

Resources and Programs for Myotonic Dystrophy

June 2020

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Presentation Outline

Review of Internal Resources & Programs

- Consensus-based Care Recommendations
- Guidelines
- Toolkits
- Resources
- Newly Diagnosed

Review of External Resources & Programs

- Insurance Programs
- Social Security
- Other Social Programs
- Medical Equipment

Consensus-based Care Recommendations

- Respiratory Care Recommendations for Myotonic Dystrophy Patients During the COVID-19 Pandemic
- Clinical Care Recommendations for Adults with Myotonic Dystrophy Type 1
- Clinical Care Recommendations for Children with Myotonic Dystrophy Type 1
- Clinical Care Recommendations for Adults with Myotonic Dystrophy Type 2
- Clinical Care Recommendations for Cardiologists Treating Adults with Myotonic Dystrophy Type 1
- Clinical Care Recommendations for Pulmonologists Treating Adults with Myotonic Dystrophy Type 1

<https://www.myotonic.org/toolkits-publications>

Guidelines

- Anesthesia Guidelines
- Care Guidelines for Speech and Language Pathologists Treating Adults and Children with Myotonic Dystrophy
- Role of Physical Therapy in the Assessment and Management of Individuals with Myotonic Dystrophy
- Occupational Therapy Guidelines
- Exercise Guidelines for Individuals with Myotonic Dystrophy
- Nutrition Guidelines for Individuals with Myotonic Dystrophy

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Toolkits

- Myotonic Toolkit
- Applying for Social Security Benefits Toolkit
- Employment Access Toolkit
- Going to School with Myotonic Dystrophy: A Guide to Understanding Special Education and IDEA
- Health Insurance Considerations for People Living with Myotonic Dystrophy in the United States
- Guide for Adults Affected by Juvenile-onset Myotonic Dystrophy and their Caregivers

<https://www.myotonic.org/toolkits-publications>

Resources

- Clinic Visit Planner
- Christopher Project Report
- Anesthesia Wristbands
- Books and other publications

<https://www.myotonic.org/toolkits-publications>

Resources

- Study and Trial Resource Center: <https://www.myotonic.org/study-trial-resource-center>
- Warmline: <https://www.myotonic.org/request-warmline-support>
- Find a doctor program: <https://www.myotonic.org/find-a-doctor-map>
- Financial Resources: <https://www.myotonic.org/financial-resources-0>
- JOA Program: <https://www.myotonic.org/juvenile-onset-adult-program>
- Digital Academy: <https://www.myotonic.org/digital-academy>

Resources

Support Groups:

- Virtual/Phone Based: German Speaking, DM2, Caregivers
- In person: <https://www.myotonic.org/find-support>
- Facebook: DM1, DM2, Caregivers, MDF page, Unaffected Male Caregivers

Events:

- Conference: <https://www.myotonic.org/myotonic-our-annual-conferences>
- Medical School Roadshow: <https://www.myotonic.org/myotonic-dystrophy-medical-school-roadshow>
- DM Days: <https://www.myotonic.org/myotonic-dm-days-bringing-community-together>

Newly Diagnosed

- Sign up for emails: <https://www.myotonic.org/sign-emails-0>
- Body Systems Tool: <https://www.myotonic.org/what-dm/how-dm-affects-your-body>
- Genetic Testing: <https://www.myotonic.org/myotonic-dystrophy-testing-diagnosis>
- Dispatch: <https://www.myotonic.org/news-and-events/newsletter-archive>
- FAQs: <https://www.myotonic.org/what-dm/faqs>
- Need more help? <https://www.myotonic.org/myotonic-contact-us>
 - 866-968-6642 toll free
 - 415-800-7777
 - info@myotonic.org

Insurance Programs

- Medicare
- Medicaid
- Private Insurance
- TRICARE/VA
- CHIP

<https://www.myotonic.org/sites/default/files/pages/files/Myotonic-InsuranceConsiderations-4-2020.pdf>

Medicare

- Enrollment and Eligibility: <https://www.medicare.gov/>
 - Aged sixty-five and older or
 - Disabled and eligible for Social Security benefits or
 - Have ESRD (permanent kidney failure requiring dialysis or transplant).
- Part A – Hospital (Inpatient)
- Part B – Medical (Outpatient)
- Part D – Prescription Medication Coverage
- 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

- Medicaid is the largest program providing medical and health-related services to America's poorest people.
- 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.
- Income must be below defined limits, usually set by the Federal Poverty Level (FPL): <https://www.healthcare.gov/glossary/federal-poverty-level-fpl/>
- To enroll in Medicaid, visit this link to find your local office: <https://www.medicaid.gov/medicaid/eligibility/index.html>

Private Insurance

- Private insurance plans are obtained through employment, 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 plan, consider pre-existing conditions, prescription medications, physician preference, upcoming medical care needs.
- Find your state's health insurance marketplace here:
<https://www.healthcare.gov/>

Other Insurance Programs

- Children's Health Insurance Program (CHIP): This program covers medical and dental care for uninsured children and teens up to age 19. CHIP qualifications are different in every state, often depend on income. You can apply for CHIP through your state:
<https://www.insurekidsnow.gov/coverage/index.html>
- Veterans Administration (VA): <https://www.va.gov/health-care/eligibility/>
- TRICARE: <https://www.tricare.mil/>
- Indian Health Services (IHS): <https://www.ihs.gov/>

Social Security

- Social Security Disability Insurance (SSDI):
 - 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
 - Information and application: www.socialsecurity.gov
- Supplemental Security Income (SSI)
 - Have income and assets under the SSI program's strict limits, see here: <https://www.disabilitysecrets.com/topics/financial-eligibility-ssi.htm>
 - Information and application: www.socialsecurity.gov

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

Social Programs

- General Assistance: <https://www.usa.gov/benefits>
- Unemployment: <https://www.careeronestop.org/LocalHelp/UnemploymentBenefits/unemployment-benefits.aspx>
- Short Term Disability/State Disability Insurance SDI: <https://eligibility.com/state-disability-insurance>
- Paid Family Leave (PFL)/Family Medical Leave Act (FMLA): <https://www.dol.gov/general/topic/benefits-leave/fmla>
- SNAP/Food Stamps: <https://www.usa.gov/benefits>

Durable Medical Equipment (DME)

- Contact doctor/care provider for referral to process through insurance
- If you have a large co-pay or equipment isn't covered by insurance, review financial resource guide for your state: <https://www.myotonic.org/financial-resources-0>
- Contact MDA in your area for potential financial assistance: <https://www.mda.org/care/care-center-list>
- Contact MDF for help with navigating/finding resources

Need more help?

Contact MDF Program Director:

Leah Hellerstein

Leah.Hellerstein@myotonic.org

415-872-7924

Request any of the toolkits by emailing above address with your mailing address and toolkit needed



Thank you!

