental health professional to pursue. Are you looking for someone who is licensed to prescribe medication? Do you want to work with someone who specializes in cognitive-behavioral therapy to help manage symptoms and improve overall functioning? Do you require the services of someone who provides diagnostic neuropsychological assessment and treatment?

Treating the neurocognitive and psychosocial symptoms associated with DM may require that the JOA be seen by more than one mental health professional, for example, a psychiatrist to focus on medication management and a psychologist or therapist who is specialized in psychotherapy and behavioral management. It is necessary to identify baseline cognitive abilities and track change with disease progression in order to provide the best care. A neuropsychologist can conduct a

neuropsychological evaluation to determine how the brain and nervous system function together and impact functioning in daily life. If a parent/caregiver is unsure of where to go for help, the JOAs primary neurologist or primary care provider is a good person to ask, as they can usually provide the contact information of a psychologist or psychiatrist. Searching for mental health providers by specialty on patient organization websites and mental health association websites may be helpful:

- Myotonic Dystrophy Foundation: https://www.myotonic.org/find-a-doctor
- Muscular Dystrophy Association: https://www.mda.org/about-mda/contact-us
- American Psychological Association: https://locator.apa.org/?_ga=2.68832728.830585145.1565183568-1572501961.1563660830
- American Psychiatric Association: http://finder.psychiatry.org/?_ga=2.85558298.220191076.1565206326-215490582.1564685147
- Autism Speaks: https://www.autismspeaks.org/applied-behavior-analysis-aba-0
- National Alliance on Mental Health: https://www.nami.org/Find-Support
- Mental Health America: https://arc.mentalhealthamerica.net/find-an-affiliate
- Center for Parent Information and Resources: https://www.parentcenterhub.org/
- National Institute of Mental Health: https://www.nimh.nih.gov/health/publications/could-i-have-adhd/index.shtml#pub1
- CDC National Resource Center on ADHD: https://chadd.org/understanding-adhd/

Here are some additional resources to help find mental health providers:

- The JOAs health insurance company can provide a list of mental health providers who are covered by the JOAs plan. Ask for at least three names and numbers of providers in case there is a long waitlist for a provider and/or the JOA and the provider do not click.
- US Department of Veteran Affairs: http://www.va.gov/health or call 877-222-8387
- Substance Abuse and Mental Health Services Administration: http://www.samhsa.gov/treatment or call 800-662-4357
- Your local health department's mental health division or community mental health center provides free or low-cost treatment.

- Some company's employee assistance programs (EAP) can issue a referral to a provider. Contact your Human Resources Department for information.
- Medicare: http://www.medicare.gov
- Medicaid (local state office): https://www.medicaid.gov/medicaid/benefits/index.html

Participation in a local support group is another valuable resource for JOAs seeking peer support. Support groups, often run by a layperson, are designed to bring together people with similar mental health or chronic health conditions. Check the links at right from the Myotonic Dystrophy Foundation about support groups, peer support, and a Facebook community for JOAs.

Which type of mental health professional should a JOA see?

Finding the right mental health provider is important. When selecting a particular provider, confirm credentials and competencies. It is reasonable to ask questions and to let the provider know that you are looking for someone that is comfortable working with adults who have a chronic disease that includes cognitive and psychosocial symptoms. When scheduling a visit, let the provider know that the JOA is a new patient so they can block out enough time for the visit. Join the wait list if the JOA is unable to get an appointment in the near future. Call other providers and if you find someone who can see the JOA sooner, remove their name from the other provider's wait list. Contact the JOAs primary care provider for help if you feel that the JOA cannot wait weeks or months for an appointment. If you feel that the JOA is in an emergency situation, go immediately to the nearest hospital emergency room or call 911. The following is a list of the types of mental health providers, the training of each type of mental health provider, and their associated competencies.

- Psychiatrist (MD): A medical doctor with special training in the diagnosis and treatment of mental and emotional illnesses. Psychiatrists are qualified to prescribe medication. Find a psychiatrist here: http://finder.psychiatry.org/?_ga=2.85558298.220191076.1565206326-215490582.1564685147
- Child/Adolescent Psychiatrist (MD): A medical doctor specially trained in the diagnosis and treatment of emotional and behavioral problems in children and adolescents. Psychiatrists are qualified to prescribe medication.
- Psychologist (PhD): A professional with a doctoral degree in psychology, two years of supervised professional experience, including a year-long internship from an approved internship site, state/provincial licensure to practice psychology and training to assess, diagnose and treat psychological and mental health problems through individual and group therapy. Find a psychologist here: https://locator.apa.org/?_ga=2.68832728.830585145.1565183568-1572501961.1563660830

RESOURCES

Myotonic Dystrophy Foundation support and community links:

- https://www.myotonic.org/find-support
- https://www.myotonic.org/myotonic-phone-buddies
- https://www.myotonic.org/juvenile-onset-adult-program

- Neuropsychologist (PhD): A professional with a doctoral degree in psychology or neuropsychology from an accredited university training program, two years of supervised professional experience, including a year-long internship from an approved internship site, two additional years of specialized training in clinical neuropsychology and a state/provincial license to practice clinical neuropsychology independently. A neuropsychologist can assess, diagnose and treat psychological disorders associated with brain-based conditions.
- Clinical Social Worker (MSW): A counselor with a master's degree in social work trained to make diagnoses and provide individual and group counseling.
- Licensed Professional Counselor (LPC): A counselor with a master's degree in psychology, counseling or a related field, trained to diagnose and provide individual and group counseling.
- Mental Health Counselor: A counselor with a master's degree and several years of supervised clinical work experience trained to diagnose and provide individual and group counseling.
- Certified Alcohol and Drug Abuse Counselor (CADC): A counselor with specific clinical training in alcohol and drug abuse trained to diagnose and provide individual and group counseling.
- Marital and Family Therapist (MFT): A professional with a master's degree with special education and training in marital and family therapy trained to diagnose and provide individual and group counseling.
- Pastoral Counselor: A member of clergy with training in clinical pastoral education trained to diagnose and provide individual and group counseling.

Building your JOA Care Team

Parents and caregivers can advocate for their JOA by recruiting team members who can help with their long-term treatment. Find supportive providers who want to collaborate with parents/caregivers and the JOA to improve the JOAs mental health and sense of well-being. Consider having the JOA be seen by a provider who works in a group practice to assure that there is someone to cover their treatment if the JOAs therapist is out of the office for an extended period of time. If the JOA wants to attend counseling with a partner or family member, find a different provider. This is important because attending couples or family counseling with the JOAs mental health provider or a family member's therapist introduces bias toward their individual patient and it is difficult for the therapist to remain neutral during couples/family treatment. SECTION 6: EMPLOYMENT

EMPLOYMENT

By Serena Master, MPH

Adults with juvenile-onset myotonic dystrophy have varying physical abilities, goals, and capacities when it comes to employment. Every JOA has a different situation and threshold to handle employment. This chapter will briefly review employment options of all kinds, but we will refer to the Employment Access Toolkit A Guide to Navigating the Employment Process for People Living with Myotonic Dystrophy as this Guide contains in depth information about the employment process. You can access the guide at this link https://www.myotonic.org/sites/default/files/pages/files/My-Employment-Toolkit-4-28-2020.pdf or request a hard copy by calling 415-800-7777.

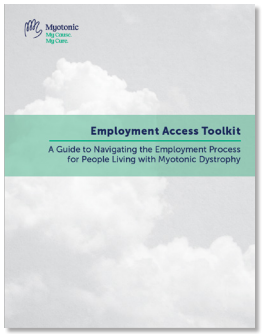
Assessing your Ability to Work

Before you (or your JOA) begin searching for a job, it is important to assess your DM symptoms and whether or not they will impact your work. People affected by myotonic dystrophy experience a wide variety of symptoms; the severity of your symptoms and the age of onset of DM (congenital, childhood, juvenile) can all affect your ability to work in any capacity. It is very important to keep track of your own symptoms, their severity, and whether or not they are getting worse over time. Keeping a log of your symptoms can help you determine whether or not you would be able to balance working and managing DM.

It's important to evaluate how your DM symptoms may affect your job. For example, if your DM causes you to have cataracts or blurred vision, it might be difficult for you to look at a computer screen for long amounts of time or read handwriting or small print. A list of questions about how to think about which jobs you want to apply for can be found on page 6 of the Employment Toolkit https://www.myotonic.org/sites/default/files/pages/files/My-Employment-Toolkit-4-28-2020.pdf

People with disabilities enrich the culture of the organizations for which they work. Parents and caregivers should assist the JOA they are supporting in networking for opportunities just as they would in their own job search. Competition for work can be fierce, especially during economic downturns. Don't be shy about calling your contacts; you are connecting them with a candidate who will add value to their organization.

RESOURCE



Employment Access Toolkit

Searching and Applying for Employment

If you would like to search for traditional employment, part-time or full-time, you may have to submit a resume tailored to the position that you are applying to. It is important to have a strong resume that stands out when applying for jobs. The following basic tips can help you create your resume but a more detailed version of this list and a resume builder worksheet can be found on pages 14-16 of the Employment Toolkit https://www.myotonic.org/sites/default/files/pages/files/My-Employment-Toolkit-4-28-2020.pdf

1. Read and analyze the position description
2. Develop a list of your accomplishments, experiences, and skills
3. Identify relevant skills
4. Choose a resume format
5. Keep it up to date

In addition to a resume, many employers require a cover letter with their job applications. The cover letter is an introduction to your job application and allows you to introduce yourself to a potential employer and explain how your strengths, skills, and/or accomplishments make you qualified for the position you are applying for. The content in your cover letter should match up with the content of the position description. Cover letters are great because they give you space beyond your resume to describe yourself. If you have no or limited work experience, do not be intimidated by the cover letter; you are not required to have work experience to write a cover letter. You may have qualities or skills that make you qualified for a job through your lived experience and you can incorporate this content into your cover letter. Some examples are personal projects, hobbies, interests, and school-related project. Writing a cover letter with limited work experience shows professionalism and maturity which are qualities that employers look for in applicants.

If you are ready to fill out a job application, consider how you will retrieve the application, either online or on paper. Most job applications are done online and can be done through the companies "Career" sections of their websites. You can retrieve a paper application for a job/career fair or by visiting a company yourself. Once you are ready to complete the application, be thoughtful, concise, and creative with your answers, and answer questions truthfully. Make sure you proofread your application before submitting it online or in person. Be careful with your personal information; many job applications ask you to fill out personal pieces of information like your social security number, so it is important to validate that the company you are applying to is real.

Don't be afraid to ask for help with the job application process; you can ask your family, friends, career/school counselors, or whoever you trust to guide you through the process. It may take some time for an employer to review your application and get back to you.

Consider applying to multiple jobs to increase your chances of getting an interview but remember that rejection is a natural part of the process, so stay positive if you don't get an interview. Information about the job application process can be found starting on page 23 of the Employment Toolkit https://www.myotonic.org/sites/default/files/pages/files/My-Employment-Toolkit-4-28-2020.pdf

The Interview Process

If you get an interview, consider the following steps to prepare yourself: Research the company

1. Practice your interview questions
2. Figure out what you will wear
3. Print out any materials
4. Plan your transportation
5. Get a good night's sleep

After your interview, write a thank you email or letter to the interviewer. Information about the interview process can be found starting on page 30 of the Employment Toolkit https://www.myotonic.org/sites/default/files/pages/files/My-Employment-Toolkit-4-28-2020.pdf

If you accept a job offer, remember that your DM symptoms may have effects in your workplace environment. You are not obligated to tell your employer about your DM diagnosis or symptoms, however, if you decide that you want to disclose that information, you are protected under Title I of the Americans with Disabilities Act (ADA). The ADA requires your employer to provide you reasonable accommodations in the workplace as long as they do not cause any undue hardship. You can find out more about how DM symptoms can affect your job on page 5 of the Employment Toolkit, and information about workplace accommodations can be found starting on page 45 https://www.myotonic.org/sites/default/files/pages/files/My-Employment-Toolkit-4-28-2020.pdf

Information about reasonable accommodations is available on the US Equal Employment Opportunity Commission's (EEOC) websites:

- https://www.eeoc.gov/disability-discrimination
- www.eeoc.gov/policy/docs/accommodation.html

Resources for the Job Search

AbilityJOBS allows job seekers to find thousands of open positions, while also providing a large resume bank for employers looking to hire qualified individuals. Job seekers can find potential employers and be found as well. http://www.abilityjobs.com/

The Employer Assistance and Resource Network on Disability Inclusion (EARN) supports employers in recruiting, hiring, retaining, and

advancing qualified individuals with disabilities through consultation and technical assistance, customized training, online resources and links to state and local community-based organizations serving job seekers with disabilities. https://askearn.org/

Idealist strives to connect people to different opportunities and collaborations that suit their needs and wants. Idealist lists opportunities for jobs, internships, volunteer, organizations, and graduate school programs. https://www.idealist.org/en/

Indeed strives to give job seekers free access to search for jobs, post resumes, and research companies. Their goal is to connect people to new opportunities and help people get jobs. https://www.indeed.com/

Institute for Community Inclusion (ICI) offers training, clinical and employment services, conducts research, and provides assistance to organizations to promote inclusion of people with disabilities in school, work, and community activities. https://www.communityinclusion.org/

The Job Accommodation Network (JAN) is the leading source of free, expert, and confidential guidance on workplace accommodations and disability employment issues. Working toward practical solutions that benefit both employer and employee, JAN helps people with disabilities enhance their employability, and shows employers how to capitalize on the value and talent that people with disabilities add to the workplace. http://www.askjan.org/

Office of Disability Employment Policy (ODEP) provides national leadership by developing and influencing disability employment-related policies and practices, with the goal of increasing the employment of people with disabilities. https://www.dol.gov/odep/

National Collaborative on Workforce and Disability (NCWD) assists state and local workforce development systems to better serve all youth, including youth with disabilities and other disconnected youth. Services include career development, education, families, transitions, professional development, workforce development, youth development and leadership. http://www.ncwd-youth.info/

State Directory of Vocational Rehabilitation (VR) agencies provide a state-by-state list of contact information for state VR agencies. Agencies are state-sponsored divisions of services that assist individuals with disabilities who are pursuing meaningful careers. https://askearn.org/state-vocational-rehabilitation-agencies/. Find VR agencies in your area here: https://choosework.ssa.gov/

VOCATIONAL EMPLOYMENT, INTERNSHIPS, APPRENTICESHIPS, AND VOLUNTEERING

By Serena Master, MPH

Vocational employment, internships, apprenticeships, and volunteer positions are all great options for adults with juvenile-onset myotonic dystrophy. These opportunities provide a variety of exposure for JOAs and can be tailored to the JOAs cognitive and physical needs.

Vocational education programs offer courses that prepare individuals for employment in current or emerging occupations that do not require a bachelor's degree or other advanced degrees. The National Center for Education Statistics groups vocational education into seven occupational categories:

1. Agriculture
2. Business and office
3. Marketing and distribution
4. Health
5. Occupational home economies
6. Trade and industry (e.g. construction, mechanics, and repairs)
7. Technical and communications

Types of Vocational Education

There are many types of vocational education programs offered through the public high school system including wood shop, metal shop, culinary arts, graphic design, business administration, etc. Regional vocational high schools allow students to attend part-time to get trained in occupational skills, while full-time vocational high schools offer academic studies with a focus on occupational and vocational training.

State Vocational Rehabilitation (VR) agencies help place people with disabilities with jobs that match their interests and abilities. This can be particularly helpful for people not looking for full-time work. VR funded job developers work with employers to meet their needs, which can sometimes be addressed in ways that the employer hadn't thought of. For example, shredding/scanning documents or watering plants could be of need for some businesses. The business may not have been advertising for those positions, but a job developer can help employers carve out positions that are of interest to the people with disabilities they support. To find the VR agency in your state, visit https://askearn.org/state-vocational-rehabilitation-agencies/



REMINDER

You will find a list of key terms and abbreviations in Glossary. All blue bolded words and phrases have definitions listed there.

Vocational education is also offered at post-secondary (post-high school) institutions including public and private four-year universities, community colleges, and vocational technical institutes. These institutions usually offer organized programs that teach subject-based occupational skills. Some vocational institutions allow students to graduate with degrees (e.g. Associate's degree) or certificates, while other institutions allow students to take courses to gain practical experience in a field or occupation.

Some people attend community colleges (also known as junior colleges, city colleges, or technical colleges), in order to receive an associate's degree. Associate's degrees are two-year degree programs that equate to the first two years of a Bachelor's degree program. Some people attend community college with the goal of receiving an Associate's degree in order to transfer to a four-year college and get a Bachelor's degree, while others pursue Associate's degrees to pursue vocational careers. There are three types of Associate degrees: Associate of Arts (A.A.), Associate of Science (A.S.), and Associate of Applied Science (A.A.S.). A.A. and A.S. degrees focus on providing students with courses that fulfill the academic and general education requirements of four-year institutions. These degrees are geared towards students whose goal is to attend a four-year university post-community college graduation. A.A.S. degrees are more career-targeted, vocational degrees which give students practical skills for vocational employment.

A certification such as ServSafe for food service may give you a competitive edge over other job seekers. Community Colleges are a good source of certificate programs for careers in fields including, but not limited to, animal care, childcare, food service, horticulture, information technology, web design and many others. Locate the community colleges in your area to determine which certificate programs they offer by visiting the American Association of Community Colleges at https://aacc.nche.edu. Check with your local vocational rehabilitation agency (https://askearn.org/state-vocational-rehabilitation-agencies/) or Career Center (https://careeronestop.org) to inquire about funding available for employment training. When you are exploring career opportunities, "job shadowing" can give you a better sense of the tasks involved in specific jobs and what education, training and/or experience are needed for the job. If you have a job coach through your school or vocational rehabilitation agency, they can assist you in setting up these one-day job shadowing visits.

Internships

Internships are professional learning experiences that offers meaningful, practical work related to a person's field of study or career interest. An internship gives the opportunity for career exploration, development, and to learn new skills. Participating in an internship is beneficial as Interns can temporarily "try out" working in a specific field to figure

out if they like it. Internships are helpful for people who have limited work experience and want to build their resume and skill set. They last a limited period of time and have an end date, therefore, are not permanently bound, and are useful for people who want to get their foot in the door at a place where they want to work. Some internships are paid, while others are unpaid, but unpaid internships are valuable because they teach skills that will help with obtaining a paid job in the future. Some internship openings will be posted on job sites, while other times, you have to inquire directly with employers to ask for an internship at their company. Getting an internship can be competitive so it is important to apply to multiple internships at once in order to increase your chances of being hired.

Apprenticeships

Apprenticeships are similar to internships but allow apprentices to learn new skills and on the job training for a specific job or field. However, an apprenticeship usually leads to a full-time job right after the training is completed. Apprenticeships are usually paid and last longer than internships. Apprenticeships allow apprentices to learn everything about a trade so that they can eventually do the job on their own. If an employer is willing to teach an apprentice an extensive skill set for a job, the apprentice is usually required to work for that employer after the apprenticeship ends. Apprenticeships are useful for people who know exactly what field or job they want to work in and need the skills and training to be able to get that job. Apprenticeship are less common than internships and can be difficult to find. Applying to more than one apprenticeship is a good way to increase your chances of getting hired.

Volunteering

Volunteering is an option if you want to give back to your community and/or gain new skills for future employment opportunities. Volunteering can be a practical and meaningful option due to the wide variety of settings that accept volunteers. There are various places where you can volunteer including company events, community events, philanthropic events, and more. For a list of volunteer opportunities near you, search www.Google.com, look for events on www.Facebook.com, look for local listings at community centers, or ask family members or friends if they know of any opportunities within their networks.

SECTION

8

SOCIAL AND RECREATIONAL PROGRAMS

By Susan Ring Brown, MPA

There are various social, recreational, and supportive programs and resources in the community that can provide critical support to juvenile-onset adults with myotonic dystrophy. This section will review these programs in depth.

Independent Living Centers

Independent Living Centers are community-based, cross-disability, non-profit organizations designed and operated by people with disabilities. According to the National Council on Independent Living, Centers for Independent Living provide:

- Peer support
- Information and referral
- Individual and systems advocacy
- Independent living skills training
- Transition

To find an Independent Living Center in your area, visit the Independent Living Research Utilization's (ILRU) directory at https://www.ilru.org/projects/cil-net/cil-center-and-association-directory or call 713-520-0232 (Voice/TTY). This directory is user-friendly, with options listed by state via the map and listed alphabetically by state on a list.

Day Programs

Adults with juvenile-onset myotonic dystrophy may be eligible for Medicaid funded day habilitation programs which support maintenance of daily living skills and provide opportunities to develop friendships. These day habilitation programs typically offer a range of services such as physical and occupational therapy, arts, current events, volunteer opportunities, and community activities.

The Arc, a national nonprofit organization with over 600 independent chapters across the U.S. offers a range of services for people with intellectual and developmental disabilities such as day habilitation, recreation and volunteer opportunities which may be beneficial to JOAs Available services vary by chapter and may require referral from a state disability service agency. To find the Arc chapter in your area, visit https://thearc.org/find-a-chapter/ or call 800-433-5255.

United Cerebral Palsy, a national organization with affiliates operating independently around the country, supports individuals with a very broad range of developmental and physical disabilities. Services vary by affiliate and include day habilitation. To find the United Cerebral Palsy affiliate in your area, log onto https://ucp.org/find-us/ or call 202-776-0406.

REMINDER

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Social and Recreational Programs

A social life can be difficult for some juvenile-onset adults with myotonic dystrophy due to their lack of age appropriate behavior and inability to read social cues. These social and recreational resources are available to support JOAs, to help develop friendships and social connection.

The YMCA is a welcoming organization with over 2,700 branches/associations across the U.S. Becoming a member of the YMCA allows access to fitness equipment, classes such as swimming, water aerobics, yoga, and personal coaching. Some YMCA branches offer classes and programs that provide additional support or accommodations for people with disabilities. The YMCA serves as places to foster social networks, providing opportunities to get to know others with similar interests. As with other national organizations with chapters across the county, services vary by individual branch. To find a YMCA near you and to inquire about local services, visit http://www.ymca.net/find-your-y/ or call 800-872-9622.

Special Olympics offers opportunities for individuals with disabilities to participate in over 30 sports. Teams may be made up entirely of participants with disabilities or unified teams comprised of people with and without disabilities. The Special Olympics is not restricted by age, in fact, a third of Special Olympic athletes are age 22 or older. Joining Special Olympics can be a great option for a JOA, if they are physically able and motivated to participate. For more information and to find the Special Olympics chapter near you, visit https://www.specialolympics.org/ or call 1-800-700-8585.

Best Buddies provides people with intellectual and developmental disabilities with the opportunity to develop friendships both in-person and online. Their Citizens Program matches participants age 18 and older in a one-to-one friendship with a peer without a disability. A Best Buddies staff member creates the matches, provides ongoing support, and helps plan activities for buddy pairs. E-Buddies is an e-mail pen pal program that matches participants in one-to-one e-mail friendships with peer volunteers. E-Buddies e-mail each other at least once a week for a minimum of one year. Best Buddies addresses the safety and privacy of all participants with and without disabilities by screening all applicants and requiring adherence to the terms of the e-Buddies Code of Conduct. All communication between e-Buddies is conducted through the e-Buddies E-mail System. To learn more and to locate a Best Buddies chapter near you, visit https://www.bestbuddies.org/find-programs/ or call 305-374-2233.

Social skills groups are an option for JOAs who would like to interact with others at their level. Social skills groups are small groups (typically two to eight) led by a facilitator who teaches how to interact appropriately with others their age. These groups can help

JOAs learn conversational, friendship and problem-solving skills. Ask your occupational therapist for a social skills group in your area.

It is getting easier for people with disabilities to travel. Advocacy and the aging of the U.S. population have prompted tourist attractions and the travel industry to help break down barriers for participation. Preparation is key. The American Automobile Association, AAA, featured a series of accessibility articles in their April 2019 newsletter https://magazine.northeast.aaa.com/daily/travel/air-travel/accessible-travel/

The National Park Service has made a concerted effort to provide information that people with disabilities need to have an enjoyable visit to national parks across the country (https://www.nps.gov/aboutus/accessibilityforvisitors.htm). You'll find this information under "Plan Your Visit" on individual park's website https://www.nps.gov/findapark/index.htm

For those rainy days that make us all want to curl up at home with a good book, individuals with DM may utilize the National Library Service for the Blind and Physically Handicapped (NLS) free loan service of recorded books and magazines plus specially designed playback equipment. To find NLS resources near you, click the following link https://www.loc.gov/nls/braille-audio-reading-materials/find-a-local-library/ or call 1-888-657-7323.

Supports to Achieve and Maintain Self-Sufficiency Within the Community

In-Home Support Services (IHSS), also known as Personal Care Assistance, helps people with disabilities preserve their independence and avoid placement in an institutional facility. Aides provide assistance with tasks such as dressing and undressing, bathing and grooming, toileting, shopping, meal-prep, eating and clean-up, taking medications, mobility/transfers, laundry and other housekeeping, transportation to medical appointments and maintaining adaptive equipment. These in-home supports are available on both a private-pay and a Medicaid-funded basis for eligible individuals with disabilities. These aides are typically employed by the person with the disability, with administrative support from an Independent Living Center (https://www.ilru.org/projects/cil-net/cil-center-and-association-directory or 713-520-0232) or other nonprofits including some chapters of The Arc (https://thearc.org/find-a-chapter/ or 800-433-5255) and some United Cerebral Palsy affiliates (https://ucp.org/find-us/ or 202-776-0406). The aides may be, but are not necessarily, relatives of the person served.

The National Council on Aging is leading a collaboration to make it easier for people with disabilities to access the long-term support services that they need. Around the country, disability and elder

service organizations are partnering to raise awareness about and provision of these services. To learn about partnerships in your area, view the National Council on Aging's map (https://www.ncoa.org/ncoa-map/) and enter your zip code or call 571-527-3900.

For some adults with juvenile-onset DM, addressing complex medical needs in the home setting may be the key to remaining at home. Home health agencies provide medical care and rehabilitation services in the home, often for people who are recently discharged from the hospital. Services are covered by insurance and can include physical therapy, nursing, occupational therapy, speech therapy, social work, and home health aides. The federal government has created a link to locate and compare home health agencies in your area: https://www.medicare.gov/homehealthcompare/search.html. The National Association for Home Care and Hospice can also connect you with providers in your area, visit https://agencylocator.nahc.org/ or call 202-547-7424. Please note that hospice is not just for people at the end of their lives; some hospice programs also offer pain management services for people with chronic illness. These in-home services may also be accessible through your local community health center or medical clinic.



MORE RESOURCES

All In! Accessibility in the National Park Service, 2015–2020: https://www.nps.gov/aboutus/accessibility.htm

Federal government assistance guide for people with disabilities: https://www.usa.gov/disability-financial-support

SECTION

9



REMINDER

You will find a list of key terms and abbreviations in the Glossary. All blue bolded words and phrases have definitions listed there.

HOUSING

By Susan Ring Brown, MPA

Adults with juvenile-onset myotonic dystrophy (DM) may have a broad range of housing needs but there are options for every situation. Enlist the help of local disability service providers and other parents/caregivers as you explore the possibilities to best address your JOAs housing goals. Chapters of The Arc and United Cerebral Palsy offer multiple housing programs, Independent Living Centers and resources for information and related services. To find a chapter of The Arc in your area, visit https://www.thearc.org/find-a-chapter or call 800-433-5255. To find the United Cerebral Palsy affiliate in your area, visit https://ucp.org/find-us/ or call 202-776-0406. Chapters and affiliates that do not provide housing will often have information and referral services. To find your local Independent Living Center, visit https://www.ilru.org/projects/cil-net/cil-center-and-association-directory or call 713-520-0232.

For some individuals, an in-law type apartment, carriage house or small manufactured home on the property of a parent, sibling or other relative may offer the right combination of independence and support. If this seems to be the best option for your JOA, contact your city or town hall to inquire about any zoning restrictions that may apply.

In some cases, living in a family setting with a family other than one's own is a good option. Adult Family Care/Shared Living models, previously known as Adult Foster Care, are not new but are becoming increasingly popular both for financial and philosophical reasons. Local disability service organizations provide case management services and help match the person with the disability with an individual or family based on common interests such as a love of sports, animals, outdoor activities, etc. In some instances, the provider may be a relative. In all cases, the individual receiving support becomes part of the family. Placements in which only one person with a disability is placed with a provider may result in a greater focus on the individual's specific needs and interests. These services may be covered through Medicaid or by state disability service agencies.

The range of supports provided in Community Residences (formerly known as Group Homes) is based on the needs of the residents. This may include some level of nursing support which may be on-site or on a more limited basis, with nursing staff coordinating and reviewing the medical care that the individual receives through community-based providers. Community Residences are operated and usually owned by a nonprofit. A group of two to six individuals with disabilities live in a home together with on-site staff support. Residents have their own bedrooms and share bathrooms and common areas such as a living room and kitchen. They usually go to work or day habilitation programs during the day and often socialize together during the evenings and on weekends. Nonprofit providers typically staff and provide transportation for social activities.

Supported or Independent Living Services are for people who have the ability to live safely in their own apartment, condo or house but may need a few hours of help per week with tasks like scheduling, getting to medical appointments, bill payment, and balancing a checkbook. Disability service providers offer case management and training in areas such as nutrition and safety for individuals in supported or independent living.

It is important to note that for the housing models described above that are provided by disability service organizations, admission is often based on referral from government disability service agencies, but private pay options may also be available on a self-referral basis.

A national philosophy of community inclusion and increased competition for resources have led to increased collaboration among nonprofit housing organizations. As a result, you may find housing for JOAs in unexpected places. Affordable housing organizations and nonprofits such as YMCAs may partner with disability service organizations in your area to provide housing options. The YMCA has provided affordable housing since the 1860s. To determine whether your local YMCA offers single room and/or family housing, and whether they are partnering with other organizations to provide housing support services for people with disabilities, visit http://www.ymca.net/find-your-y/ or call 800-872-9622.

Assisted Living Facilities are a private pay housing option for people interested in maintaining their own apartment but desire meal service and social opportunities in a community setting. These facilities are primarily designed for and marketed to seniors, which may be a drawback for some JOAs. These facilities are not based on a medical model so they are not required to employ medical personnel. Depending on your area, Assisted Living Facilities may also be known as Residential Care Facilities, Board and Care Homes, or Rest Homes. Although Assisted Living Facilities are not considered nursing homes by definition, some offer different levels of care on the same property, providing nursing services as residents' health needs increase over time. For Assisted Living resources in your area and tips on choosing a facility, visit the National Center for Assisted Living website at https://www.ahcancal.org/ncal/about/assistedliving/Pages/default.aspx

JOAs may need financial assistance to afford the cost of housing, thus rental assistance can be an option based on income. Your local housing authority is the best resource for information about available public housing and rental assistance for individual apartments through the Housing Choice Voucher Program (formerly known as Section 8). These two models are considered Project-Based Rental Assistance (PRA), which is associated with particular residential units (public housing), whereas Tenant Based Rental Assistance (TBRA) is not associated with particular units and can be used to obtain housing in any independent housing unit that meets the program guidelines. Keep in mind that once you apply to these programs, the waiting period can be very long since demand far exceeds availability.



QUICK TIP

To find the phone number and email address for your local housing authority, visit the map on the U.S. Department of Housing and Urban Development web site https://www.hud.gov/program_offices/public_indian_housing/pha/contacts

SECTION

10

MY LIFE AND WELCOME TO IT: LIVING WITH MYOTONIC DYSTROPHY

By Scott Valek

Back in 2006, my dad, Karl Valek, was diagnosed with the adult-onset form of type 1 myotonic dystrophy. He was 47 years old. At that time, knowledge about the disease seemed out of reach for most people. Myotonic dystrophy (DM) is a form of muscular dystrophy that creates many extra chains of three amino acids and results in the formation of toxic proteins in all the muscle cells (especially damaging in heart and lung muscles).

Dad's diagnosis did not come as a complete surprise because earlier in 2006, both of his younger sisters had already received the same diagnosis of juvenile-onset DM. My Mom, Carolyn Valek, realized that Dad had many of the same symptoms as my aunts and she scheduled an appointment with a neurologist to do a genetic test and to confirm the diagnosis. It was really hard for Mom to find any information about DM education and patient support on the Internet. She found an organization based in Great Britain that had some dated information. She also signed up for the Muscular Dystrophy Association (MDA) to qualify for some services for Dad, but they really didn't have a specific education or support program for myotonic dystrophy at the time.

Luckily for my family, the San Francisco Bay area based Myotonic Dystrophy Foundation (MDF) was launched in 2007. When Mom connected with MDF, she found all the information she needed in one place. After registering Dad, MDF sent out a toolkit and a couple of books explaining DM and how to manage symptoms. There was a phone number to call (415-800-7777) where MDF staff would connect callers to experts to address their questions. This information was important to her because many of Dad's current doctors had not heard of DM and did not know much about how the disease affected Dad's healthcare. Through MDF's Find a Doctor interactive map (https://www.myotonic.org/find-a-doctor-map), Mom found DM specialists close-by at Ohio State Wexner Medical Center. She was so grateful for this information that she became one of the first support group facilitators in the U.S. and became involved with many of MDF's efforts.



The Valek's enjoying a visit to Venice.

By 2013, when I was diagnosed with juvenile-onset DM, my family knew where to turn to find the specialists and care that I needed. Through MDF, I have attended meetings with legislators including U.S. Senator Sherrod Brown (D-OH) to advocate for funding for rare diseases. I have also been connected to research which I participated in at the Ohio State Wexner Medical Center.

Most importantly, I have participated for two years in the juvenile-onset adult ambassador program at the annual MDF conferences. Through the JOA program, I have met other adults who have the same form of DM as me. During the conferences, we spend an entire day together getting to know each other and sharing our challenges of dealing with DM. Because of this personalized support, I think MDF is the most successful at education and services for people with myotonic dystrophy and I am grateful for their efforts.

Update on Scott: He is 24 years old. In May 2020, he reached his long-time goal of attaining an Associate Degree in recreation and leisure from Columbus State University College through an online program. He was excited about it even though his commencement ceremony was rescheduled for December 2020. Congrats Scott!

A GLOSSARY

A

Adult family care: A family-type living arrangement in a private home providing room, board, and personal care. A match between the individual and the provider may be made by a disability service organization. Covered by Medicaid funded for income eligible adults. Also known as Adult Foster Care or Shared Living.

Adult foster care: A family-type living arrangement in a private home providing room, board, and personal care. A match between the individual and the provider may be made by a disability service organization. Covered by Medicaid funded for income eligible adults. Also known as Adult Family Care or Shared Living.

Adult onset: First presents after the age of 21; often refers to DM1 that.

Anticipation: The tendency in certain genetic disorders like myotonic dystrophy for individuals in successive generations to present with symptoms at an earlier age and/or with more severe manifestations. The mutation tends to increase in size and have a more significant effect when passed from one generation to the next.

Assisted living: A form of housing where residents have their own apartments and share common areas such as a dining rooms and sitting rooms. Services include meals and social opportunities. Unlike nursing homes, these facilities are not required to engage medical professionals. Personal care assistance may be included or available through other providers. Also known as board and care homes, residential care facilities or rest homes.

Attention Deficit Hyperactivity Disorder (ADHD): Mental health disorder that can cause above-normal levels of hyperactive and impulsive behaviors. People with ADHD may also have trouble focusing attention on a single task or sitting still for long periods of time. Both adults and children can have ADHD.

Atrophy: The wasting away of a body tissue or organ, especially as a result of the degeneration of cells.

Autism spectrum disorder (ASD): A condition related to brain development that impacts how a person perceives and socializes with others, causing problems in social interaction and communication.

B

Board and care homes: A form of housing where residents have their own apartments and share common areas such as a dining rooms and sitting rooms. Services include meals and social opportunities. Unlike nursing homes, these facilities are not required to engage medical professionals. Personal care assistance may be included or available through other providers. Also known as Assisted living, residential care facilities or rest homes.

C

Chromosome: One of the bodies (normally 23 pairs) located in the nucleus of a cell that hosts the genes.

Coinsurance: Coinsurance is your share of the costs of a covered health care service calculated as a percent of the allowed amount for the service. You pay coinsurance plus any deductibles you still owe for a covered health service.

Community residences: Operated and typically owned by nonprofit organizations, these residences support a small group of unrelated individuals in a traditional home setting. Residents have their own rooms and share common spaces. Staff assist with activities of daily living such as meal preparation, personal care and grooming as needed. Residents are supported in being as independent as possible. Formerly known as Group Homes.

Congenital: Present at birth.

Copayment: Fixed amount you pay for a covered health care service, usually when you get the service. The amount can vary by the type of covered health care service.

D

Day habilitation: Facility and community-based assistance with the acquisition, retention, or improvement of self-help, socialization and adaptive skills. Medicaid funded or private pay.

Deductible: A amount you owe for health care services each year before the insurance company begins to pay. The deductible may not apply to all services, such as preventive care services, and are useful for keeping the cost of insurance low. The amount varies by plan, with lower deductibles generally associated with higher premiums, but are fairly standard on most types of private health coverage.

DM1: Common abbreviation for myotonic dystrophy type 1.

DM: Common abbreviation for myotonic dystrophy in general.

DNA: Stands for deoxyribonucleic acid, a self-replicating material which is present in nearly all living organisms as the main constituent of chromosomes. It is the carrier of genetic information.

Dystrophia myotonica (DM): Latin name and most common abbreviation for Myotonic Dystrophy.

Dystrophy: An inherited muscle disorder in which the muscles become weaker.

E

Elder Cottage Housing Opportunity (ECHO) units: Small, free-standing, barrier-free, energy-efficient, and removable units designed to be installed adjacent to existing single-family homes.

Expansion: Refers to the enlargement of the myotonic dystrophy genetic mutation, or abnormality, as it passes to offspring. It also refers to the enlargement of mutations within a given organ or system over the life of an affected individual, which happens often in myotonic dystrophy.

G

Gene: A functional unit of heredity (like eye color, height, etc.) that occupies a specific place on a chromosome; it is capable of reproducing itself at each cell division and directs the formation of an enzyme or protein.

Genetic: Pertaining to genes; inherited.

Genetic counseling: Meeting with a medical professional, often a geneticist, to learn how a possible inherited disease can affect you and how you can avoid passing it to your offspring.

Genetic testing: Also known as DNA testing, this is a test to determine a genetic condition. DNA is isolated from the blood or other tissue and then analyzed to determine whether or not a specific mutation is present.

Group homes: Operated and typically owned by nonprofit organizations, these residences support a small group of unrelated individuals in a traditional home setting. Residents have their own rooms and share common spaces. Staff assist with activities of daily living such as meal preparation, personal care and grooming as needed. Residents are supported in being as independent as possible. Also called Community Residences.

H

Housing Choice Voucher Program: A rental assistance program of the U.S. Department of Housing and Urban Development administered by local housing authorities. Formerly known as Section 8.

I

Independent living: Residential support services for people with disabilities who have the ability to live safely on their own. Training and technical support around areas such as community safety, nutrition, and managing finances and medical appointments are provided by nonprofit organizations. May be government funded for eligible individuals or fee for service. Also known as Supported Living.

In Home Support Services (IHSS): A program that helps people with disabilities preserve their independence and avoid placement in an institutional facility. Assistance with tasks such as bathing, grooming, meals and housekeeping. Covered by Medicaid for eligible participants or fee for service. Also known as Personal Care Assistance.

In Vitro Fertilization (IVF): A process in which eggs are obtained from the female after drugs have been used to stimulate ovarian production. While under sedation and with the use of ultrasound guidance, a needle is inserted into the ovaries and eggs are aspirated. Eggs are then fertilized in the laboratory (in-vitro) with the partner's sperm and the developing embryos are cultured from three to six days.

J

JOA: Abbreviation for a juvenile-onset adult with myotonic dystrophy, meaning an adult that was diagnosed with myotonic dystrophy before the age of 18.

Juvenile-onset myotonic dystrophy: A form of myotonic dystrophy type 1 that is diagnosed before the age of 18, but not at birth.

L

Long-term support services: Medicaid funded services to enable seniors and people with disabilities and/or chronic illness to decide where and with whom they live, to have control over the services they receive and who provides the services, to work and earn money, and to include friends and supports to help them participate in community life.

M

Medicare: Federal health insurance program for the elderly and disabled which covers in-patient and outpatient medical care.

Medicaid: The largest insurance program providing medical and health-related services to low-income individuals.

Myopathy: Muscle weakness.

Myotonic muscular dystrophy (MMD): Name and abbreviation sometimes used for myotonic dystrophy.

Myotonia: Inability of contracted muscles to relax on command, or a special kind of muscle stiffness.

O

Outpatient services: Services that do not need an overnight stay in a hospital; often provided in a doctor's office, hospital or clinic.

P

Personal care assistance: A program that helps people with disabilities preserve their independence and avoid placement in an institutional facility. Assistance with tasks such as bathing, grooming, meals and housekeeping. Covered by Medicaid for eligible participants or fee for service. Also known as In-Home Support Services (IHSS).

Premium: The amount of money charged by an insurance company for coverage. The cost of premiums may be determined by several factors, including age, geographic area, number of dependents, tobacco consumption, etc. Policyholders pay these rates annually or in smaller payments over the course of the year and the amount may change over time.

Prognosis: Forecast of the probable course and outcome of a disease.

Project-Based Rental Assistance (PRA): Financial assistance through HUD's Housing Choice Voucher Program administered by local housing authorities for low income adults that is associated with particular residential units (public housing developments).

R

Reasonable accommodations: A modification to a job or work environment in order to enable an individual with a disability to have an equal opportunity not only to get a job, but successfully perform their job tasks to the same extent as people without disabilities.

Residential care facilities (RCF): A form of housing where residents have their own apartments and share common areas such as a dining rooms and sitting rooms. Services include meals and social opportunities. Unlike nursing homes, these facilities are not required to engage medical professionals. Personal care assistance may be included or available through other providers. Also known as Assisted Living, Board and Care Homes, or Rest Homes.

Rest homes: A form of housing where residents have their own apartments and share common areas such as a dining rooms and sitting rooms. Services include meals and social opportunities. Unlike nursing homes, these facilities are not required to engage medical professionals. Personal care assistance may be included or available through other providers. Also known as assisted living, board and care homes, or residential care facilities.

S

Shared living: A family-type living arrangement in a private home providing room, board, and personal care. A match between the individual and the provider may be made by a disability service organization. Covered by Medicaid funded for income eligible adults. Also known as Adult Family Care or Adult Foster Care.

Social Security Disability (SSDI): A cash benefit for people who have worked and paid enough Social Security taxes. Benefits are funded by Social Security deductions from paychecks.

Supplemental Security Income (SSI): A cash benefit program for low-income people, the blind, and children. Individuals must have income and assets under the SSI programs strict limits.

Steinert's Disease: The first name given to myotonic dystrophy when it was identified as a disease by Dr. Hans Steinert of Germany in 1909.

T

Tenant-Based Rental Assistance (TRA): Financial assistance through HUD's Housing Choice Voucher Program administered by local housing authorities for low income adults that follows the person rather than being facility-based.

B

References and Resources for Section 5: Psychological and Social Considerations

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Resources

American Association on Intellectual and Developmental Disabilities www.aaidd.org

American Psychological Association https://locator.apa.org/?_ga=2.68832728.830585145.1565183568-1572501961.1563660830

American Psychiatric Association http://finder.psychiatry.org/?_ga=2.85558298.220191076.1565206326-215490582.1564685147

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Foundr Magazine http://www.Foundr.com/find-a-mentor

Medicaid (local state office) http://www.benefits.gov/benefits/browse-by-category/category/MED.

Medicare http://www.medicare.gov

Mental Health America https://arc.mentalhealthamerica.net/find-an-affiliate

Muscular Dystrophy Association https://www.mda.org/about-mda/contact-us

Myotonic Dystrophy Foundation https://www.myotonic.org/find-a-doctor

National Alliance on Mental Health https://www.nami.org/Find-Support

Substance Abuse and Mental Health Services Administration http://www.samhsa.gov/treatment or call 800-662-4357

US Department of Veteran Affairs. http://www.va.gov/health or call 877-222-8387

Resources

Literature:

Applying for Social Security Disability Benefits: A Toolkit and Guide for People Living with Myotonic Dystrophy. https://www.myotonic.org/sites/default/files/pages/files/Myotonic-MySSA-Toolkit-2019.pdf

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Social Security Administration, Disability Benefits: https://www.ssa.gov/pubs/EN-05-10029.pdf

Employment Access Toolkit: A Guide to Navigating the Employment Process for People Living with Myotonic Dystrophy. https://www.myotonic.org/sites/default/files/pages/files/My-Employment-Toolkit-4-28-2020.pdf

Going to School with Myotonic Dystrophy: A Guide to Understanding Special Education and IDEA. https://www.myotonic.org/sites/default/files/pages/files/Myotonic-GoingToSchoolWithMyotonicDystrophy-2019.pdf

Health Insurance Considerations for People Living with Myotonic Dystrophy in the United States. https://www.myotonic.org/sites/default/files/pages/files/Myotonic-InsuranceConsiderations-4-2020.pdf

MDA: Road Map to Independence for Young Adults; https://www.mda.org/sites/default/files/publications/Road_Map_to_Independence.pdf

Myotonic Toolkit. https://www.myotonic.org/sites/default/files/pages/files/Myotonic-Toolkit-2019.pdf

Online Resources:

AARP. Understanding Medicare's Options: https://www.aarp.org/health/medicare-insurance/info-01-2011/understanding_medicare_the_plans.html

American Association on Intellectual and Developmental Disabilities. www.aaidd.org

Child Neurology Foundation. Transition of Care: https://www.childneurologyfoundation.org/transitions/

Department of Veteran Affairs. http://www.va.gov/health

National Institutes of Health. Talking to Your Doctor: https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication/talking-your-doctor

Health Insurance is a Family Matter: Overview of Public Health Insurance Programs: https://www.ncbi.nlm.nih.gov/books/NBK221009/

How to Choose the Best Health Insurance Plan for You: https://www.verywellhealth.com/health-insurance-4014713

Know Your Insurance: https://www.thealphaga.com/portals/16/assets/pdf/individual_health_insurance_101_guide.pdf

Medicaid.gov. Eligibility: https://www.medicaid.gov/medicaid/eligibility/index.html

Medical Mutual. What is an HMO? Understanding HMO Health Plans: https://www.medmutual.com/For-Individuals-and-Families/Health-Insurance-Education/Health-Insurance-Basics/About-HMO-Health-Insurance-Plans.aspx

Medical Mutual. What is a PPO? Understanding PPO Health Plans: https://www.medmutual.com/For-Individuals-and-Families/Health-Insurance-Education/Health-Insurance-Basics/Types-Health-Insurance/PPO-Health-Insurance-Plans.aspx

Medicare.gov. http://www.medicare.gov

Mental Health America. Find an Affiliate: https://arc.mentalhealthamerica.net/find-an-affiliate

Muscular Dystrophy Association. https://www.mda.org

Myotonic Dystrophy Foundation. https://www.myotonic.org

National Alliance on Mental Health. Find Support: https://www.nami.org/Find-Support

Substance Abuse and Mental Health Services Administration. Behavioral Health Treatment and Services: http://www.samhsa.gov/treatment

Myotonic Dystrophy Foundation's mission is to enhance the quality of life of people living with myotonic dystrophy and accelerate research focused on treatments and a cure.

Myotonic Dystrophy FOUNDATION

My Cause. My Cure.

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