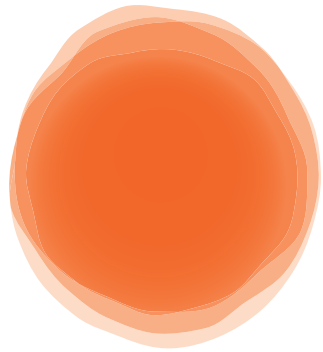


Patient Survey



the
christopher
project

SAMPLE

Who should fill out this survey?

Each person in your family with myotonic dystrophy who is 18 years of age or older should fill out a copy of this survey. For minors with myotonic dystrophy (affected family members under the age of 18), an adult family member or caregiver can fill it out on their behalf with their permission.

You can get additional copies of this survey by email at support@christopherproject.org or by phone at 1-855-506-4646 (toll free).

You can also complete the survey online at www.christopherproject.org

SAMPLE

Contact Information

Providing your contact information is completely optional and is not required for you to take part in the Christopher Project. Any information you choose to provide will only be used by the Christopher Project Study Coordinator to communicate with you about your participation, including opportunities to take part in follow-up surveys and interviews. Your contact information will be kept strictly confidential.

Select one

- ☐ I do NOT want to provide my contact information or be contacted by the Study Coordinator.

-or-

- ☐ I am willing to be contacted by the Study Coordinator about the Christopher Project and the opportunity to participate in further research. My contact information is as follows:

Full name: _____

Mailing Address: _____ Apt Number: _____

City: _____

Province / State: _____

Postal / Zip Code: _____ ☐ USA ☐ Canada

Email: _____

Phone Number: _____

How would you like to be contacted?

Check all that apply

☐ Email

☐ Lettermail

☐ Phone

*A copy of the final Project Report will be sent directly to those people who provide their contact information above.

SAMPLE

Survey Instructions

This survey contains about 60 questions and should take less than an hour to complete. All your answers will be kept confidential. Your personal information will not be published or shared. You will not receive any compensation for your participation. Importantly, your medical care will not be affected by your participation and your responses will never be connected to your medical records.

- Do your best to answer all of the questions by yourself.
- If you need help, you can ask a friend or family member for assistance but all of your responses should be your own.
- Complete the questions with a simple checkmark or 'x' or you can fill in the bubbles, whichever you prefer.
- If you are not sure how to answer a question, pick the response that fits the best.
- If you are completing this survey on behalf of a minor (a person under the age of 18) with myotonic dystrophy, all of your responses should relate to that individual (i.e., provide the country THEY live in; provide THEIR year of birth; describe THEIR experiences).
- Please return your completed survey in the self-addressed stamped envelope provided -OR- you can complete a copy online at www.christopherproject.org.
- If you still have questions or require assistance in completing this survey contact:

Sarah Howe
The Christopher Project Study Coordinator
Toll Free 1-855-506-4646 or Phone 1-403-255-4646
Email support@christopherproject.org

PLEASE NOTE: By responding to this survey, you are giving your consent for the anonymous data to be used for research purposes. Once you have submitted your answers, it will not be possible to remove them because they will be aggregated and stored anonymously in the study database. This data will then be analyzed by professional researchers to better understand how myotonic dystrophy impacts patients and families and to identify ways to improve the lives of people living with this disease.

Your Participation

Each person in your family with myotonic dystrophy who is 18 years of age or older should fill out a copy of this survey. For minors living with myotonic dystrophy (under 18 years of age), an adult family member or adult caregiver can fill it out on their behalf provided they have express permission to do so.

Select one

- ☐ I am 18 years of age or older and I am completing this survey on my own behalf. I understand that I may ask a friend or family member for assistance but all of my answers will be my own.

-or-

- ☐ I am an adult family member or caregiver of a minor living with myotonic dystrophy (a person under 18 years of age) and I am responding to this survey on their behalf. I understand that the answers I provide will be what that person the minor would answer THEMSELVES (i.e., I will provide the country THEY live in; provide THEIR date of birth; and describe THEIR experiences).

Let's get started!

About You

This brief section collects basic information about you.

1. What country do you live in? ☐ USA ☐ Canada
2. What state or province do you live in? _____
3. What is your date of birth (D.O.B.)? _____
4. What is your gender? ☐ Female ☐ Male
5. How would you describe your living situation?
Check all that apply
- | | |
|---|--|
| <input type="radio"/> I live alone | <input type="radio"/> I live with my sibling(s) and/or other relative(s) |
| <input type="radio"/> I live with my spouse/partner | <input type="radio"/> I live with a roommate(s) |
| <input type="radio"/> I live with my child/children | <input type="radio"/> I live with a professional caregiver (in my home) |
| <input type="radio"/> I live with my parent(s) | <input type="radio"/> I live in a care facility |
| <input type="radio"/> Other, specify: _____ | |
6. What is your current employment status?
Check all that apply
- | | |
|---|--|
| <input type="radio"/> Student | <input type="radio"/> Unemployed by choice |
| <input type="radio"/> Employed full-time | <input type="radio"/> Seeking employment |
| <input type="radio"/> Employed part-time | <input type="radio"/> Unable to work due to myotonic dystrophy |
| <input type="radio"/> Retired | <input type="radio"/> Unable to work due to other reasons |
| <input type="radio"/> Other, specify: _____ | |
7. What is the highest level of education you have completed?
Select one
- | | |
|---|--|
| <input type="radio"/> Currently in primary/secondary school | <input type="radio"/> Trade/technical/vocational certification |
| <input type="radio"/> Some high school (no diploma) | <input type="radio"/> College/university graduate |
| <input type="radio"/> High school graduate | <input type="radio"/> Post graduate degree |
| <input type="radio"/> Some college | <input type="radio"/> Other, specify: _____ |

About You

Continued

8. What is your annual PERSONAL income?

Select one

☐

None

☐

\$1,000 to \$10,000

☐

\$10,001 to \$25,000

☐

\$25,001 to \$40,000

☐

Over \$40,000

9. What is your annual TOTAL HOUSEHOLD income?

Select one

☐

Under \$25,000

☐

\$25,000 to \$50,000

☐

\$50,001 to \$75,000

☐

\$75,001 to 100,000

☐

Over \$100,000

End of Section

Your Current Health

This brief section asks you to fill us in on your overall health.

1. In general, would you say your health is:

☐

Excellent

☐

Very good

☐

Good

☐

Fair

☐

Poor

2. What is your current height? _____ feet _____ inches

3. What is your current weight? _____ pounds

4. Are you a cigarette smoker?

☐

Yes

☐

No

End of Section

Your Diagnosis

This section explores how your diagnosis has impacted you and your family.

1. What type of myotonic dystrophy do you have?

Select one

- ☐ Congenital myotonic dystrophy type 1
- ☐ Myotonic dystrophy type 1 (DM1)
- ☐ Myotonic dystrophy type 2 (DM2)
- ☐ Unknown/unsure

2. About how old were you when you first noticed significant symptoms?

Age (years): _____;

What was the first symptom you noticed? _____

-or-

- ☐ I do not experience symptoms

3. About how old were you when you received a medical diagnosis for myotonic dystrophy?

Age (years): _____

-or-

- ☐ I do not have a medical diagnosis for myotonic dystrophy

4. Were you the first person in your family to receive a diagnosis for myotonic dystrophy?

- ☐ Yes ☐ No ☐ Unknown ☐ I do not have a medical diagnosis for myotonic dystrophy

5. If you have received a medical diagnosis, was it confirmed through genetic testing?

- ☐ Yes ☐ No ☐ Unknown ☐ I do not have a medical diagnosis for myotonic dystrophy

6. Some people are provided with a repeat count or repeat number at the time of their genetic confirmation. Did you receive a repeat count?

- ☐ Yes, my repeat count is _____ (approx)
- ☐ Yes, but I don't remember what it is
- ☐ No, I did not receive one

Your Diagnosis

Continued

7. If you do not have a genetically confirmed diagnosis for myotonic dystrophy, please tell us why:

8. What type of assistance DID YOU RECEIVE around the time of your diagnosis?

Check all that apply

- ☐ I do not have a diagnosis for myotonic dystrophy
- ☐ No assistance
- ☐ Referrals to specialist doctors (e.g., cardiologist, neurologist, etc.)
- ☐ Referrals to other health care providers (e.g., nutritionist, physical therapist, etc.)
- ☐ Genetic counseling
- ☐ Directed to a patient organization (i.e., MDA, MDF, MDC)
- ☐ Handout/information package
- ☐ Psychological/emotional support
- ☐ Workplace accommodations
- ☐ School accommodations
- ☐ Other, specify: _____

9. What was the MOST helpful?

10. What type of assistance WOULD HAVE BEEN HELPFUL but was not offered?

11. What were the specific challenges surrounding your diagnosis?

Check all that apply

- | | |
|---|---|
| <input type="radio"/> Length of time it took | <input type="radio"/> Lack of resources available about my disease |
| <input type="radio"/> Financial impact/expense | <input type="radio"/> Provided incorrect information about my disease |
| <input type="radio"/> Incompleteness of explanation | <input type="radio"/> Emotional impact |
| <input type="radio"/> Received incorrect diagnosis | <input type="radio"/> Other, explain: _____ |

End of Section

Information and Resources

This section explores what information has been and would be helpful for you and your family.

1. How **HELPFUL** have the following sources of information been **FOR YOU**?

Select the appropriate response for each item listed below

INFORMATION YOU RECEIVED FROM:	Never Used	Not Very Helpful	Somewhat Helpful	Very Helpful
General practitioner/family doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other medical specialists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family/friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patient organizations (i.e., MDA, MDF, MDC)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
General health-related websites	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Printed materials/books	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2. Who or what has been the **MOST** helpful source of information for you?

Please be specific

3. What are the **BEST** ways for you to receive information about myotonic dystrophy?

Check all that apply

- ☐ Attending support group/patient meetings
- ☐ Receiving information by LETTERMAIL (printed)
- ☐ Receiving information by EMAIL (electronically)
- ☐ Talking with family/friends
- ☐ Talking with health care providers
- ☐ Visiting patient organization websites (i.e., MDA, MDF, MDC)
- ☐ Visiting other health-related websites
- ☐ Participating in online discussion forums/chat rooms
- ☐ Reading books and other printed material
- ☐ Other, specify: _____

4. What is the number one **BEST** way for you to receive information about myotonic dystrophy?

Information and Resources

Continued

5. Which areas would you like to get more information about?

Check all that apply

- | | |
|---|---|
| <input type="radio"/> Available treatments/medications | <input type="radio"/> Technical aids |
| <input type="radio"/> Where to find specialists/disease experts | <input type="radio"/> Disclosure (talking with others about my disease) |
| <input type="radio"/> Clinical trials | <input type="radio"/> Patient organizations (i.e., MDA, MDF, MDC) |
| <input type="radio"/> Scientific research | <input type="radio"/> School accommodations/assistance |
| <input type="radio"/> Genetic counseling/family planning | <input type="radio"/> Workplace accommodations |
| <input type="radio"/> Anesthesia risks | <input type="radio"/> Community supports |
| <input type="radio"/> Cardiac implications | <input type="radio"/> Psychological supports |
| <input type="radio"/> Financial assistance | <input type="radio"/> Exercise |
| <input type="radio"/> Health insurance | <input type="radio"/> Nutrition |
| <input type="radio"/> Other, specify: _____ | |

6. How often do you use a computer/device to search the Internet and/or check email?

- ☐ Daily ☐ Weekly ☐ Monthly ☐ Rarely ☐ Never

7. How often do you access information about myotonic dystrophy?

- ☐ Daily ☐ Weekly ☐ Monthly ☐ Rarely ☐ Never

8. Have you registered in a patient registry?

- ☐ Yes ☐ No ☐ Unknown If yes, which one(s)? _____

9. Have you ever participated in a research study or another survey about myotonic dystrophy?

- ☐ Yes ☐ No ☐ Unknown If yes, which one(s)? _____

10. Would you attend a support group meeting if one was available in your area?

- ☐ Not likely ☐ Yes, if one was available ☐ I already attend my local support group

End of Section

Your Symptoms

This section asks which symptoms impact you the most.

1. Please rate how much the following problems/symptoms impact your daily life:

Select the appropriate response for each item listed below

MUSCLE	Do Not Experience	Have Symptom but NO Impact	Have Symptom with MINOR Impact	Have Symptom with MODERATE Impact	Have Symptom with MAJOR Impact
myotonia (difficulty relaxing muscle)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
muscle weakness (dystrophy)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
muscle aches, cramps	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
muscle pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

GASTROINTESTINAL	Do Not Experience	Have Symptom but NO Impact	Have Symptom with MINOR Impact	Have Symptom with MODERATE Impact	Have Symptom with MAJOR Impact
difficulty swallowing (dysphagia)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
diarrhea	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
constipation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
frequent hiccups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
abdominal pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

CARDIORESPIRATORY	Do Not Experience	Have Symptom but NO Impact	Have Symptom with MINOR Impact	Have Symptom with MODERATE Impact	Have Symptom with MAJOR Impact
abnormal heart rhythm	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
recurrent lung infections/pneumonia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
shortness of breath	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
dizziness/fainting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

SLEEP and FATIGUE	Do Not Experience	Have Symptom but NO Impact	Have Symptom with MINOR Impact	Have Symptom with MODERATE Impact	Have Symptom with MAJOR Impact
daytime sleepiness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
fatigue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
difficulty falling asleep	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
trouble breathing during sleep (apnea)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Your Symptoms

Continued

PSYCHOLOGICAL	Do Not Experience	Have Symptom but NO Impact	Have Symptom with MINOR Impact	Have Symptom with MODERATE Impact	Have Symptom with MAJOR Impact
learning difficulties/challenges	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
difficulty concentrating	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
depression	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
anxiety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

BIOLOGICAL, HORMONAL, ENDOCRINE	Do Not Experience	Have Symptom but NO Impact	Have Symptom with MINOR Impact	Have Symptom with MODERATE Impact	Have Symptom with MAJOR Impact
diabetes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
sexual/intimacy problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
fertility problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

OTHER	Do Not Experience	Have Symptom but NO Impact	Have Symptom with MINOR Impact	Have Symptom with MODERATE Impact	Have Symptom with MAJOR Impact
balding/thinning hair	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
headaches, migraines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
drooping eyelids (ptosis)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
hearing loss	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
balance issues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

List any other problems/symptoms you experience that have a MAJOR impact on your daily life:

2. Of all of the problems/symptoms you experience, which ones IMPACT YOUR LIFE THE MOST?

List up to THREE

End of Section

Your Healthcare Related Experience

This section asks about the healthcare providers you visit and what your experience has been.

1. Since your diagnosis, how **OFTEN** do you see or have you seen the following **HEALTHCARE PROVIDERS**?

Select the appropriate response for each item listed below

	Never	Only ONCE with NO planned follow-up	Only ONCE with planned follow-up	INFREQUENTLY (every two to five years)	FREQUENTLY (once a year or more)
General practitioner/family doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neurologist/neuromuscular specialist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cardiologist (heart doctor)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gastroenterologist (stomach doctor)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pulmonologist (breathing specialist)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ophthalmologist (eye doctor)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetic counselor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psychiatrist/psychotherapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nurse/nurse case manager	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical therapist/physiotherapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Speech/swallowing specialist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleep specialist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Occupational therapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nutritionist/dietician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social Worker	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psychologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

List any other healthcare providers you see or have seen:

2. Of all of the healthcare providers above, which ones **HELP YOU THE MOST** in managing your disease?

List up to THREE

Your Healthcare Related Experience

Continued

3. How satisfied are you with the OVERALL medical care you receive?

☐
Very
Dissatisfied

☐
Dissatisfied

☐
Neutral

☐
Satisfied

☐
Very
Satisfied

4. How much do you know about the general anesthesia risks associated with myotonic dystrophy?

- ☐ I am not aware of the specific risks
- ☐ I am aware but I have NOT discussed it with a medical professional
- ☐ I am aware and I have discussed it with a medical professional

5. How much do you know about the cardiac complications associated with myotonic dystrophy?

- ☐ I am not aware of the complications
- ☐ I am aware but I have NOT discussed it with a medical professional
- ☐ I am aware and I have discussed it with a medical professional

6. Have you ever had your heart tested? (e.g., electrocardiogram (ECG or EKG), echocardiogram, cardiac MRI, etc.)

- ☐ Yes ☐ No ☐ Unknown

7. Have you ever been diagnosed with an abnormal heartbeat/heart conduction problem?

- ☐ Yes ☐ No ☐ Unknown

8. What medical needs or concerns do you have that you feel have not been met through your health care?

9. What advice do you have for medical professionals working in myotonic dystrophy?

End of Section

Treatments and Interventions

Doctors can prescribe a number of medications, devices and interventions for myotonic dystrophy symptoms. This section asks how effective/helpful these have been for you.

1. Do you take medication for myotonia (difficulty relaxing muscles)?

☐ Yes ☐ No ☐ Unknown If YES, which one(s)? _____

If you take medication for myotonia, how satisfied are you with its effect?

☐ Not at all Satisfied ☐ Slightly Satisfied ☐ Moderately Satisfied ☐ Very Satisfied ☐ Extremely Satisfied

2. Do you take medication for daytime sleepiness and/or fatigue?

☐ Yes ☐ No ☐ Unknown If YES, which one(s)? _____

If you take medication for daytime sleepiness and/or fatigue, how satisfied are you with its effect?

☐ Not at all Satisfied ☐ Slightly Satisfied ☐ Moderately Satisfied ☐ Very Satisfied ☐ Extremely Satisfied

3. Do you take medication for gastrointestinal problems associated with myotonic dystrophy?

☐ Yes ☐ No ☐ Unknown If YES, which one(s)? _____

If you take medication for gastrointestinal problems, how satisfied are you with its effect?

☐ Not at all Satisfied ☐ Slightly Satisfied ☐ Moderately Satisfied ☐ Very Satisfied ☐ Extremely Satisfied

List any other MEDICATION, HOMEOPATHIC REMEDIES, or NATURAL PRODUCTS that have been helpful in managing your disease:

4. Has your doctor ever recommended that you receive a pacemaker or a defibrillator for your heart?

Check all that apply

☐ Yes, a pacemaker ☐ Yes, a defibrillator ☐ No, neither ☐ Unknown

If YES, did you go ahead with it?

☐ Yes ☐ No

If a pacemaker/defibrillator was recommended but you DID NOT go ahead with it, please tell us why:

Treatments and Interventions

Continued

5. Has your doctor ever recommended that you use a device to help you breathe at night (e.g., CPAP or BiPAP)?

☐ Yes ☐ No ☐ Unknown If YES, do you use it? ☐ Yes ☐ No

If you do use it, how satisfied are you with its effect?

☐ Not at all Satisfied ☐ Slightly Satisfied ☐ Moderately Satisfied ☐ Very Satisfied ☐ Extremely Satisfied

If a breathing device was recommended and you DO NOT use it, please tell us why:

6. Have you ever had cataracts?

☐ Yes ☐ No ☐ Unknown If YES, did you have surgery? ☐ Yes. at age: _____ ☐ No

7. How HELPFUL have the following devices been for you?

Select the appropriate response for each item listed below

DEVICES:	Never Used	Not at all Helpful	Somewhat Helpful	Very Helpful
Leg or ankle braces	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cane, crutches, walker	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Manual wheelchair	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Electric wheelchair	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

List any other DEVICES that have been helpful in managing your disease:

8. How often do you follow your doctors' advice (i.e., follow-up on referrals, take prescribed medications)?

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Always

9. If you do NOT consistently follow your doctors' advice, please tell us why:

End of Section

Managing Daily Life

Daily activities and other aspects of day-to-day life can be challenging for some people.

This section asks how myotonic dystrophy impacts your daily life.

1. Rate how much of a challenge the following activities are for you:

MOBILITY	Not a Challenge	Minor Challenge	Moderate Challenge	Major Challenge	Unable to Perform
Walking outside or inside	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Standing up, sitting down, bending down	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Going up and down stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Standing (for any length of time)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Maintaining your balance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Driving a car	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

HOUSEHOLD and PERSONAL NEEDS	Not a Challenge	Minor Challenge	Moderate Challenge	Major Challenge	Unable to Perform
Preparing meals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Housekeeping (cleaning, laundry)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Handling objects (opening jar, turning knob)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Using cutlery and kitchen utensils	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Swallowing, eating, drinking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Washing (showering, bathing)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dressing (doing up buttons, zippers)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

COMMUNICATION	Not a Challenge	Minor Challenge	Moderate Challenge	Major Challenge	Unable to Perform
Speaking (pronouncing words)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Writing (holding pen)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

PSYCHOLOGICAL	Not a Challenge	Minor Challenge	Moderate Challenge	Major Challenge	Unable to Perform
Concentrating	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Alertness (difficulty staying awake)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Putting thoughts into words	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Planning daily activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Remembering things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Managing Daily Life

Continued

SOCIAL	Not a Challenge	Minor Challenge	Moderate Challenge	Major Challenge	Unable to Perform
Romantic, emotional, intimate life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relationships/interactions with others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Disclosure (talking about my disease)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

DOCTORS' OFFICE	Not a Challenge	Minor Challenge	Moderate Challenge	Major Challenge	Unable to Perform
Preparing for a visit to the doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Advocating for appropriate care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Booking/tracking appointments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

WORK/SCHOOL	Not a Challenge	Minor Challenge	Moderate Challenge	Major Challenge	Unable to Perform
Completing my education/schooling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Employment (obtaining/retaining work)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Performing my tasks at work/school	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2. Which of these challenges impact your daily life the MOST?

List up to THREE

3. What is your biggest obstacle in managing myotonic dystrophy in your daily life?

4. Do you have any "tricks" or strategies you use to manage your myotonic dystrophy that you'd like to share?

End of Section

Your Insurance

This section asks about how well your health insurance coverage meets your needs.



If you live in the **United States** please answer the following four questions.

1. What is your level of health insurance coverage?

- ☐ I do not have health insurance coverage
- ☐ I have partial coverage
- ☐ I have full coverage

2. If you do not have full health insurance coverage, please tell us why:

3. Do you feel you have adequate insurance to meet the costs associated with your myotonic dystrophy?

- ☐ Yes
- ☐ No
- ☐ Unknown

4. Have you ever had difficulty meeting the costs associated with managing your disease?

- ☐ Yes
- ☐ No
- ☐ Unknown



If you live in the **Canada** please answer the following three questions.

1. What is your level of health insurance coverage (over and above universal health care)?

- ☐ I do not have additional/supplemental health insurance coverage
- ☐ I have additional/supplemental health insurance coverage

2. Do you feel you have adequate insurance to meet the costs associated with your myotonic dystrophy?

- ☐ Yes
- ☐ No
- ☐ Unknown

3. Have you ever had difficulty meeting the costs associated with managing your disease?

- ☐ Yes
- ☐ No
- ☐ Unknown

End of Section

End of Survey

Did anyone help you fill out the survey?

- ☐ Yes ☐ No

If YES, who helped you?

- ☐ Spouse
☐ Parent/guardian
☐ Other family member or caregiver
☐ Other, specify: _____

If YES, how much assistance did you receive?

- ☐ MINOR: I only needed help with reading or filling in questions; all answers are my own.
☐ MODERATE: I needed some help understanding and/or completing the questions.
☐ MAJOR: I needed SUBSTANTIAL help understanding and/or completing the questions.
-

That's it!

Thank you for taking the time to complete this survey.
Please return it in the self-addressed, stamped envelope provided.

A large, textured orange circle with a slightly irregular, hand-drawn appearance. It has a gradient from a darker orange in the center to a lighter orange at the edges, with some darker spots and a soft shadow effect.

thank you!

SAMPLE

Please return your completed survey to:

The Christopher Project
1550 Larimer Street, Suite 503
Denver, Colorado
USA 80202

Partners:



MYOTONIC
DYSTROPHY
FOUNDATION



Muscular
Dystrophy Canada

MDA
Fighting Muscle Disease



The Marigold Foundation
Creating Hope & Opportunity



STANFORD
SCHOOL OF MEDICINE



UNIVERSITY of
ROCHESTER



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