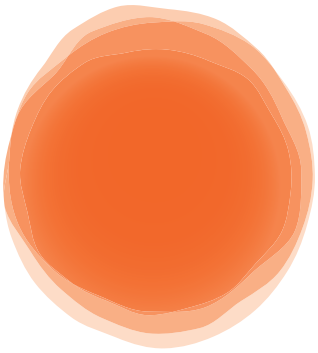
Family Member/Caregiver Survey



the christopher project

Who should fill out this survey?

You are being asked to fill out this survey because you are a family member, caregiver, or friend of someone who completed a patient survey for the Christopher Project. Please take the time to give us your input—your insights will help us better understand the impact myotonic dystrophy has on patients, families, and caregivers.

Family Member/Caregiver 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? ◯ Email ◯ Lettermail ◯ Phone
Check all that apply

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

Survey Instructions

The anonymous responses you provide in this survey will be analyzed with the original patient responses to better understand the patient experience and the impact of myotonic dystrophy. All of your answers will be kept strictly confidential, your personal information will not be published or shared, and you will not receive any compensation for your participation.

- This survey has two parts and should take you about half an hour to complete.
- Throughout this survey, the person with myotonic dystrophy who filled out the original, patient survey will be referred to as the subject.
- It's OK to respond to this survey if you have myotonic dystrophy yourself but your answers should be about your experience and perspective as a family member, caregiver, or friend of the subject.
- Fill in the questions with a simple checkmark or 'x', whatever is easiest for you.
- Please return your completed survey in the self-addressed stamped envelope provided **by March 31, 2015**.
- If you still have questions or need more information please 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.

Let's get started!

Part I: Adding Context to the Patient Perspective

About You

This brief section collects basic information about you as a family member, caregiver, or friend.

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.)?** _____ **(MM/DD/YYYY)**

4. **What is your gender?** ◯ Female ◯ Male

5. **Do you have myotonic dystrophy yourself?** ◯ Yes ◯ No ◯ Unknown

6. **What is your relationship to the person who filled out the original patient survey (the subject)?**
Select one

◯ I am their parent/guardian ◯ I am their child

◯ I am their spouse/partner ◯ I am their friend

◯ I am their sibling (brother or sister) ◯ I am their professional caregiver

◯ Other, specify: _____

7. **How much assistance did you provide the subject in completing the original patient survey?**
Select one

◯ NONE: I did not provide any assistance.

◯ MINOR: I only helped them with reading or filling in questions; the subject provided all of the answers.

◯ MODERATE: I provided some help to the subject in understanding and/or completing the questions.

◯ MAJOR: I provided SUBSTANTIAL help to the subject in understanding and/or completing the questions.

-or-

◯ I completed the entire patient survey on behalf of the **subject**.

End of Section

Your Role

This section is about how you help the subject manage their myotonic dystrophy.

1. How much time do you spend with the **subject**?
Select one

- ◯ I live with the subject full-time
- ◯ I see the subject each day
- ◯ I see the subject several times a week
- ◯ I see the subject once a week or less

2. **How much assistance do you provide the subject in managing their daily life and myotonic dystrophy related issues?**
Select one

- ◯ MINOR ASSISTANCE: I support them occasionally but they are normally independent
- ◯ MODERATE ASSISTANCE: I support them frequently, we work together often
- ◯ MAJOR ASSISTANCE: I support them constantly, we work together all of the time

3. **In what ways do you help the subject?**
Check all that apply

- ☐ I provide financial support
- ☐ I provide emotional support
- ☐ I help them with their household tasks and chores
- ☐ I help them with their personal needs (e.g., bathing, dressing)
- ☐ I help them with their schoolwork
- ☐ I help them with their healthcare
- ☐ I attend clinical visits with them
- ☐ Other, specify: _____

4. **Considering all the things you do to help the subject, what do you think are the MOST important?**

_____

_____

5. **Do you help other people manage their myotonic dystrophy?** ◯ Yes ◯ No

If YES, how many? _____ **(enter total number of people you help, including the subject)**

End of Section

Information and Resources and You

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

1. How HELPFUL have the following sources of myotonic dystrophy information been for YOU as a family member/caregiver? *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	◯	◯	◯	◯
Other medical specialists	◯	◯	◯	◯
Family/friends	◯	◯	◯	◯
Patient organizations (i.e., MDA, MDF, MDC)	◯	◯	◯	◯
General health-related websites	◯	◯	◯	◯
Printed materials/books	◯	◯	◯	◯

2. Who or what has been the MOST helpful source of myotonic dystrophy information for YOU?
Please be specific

_____

3. What is the NUMBER ONE best way for YOU to receive information about myotonic dystrophy?

_____

4. Which areas would you like to get more information about?
Check all that apply

- ◯ Available treatments/medications
- ◯ Where to find specialists/disease experts
- ☐ ◯ Clinical trials
- ◯ Scientific research
- ◯ Genetic counseling/family planning
- ◯ Anesthesia risks
- ◯ Cardiac complications
- ◯ Financial assistance
- ◯ Health insurance
- ☐ ◯ Caregiver support/training
- ◯ Technical aids
- ◯ Disclosure (talking with others about myotonic dystrophy)
- ◯ Patient organizations (i.e., MDA, MDF, MDC)
- ◯ School accommodations/assistance
- ◯ Workplace accommodations
- ◯ Community supports
- ◯ Psychological supports
- ◯ Exercise
- ◯ Nutrition
- ☐ ◯ Other, specify: _____

End of Section

Additional Insights from You

This section asks you to comment on other aspects of managing myotonic dystrophy.

1. How satisfied are YOU with the overall medical care the subject receives?

◯	◯	◯	◯	◯
Very Dissatisfied	Dissatisfied	Neutral	Satisfied	Very Satisfied

2. As a family member/caregiver, what advice do YOU have for medical professionals working with patients and/or families affected by myotonic dystrophy?

3. What is YOUR biggest challenge in helping the subject manage their myotonic dystrophy?

4. Do you have any "tricks" or strategies that would help someone better manage their myotonic dystrophy that you'd like to share?

End of Section

Part II: Your Perspective on the Subject's Experience

This section asks about YOUR perspective on the subject's experience. For example:

- What symptoms do you think impact their life the most?
- What do you think are their greatest challenges in daily life?

The answers you provide might be different than how the subject would respond—that's OK. Your unique insights will add context and increase our shared understanding of what it's like to live with this complex condition.

The Subject's Symptoms

This section asks about your understanding of the subject's condition.

1. **What type of myotonic dystrophy does the subject have?**
   Select one

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

2 **In general, would you say the subject's current health is:**

   ◯ Excellent
☐ ◯ Very good
☐ ◯ Good
   ◯ Fair
   ◯ Poor

3. **About how old was the subject when the first significant symptoms were noticed?**

☐ Age (years): _____

What was the first symptom noticed? _____

-or-

◯ The **subject** does not experience symptoms

The Subject's Symptoms

Continued

4. **Please rate how much you think the following problems/symptoms impact the subject's daily life:**
Select the appropriate response for each item listed below

MUSCLE	Does Not Experience	Has Symptom but NO Impact	Has Symptom with MINOR Impact	Has Symptom with MODERATE Impact	Has Symptom with MAJOR Impact
myotonia (difficulty relaxing muscle)	◯	◯	◯	◯	◯
muscle weakness (dystrophy)	◯	◯	◯	◯	◯
muscle aches, cramps	◯	◯	◯	◯	◯
muscle pain	◯	◯	◯	◯	◯

GASTROINTESTINAL	Does Not Experience	Has Symptom but NO Impact	Has Symptom with MINOR Impact	Has Symptom with MODERATE Impact	Has Symptom with MAJOR Impact
difficulty swallowing (dysphagia)	◯	◯	◯	◯	◯
diarrhea	◯	◯	◯	◯	◯
constipation	◯	◯	◯	◯	◯
frequent hiccups	◯	◯	◯	◯	◯
abdominal pain	◯	◯	◯	◯	◯

CARDIORESPIRATORY	Does Not Experience	Has Symptom but NO Impact	Has Symptom with MINOR Impact	Has Symptom with MODERATE Impact	Has Symptom with MAJOR Impact
abnormal heart rhythm	◯	◯	◯	◯	◯
recurrent lung infections/pneumonia	◯	◯	◯	◯	◯
shortness of breath	◯	◯	◯	◯	◯
dizziness/fainting	◯	◯	◯	◯	◯

SLEEP and FATIGUE	Does Not Experience	Has Symptom but NO Impact	Has Symptom with MINOR Impact	Has Symptom with MODERATE Impact	Has Symptom with MAJOR Impact
daytime sleepiness	◯	◯	◯	◯	◯
fatigue	◯	◯	◯	◯	◯
difficulty falling asleep	◯	◯	◯	◯	◯
trouble breathing during sleep (apnea)	◯	◯	◯	◯	◯

The Subject's Symptoms

Continued

PSYCHOLOGICAL	Does Not Experience	Has Symptom but NO Impact	Has Symptom with MINOR Impact	Has Symptom with MODERATE Impact	Has Symptom with MAJOR Impact
learning difficulties/challenges	◯	◯	◯	◯	◯
difficulty concentrating	◯	◯	◯	◯	◯
depression	◯	◯	◯	◯	◯
anxiety	◯	◯	◯	◯	◯

BIOLOGICAL, HORMONAL, ENDOCRINE	Does Not Experience	Has Symptom but NO Impact	Has Symptom with MINOR Impact	Has Symptom with MODERATE Impact	Has Symptom with MAJOR Impact
diabetes	◯	◯	◯	◯	◯
sexual/intimacy problems	◯	◯	◯	◯	◯
fertility problems	◯	◯	◯	◯	◯

OTHER	Does Not Experience	Has Symptom but NO Impact	Has Symptom with MINOR Impact	Has Symptom with MODERATE Impact	Has Symptom with MAJOR Impact
balding/thinning hair	◯	◯	◯	◯	◯
headaches, migraines	◯	◯	◯	◯	◯
drooping eyelids (ptosis)	◯	◯	◯	◯	◯
hearing loss	◯	◯	◯	◯	◯
balance issues	◯	◯	◯	◯	◯

5. Of all of the problems/symptoms the subject experiences, which ones do you think impact their life the most?
List up to THREE

_____

_____

_____

End of Section

The Subject's Medical Care

This section asks about your perspective on the subject's health care experience.

1. Does the subject take medication for daytime sleepiness and/or fatigue?

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

If the subject takes 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

2. How often does the subject follow their doctors' advice (i.e., follow-up on referrals, take prescribed medications)?

◯ Never ◯ Rarely ◯ Sometimes ◯ Often ◯ Always

3. If the subject does NOT consistently follow their doctors' advice, please tell us why you think that's the case:

_____

_____

4. How satisfied do you think the subject is with the overall medical care they receive?

◯ Very Dissatisfied ◯ Dissatisfied ◯ Neutral ◯ Satisfied ◯ Very

5. What medical needs or concerns do you think the subject has that have not been met through their health care?

_____

_____

6. If the subject has unmet medical needs, please explain why you think that's the case:

_____

_____

End of Section

The Subject's Daily Life

Daily activities and other aspects of day-to-day life can be challenging for some people. This section asks for your impressions on how myotonic dystrophy impacts the subject's daily life.

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

MOBILITY	Not a Challenge	Minor Challenge	Moderate Challenge	Major Challenge	Unable to Perform
Walking outside or inside	◯	◯	◯	◯	◯
Standing up, sitting down, bending down	◯	◯	◯	◯	◯
Going up and down stairs	◯	◯	◯	◯	◯
Standing (for any length of time)	◯	◯	◯	◯	◯
Maintaining your balance	◯	◯	◯	◯	◯
Driving a car	◯	◯	◯	◯	◯

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

COMMUNICATION	Not a Challenge	Minor Challenge	Moderate Challenge	Major Challenge	Unable to Perform
Speaking (pronouncing words)	◯	◯	◯	◯	◯
Writing (holding pen)	◯	◯	◯	◯	◯

PSYCHOLOGICAL	Not a Challenge	Minor Challenge	Moderate Challenge	Major Challenge	Unable to Perform
Concentrating	◯	◯	◯	◯	◯
Alertness (difficulty staying awake)	◯	◯	◯	◯	◯
Putting thoughts into words	◯	◯	◯	◯	◯
Planning daily activities	◯	◯	◯	◯	◯
Remembering things	◯	◯	◯	◯	◯

The Subject's Daily Life

Continued

SOCIAL	Not a Challenge	Minor Challenge	Moderate Challenge	Major Challenge	Unable to Perform
Romantic, emotional, intimate life	◯	◯	◯	◯	◯
Relationships/interactions with others	◯	◯	◯	◯	◯
Disclosure (talking about my disease)	◯	◯	◯	◯	◯

DOCTORS' OFFICE	Not a Challenge	Minor Challenge	Moderate Challenge	Major Challenge	Unable to Perform
Preparing for a visit to the doctor	◯	◯	◯	◯	◯
Advocating for appropriate care	◯	◯	◯	◯	◯
Booking/tracking appointments	◯	◯	◯	◯	◯

WORK/SCHOOL	Not a Challenge	Minor Challenge	Moderate Challenge	Major Challenge	Unable to Perform
Completing my education/schooling	◯	◯	◯	◯	◯
Employment (obtaining/retaining work)	◯	◯	◯	◯	◯
Performing my tasks at work/school	◯	◯	◯	◯	◯

2. **Which of these challenges do you think impacts the subject's daily life the MOST?**
List up to THREE

_____

_____

_____

3. **What do you think is the subject's biggest obstacle in managing their myotonic dystrophy in their daily life?**

_____

_____

End of Section

End of Survey

Please provide any additional comments in the space below:

That's it!

Thank you for taking the time to complete this survey.
Please return it in the self-addressed, stamped envelope provided by March 31, 2015.

Please return your completed survey to:

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

Partners:

The Christopher Project 7515 Flint Road SE Calgary, AB, Canada T2H 1G3
Toll Free 1-855-506-4646 Phone 1-403-255-4646 Email support@christopherproject.org