

# Care Programs Report



MYOTONIC  
DYSTROPHY  
FOUNDATION

Care and a Cure

## MDF Mission:

Our mission, “Care and a Cure,” is to enhance the quality of life of people living with myotonic dystrophy (DM) and accelerate research focused on treatments and a cure. When it comes to Care, MDF delivers a comprehensive array of Care resources that includes toolkits, guidelines, conferences and events, a comprehensive website, a live Warmline, support groups and much more. MDF’s goal is to anticipate and fulfill the Care needs of families living with DM.

## CARE PROGRAMS BY THE NUMBERS

MDF supported more than **220** hours of in-person and virtual support group meetings



More than **1,000** families, clinicians, researchers, industry representatives and caregivers attended MDF Annual Conferences in 2015 and 2016



The MDF community spans **62** countries

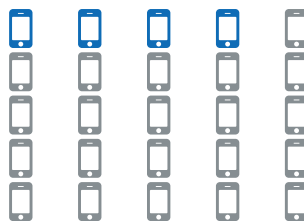
MDF answered over 500 Warmline calls and emails from people living with myotonic dystrophy, their caregivers, medical professionals and others



44,000 visitors explored the online MDF Body Systems Tool

**14,000**  
downloads

of the MDF Toolkit, Anesthesia Guidelines and other resources



MDF Facebook posts and private groups received 38,000 likes, comments and shares

Based on data from 2015–2016

## New MDF Care Initiatives

- **Clinical Care Recommendations:** MDF recruited an international team of over 65 clinical experts to develop best-in-class clinical care recommendations for professionals serving adults with myotonic dystrophy type 1 (DM1). Additional Care recommendations are currently being developed for the care of childhood myotonic dystrophy patients
- **MDF Transitions Handbook, for Parents of Children Ages 1–21:** As children with congenital and childhood-onset myotonic dystrophy transition through various stages of life, guidelines are needed to help parents communicate with education and medical professionals and ensure high-quality and

and people living with myotonic dystrophy type 2 (DM2), as well as recommendations for specialists in cardiac, gastrointestinal and respiratory care.

appropriate services and support for their children into young adulthood. MDF is currently working collaboratively with an MDF community panel and experts in early intervention, literacy, assessment, system accountability, accessibility, employment, social/emotional learning, disability and health to develop and publish a comprehensive transition guide in Fall 2017.

- **MDF DM Days:** MDF is collaborating with myotonic dystrophy clinical care centers in the United States to offer local information and resource summits. These special one-day free events will bring together clinicians, researchers and MDF community members, and will feature patient-centered programming, breakout sessions, and interactive Ask-The-Experts sessions.
- **MDF Employment Access Program:** MDF is launching an access-to-work program in 2017 that will work collaboratively with job placement experts and appropriate state and federal agencies to assist MDF community members in securing meaningful employment in work environments that accommodate the DM-related limitations they may face. A new toolkit to help the community navigate through the complex job landscape will accompany this program.

## Valuable Care Tools and Resources

- **Body Systems Tool:** One of MDF's most popular resources for individuals and families affected by myotonic dystrophy, the interactive online tool helps web users understand the complexities of this multi-systemic genetic disorder that can affect all age groups.
- **MDF Toolkit:** To help families and healthcare providers, MDF created its cornerstone resource, the MDF Toolkit. Developed and updated by the Myotonic Dystrophy Foundation's Scientific Advisory Committee, the MDF Toolkit includes valuable information for affected individuals and their families, and resources for medical professionals.
- **Applying for Social Security Disability Benefits Toolkit:** MDF published a step-by-step guidebook to help individuals and families understand the process of applying for disability benefits available through the U.S. Social Security Administration (SSA). The toolkit assists individuals in navigating the application process for Social Security Disability Insurance (SSDI) benefits and Supplemental Security Income (SSI) benefits. A supplement is currently under development.
- **Anesthesia Guidelines:** Anesthesia and opioids create special and potentially life-threatening risks for myotonic dystrophy patients. Serious complications are most common in the post-anesthesia period when risk of aspiration and other complications are increased. MDF created the Anesthesia Guidelines to offer life-saving guidelines for anesthesiologists and other healthcare providers treating DM patients.

- **Find a Doctor Program:** MDF developed an online search tool to connect members of the MDF community to a variety of medical professionals who understand DM and have experience in treating DM patients. The Find a Doctor Program is a constantly expanding, community-generated list that features clinicians based in countries across the globe.
- **Financial Resources Toolkit:** When a family or individual is faced with a progressive condition like myotonic dystrophy, additional financial expenses and loss of a steady income may often accompany the disease. This toolkit compiles national resources available to DM families across the U.S. State-based guides are currently under development.
- **Digital Academy:** The MDF website offers more than 100 hours of inspirational and informative webinars, videos, educational resources and family stories that cover topics from disease understanding to symptom management.
- **MDF Annual Conference:** The MDF Annual Conference gathers hundreds of families, clinicians, researchers, industry representatives and caregivers working to improve the lives of people living with myotonic dystrophy. The conference, which features information sessions, resource fairs, networking opportunities, research updates and industry presentations on drug development efforts, is the largest annual myotonic dystrophy conference in the world.
- **MDF Warmline:** MDF offers professionally-staffed phone support for the more than 200 family members and medical professionals who call each year for resources, support and referrals.
- **MDF Support Groups:** MDF supports dozens of in-person and virtual meetings taking place in MDF communities across the globe. The support group meetings bring community members together to share their experiences, create supportive friendships and reduce the isolation that often accompanies this disease.
- **MDF Cooks:** *MDF Cooks* is an MDF-produced recipe book that provides recipes and resources for those with dysphagia, difficulty chewing, and other swallowing disorders. Recipes were all submitted by MDF community members and tested by a nutritionist.

MDF's sole Care focus is to protect and improve the quality of life of the international community of people and families living with myotonic dystrophy.

To access professional and patient resources or find out how you can help support Care and a Cure, visit [www.myotonic.org](http://www.myotonic.org) or call 415-800-7777.