

**Supplemental Table 1. Combined parent responses to all survey items**

<b>Themes (bold) and Symptoms</b>	<b>Prevalence (%)</b>	<b>Mean Impact</b>	<b>Std Dev</b>	<b>Population Impact</b>
<b>Limitations with mobility and walking</b>	<b>71.1</b>	<b>1.71</b>	<b>1.34</b>	<b>1.22</b>
Impaired walking	58.9	1.83	1.40	1.08
Difficulty with stairs	57.9	1.86	1.57	1.08
Difficulty with balance	65.2	1.54	1.29	1.01
Falls	53.9	1.66	1.33	0.89
Inability to run	60.7	1.98	1.60	1.20
Inability to walk fast	54.6	2.03	1.42	1.11
Difficulty walking up hills or inclines	60.0	2.01	1.50	1.21
Difficulty walking on rough ground	62.9	1.97	1.48	1.24
Difficulty walking long distances	73.4	2.20	1.50	1.61
Difficulty standing	37.5	1.77	1.54	0.66
Tripping	51.1	1.77	1.52	0.91
Trouble getting around	41.4	1.76	1.53	0.73
Needing handrails	44.6	1.87	1.60	0.83
Unsteady legs	43.2	1.73	1.53	0.75
Inability to keep pace with others while walking	62.1	1.86	1.53	1.16
Inability to keep pace with others in recreation/playing	72.9	2.12	1.50	1.54
Impaired motor skills	74.6	1.80	1.44	1.34
Loss of ability to walk	16.5	2.35	1.58	0.39
Difficulty with curbs	37.1	1.90	1.59	0.71
<b>Hip, thigh, or knee weakness</b>	<b>55.4</b>	<b>1.71</b>	<b>1.39</b>	<b>0.95</b>
Difficulty getting up from the floor or ground	56.0	1.75	1.57	0.98
Difficulty rising from a seated position	41.8	1.75	1.52	0.73
Leg weakness	53.6	1.77	1.59	0.95
Difficulty getting up from a lying position	48.6	1.65	1.39	0.80
Knee weakness	40.0	1.82	1.45	0.73
Difficulty lifting objects because of leg weakness	42.8	1.90	1.48	0.81
<b>Back, chest, or abdomen weakness</b>	<b>55.4</b>	<b>1.46</b>	<b>1.27</b>	<b>0.81</b>
Difficulty sitting up from a lying position	47.5	1.49	1.47	0.71
Difficulty bending down	42.9	1.77	1.53	0.76
Neck weakness	49.6	1.38	1.46	0.68
Difficulty rolling over in bed	25.0	1.11	1.43	0.28
Poor posture	54.0	1.43	1.32	0.77
Weak trunk (core) muscles	60.4	1.48	1.30	0.89
Back weakness	50.0	1.57	1.29	0.79
Abdominal muscle weakness	52.2	1.48	1.30	0.77
Inability to get out of bed due to weakness	21.0	1.52	1.55	0.32
Weak cough	45.7	1.75	1.51	0.80
<b>Problems with hands or fingers</b>	<b>79.6</b>	<b>1.63</b>	<b>1.30</b>	<b>1.30</b>
Difficulty opening jars or bottles	84.3	1.75	1.35	1.47
Hand weakness	85.1	1.65	1.37	1.40
Decreased hand coordination	70.9	1.63	1.35	1.16
Difficulty using hands	59.3	1.52	1.34	0.90

Dropping objects	50.4	1.16	1.12	0.58
Impaired ability to open doors or drawers	44.3	1.42	1.21	0.63
Difficulty picking things up with your fingers	47.5	1.24	1.24	0.59
Impaired fine motor skills	72.1	1.41	1.30	1.01
Difficulty catching	67.9	1.51	1.39	1.02
Difficulty throwing	57.6	1.50	1.44	0.86
<b>Problems with shoulders or arms</b>	<b>55.4</b>	<b>1.53</b>	<b>1.23</b>	<b>0.85</b>
Arm weakness	58.6	1.37	1.29	0.80
Diffuculty lifting objects due to arm weakness	55.0	1.55	1.35	0.85
Shoulder weakness	43.2	1.53	1.33	0.66
Difficulty brushing or washing hair	48.6	1.84	1.48	0.89
Difficulty carrying a load	59.7	1.87	1.51	1.12
Difficulty reaching objects overhead	45.7	1.59	1.41	0.73
Reduced arm and shoulder range of motion	36.7	1.77	1.41	0.65
Difficulty putting away dishes overhead	42.6	1.79	1.62	0.76
Difficulty brushing teeth	46.0	1.63	1.46	0.75
Trouble hanging up clothes	48.6	1.47	1.43	0.72
<b>Myotonia</b>	<b>73.9</b>	<b>1.48</b>	<b>1.34</b>	<b>1.09</b>
Stiffness	52.9	1.33	1.25	0.70
Locked up muscles	48.6	1.31	1.14	0.64
Jaw stiffness (myotonia)	27.1	1.08	0.97	0.29
Cramping	42.9	1.28	1.11	0.55
Inability to release grip	50.0	1.27	1.20	0.64
Embarrassment when not able to let go of someones hand	20.3	1.18	1.28	0.24
Knees that lock up	19.7	1.15	1.13	0.23
Hand myotonia	53.2	1.68	1.24	0.89
Tongue cramping	20.0	1.14	1.08	0.23
<b>Gastrointestinal issues</b>	<b>70.4</b>	<b>2.08</b>	<b>1.35</b>	<b>1.46</b>
Constipation	48.2	1.82	1.31	0.88
Abdominal pain	46.7	1.42	1.19	0.66
Weight gain	34.8	1.58	1.27	0.55
Diarrhea	51.9	1.49	1.38	0.77
A change in diet due to illness	19.4	1.69	1.49	0.33
Stomach cramping	33.1	1.38	1.13	0.46
Gas	47.5	1.23	1.30	0.58
Bloating	30.4	1.05	1.05	0.32
A change in your activities secondary to gastrointestinal symptoms	29.2	1.55	1.36	0.45
<b>Problems with urinary or bowel control</b>	<b>51.1</b>	<b>2.06</b>	<b>1.43</b>	<b>1.05</b>
Requiring diapers	33.6	2.56	1.50	0.86
Inability to join group without toilet training	20.3	2.26	1.66	0.46
Soiled clothes	31.1	2.49	1.43	0.77
Stool incontinence	33.8	2.51	1.42	0.85
Urinary incontinence	27.3	2.33	1.53	0.64
Urinary frequency	17.3	2.00	1.54	0.35
<b>Inability to do activities</b>	<b>70.0</b>	<b>1.89</b>	<b>1.28</b>	<b>1.32</b>
Difficulty cleaning a house	56.4	1.89	1.37	1.07

Difficulty getting in and out of vehicles	41.3	1.42	1.40	0.59
Problems preparing food	55.1	1.73	1.49	0.96
Problems getting dressed	50.7	1.51	1.34	0.77
Problems maintaining a home	48.9	2.34	1.50	1.14
Difficulty playing sports	69.9	2.26	1.47	1.58
Impaired dancing	48.5	1.92	1.60	0.93
Trouble riding a bike	57.8	2.14	1.62	1.24
Problems shopping	46.3	2.16	1.36	1.00
Trouble going up step ladders	47.4	2.03	1.58	0.96
Difficulty walking dogs	33.6	1.67	1.60	0.56
Difficulty bathing or taking a shower	47.1	1.75	1.44	0.82
Difficulty holding a milk gallon	54.1	1.81	1.50	0.98
Inability to mow the lawn	35.9	2.62	1.62	0.94
Impaired ability to exercise	51.1	1.87	1.36	0.96
Problems using buttons or zippers	63.2	1.85	1.48	1.17
Problems doing the laundry	38.9	1.90	1.62	0.74
Difficulty swimming	42.9	1.83	1.47	0.78
Taking longer to do household chores	59.4	1.96	1.56	1.17
Difficulty washing dishes	48.9	1.77	1.48	0.86
Difficulty scrubbing surfaces	46.6	1.89	1.52	0.88
Difficulty doing yard work	43.4	2.05	1.53	0.89
Difficulty getting out of a tub	38.3	1.96	1.57	0.75
Difficulty changing a light bulb	35.1	1.91	1.62	0.67
Inability to hike	59.1	2.19	1.55	1.30
Difficulty putting on shoes	55.6	1.61	1.50	0.90
Difficulty cutting or manicuring nails	43.8	2.39	1.56	1.05
Trouble standing on a chair	46.6	2.05	1.68	0.96
Difficulty taking care of pets	38.5	1.82	1.52	0.70
Difficulty making a bed	47.4	1.56	1.50	0.74
Difficulty staying active	54.5	1.75	1.33	0.96
Difficulty maintaining personal hygiene	53.7	2.01	1.41	1.08
Difficulty using a computer keyboard	35.6	1.48	1.19	0.53
Increased safety risk due to disease	45.5	2.00	1.51	0.91
Trouble setting an alarm clock	34.1	1.91	1.62	0.65
Problems opening boxes	45.5	1.57	1.44	0.71
Difficulty using a remote control	24.8	1.27	1.40	0.32
Difficulty using keys	39.1	1.56	1.50	0.61
Difficulty cutting meat	53.0	1.83	1.41	0.97
Difficulty using a hammer or other tool	41.4	2.00	1.63	0.83
Difficulty with mopping	39.5	1.96	1.55	0.78
Problems washing windows	44.1	1.95	1.60	0.86
Difficulty lifting weights	54.5	2.01	1.53	1.10
Inability to be spontaneous in activities	50.4	1.75	1.43	0.88
Inability to get on amusement park rides	46.2	1.90	1.60	0.88
Difficulty painting a picture	47.4	1.75	1.52	0.83
Inability to turn on a light with a pull cord	18.2	1.29	1.30	0.24
Difficulty shoveling	43.8	2.07	1.58	0.91
Inability to participate in extracurricular activities	53.0	2.04	1.40	1.08

Difficulty walking to school	36.5	2.26	1.51	0.83
Difficulty driving a motor vehicle	41.6	2.87	1.39	1.19
Difficulty using an eating utensil	47.4	1.38	1.28	0.65
Difficulty playing video games	31.6	1.30	1.42	0.41
<b>Problems choking or swallowing</b>	<b>56.7</b>	<b>1.43</b>	<b>1.33</b>	<b>0.81</b>
Problems swallowing	54.6	1.56	1.29	0.85
Choking	47.5	1.44	1.27	0.68
Change of diet due to choking	23.0	1.69	1.49	0.39
Indigestion	36.0	1.45	1.34	0.52
Fear of choking	28.5	1.18	1.25	0.34
A change to softer foods	23.0	1.50	1.24	0.35
Difficulty using a straw	30.4	1.41	1.45	0.43
<b>Emotional issues</b>	<b>62.3</b>	<b>1.38</b>	<b>1.28</b>	<b>0.86</b>
Depression	41.9	1.16	1.13	0.49
Awareness of the disease getting worse	44.9	1.24	1.24	0.56
Burden of thinking about the future	39.9	1.42	1.27	0.57
Anxiety	47.4	1.34	1.04	0.63
Fear of falling	43.5	1.47	1.28	0.64
Moodiness	45.7	1.37	1.18	0.62
Fear of progression of disease	38.0	1.37	1.19	0.52
Frustration	59.6	1.46	1.29	0.87
Embarrassment	38.7	1.13	1.21	0.44
Feeling overwhelmed	50.7	1.24	1.12	0.63
Stress	45.7	1.33	1.14	0.61
Generalized fear	38.7	1.15	1.05	0.45
Fear of injury with activity	38.1	1.40	1.29	0.53
Grief	29.0	.85	0.98	0.25
Keeping more to oneself (introverted)	45.3	1.76	1.29	0.80
Apathy	37.8	1.65	1.26	0.62
Decreased confidence	51.8	1.41	1.25	0.73
Anger	41.0	1.44	1.18	0.59
Loss of pride	31.2	1.14	1.01	0.36
Sadness	38.2	1.21	1.19	0.46
Isolation	44.2	1.85	1.41	0.82
Self pity	25.9	.86	1.12	0.22
Being mistaken as having another disease by others	29.9	1.02	1.15	0.31
Difficulty with emotional closeness	32.6	1.52	1.34	0.50
Increased emotional sensitivity	39.4	1.28	1.24	0.50
Hopelessness	26.1	1.06	1.15	0.28
Irritable	41.7	1.36	1.20	0.57
Fear of a worsening ability to think	19.9	0.89	0.97	0.18
Fear of death	25.0	0.97	1.17	0.24
Feeling of losing control	21.5	1.24	1.33	0.27
Fear of being mistaken for another myotonic dystrophy patient	9.4	1.46	1.81	0.14
Envy of people without a disability	29.0	1.10	1.19	0.32
Changed perspective on how to live life	28.1	1.40	1.39	0.39

Shyness	38.7	1.26	1.30	0.49
Concern about worsening heart	23.4	1.06	1.13	0.25
Impulsiveness	36.0	1.57	1.31	0.57
A narrow scope of interest	53.6	1.92	1.42	1.03
Talking to oneself	46.0	1.56	1.52	0.72
Bossiness	34.8	1.21	1.20	0.42
Difficulty with transitions or changes in plan	56.9	1.73	1.44	0.99
Frequent meltdowns/tantrums	33.3	1.46	1.33	0.49
Overly sensitive touch, light, or sound	45.3	1.55	1.35	0.70
Fear of specific things or situations	52.6	1.45	1.24	0.76
Frustration with not being understood	64.7	1.44	1.29	0.94
<b>Changed body image due to disease</b>	<b>55.1</b>	<b>1.05</b>	<b>1.17</b>	<b>0.58</b>
Impaired self image	37.3	1.14	1.13	0.43
Skin abnormalities	17.0	1.22	1.24	0.21
Impaired body image	31.3	1.17	1.15	0.37
Worry about how others perceive him/her	36.8	1.41	1.19	0.52
Muscle loss	62.0	1.69	1.44	1.05
Self-consciencious of muscle loss	30.1	1.55	1.36	0.47
Hair loss	23.5	1.50	1.37	0.35
Impaired body image due to gait	29.1	1.15	1.29	0.34
Embarrassment in wearing a bathing suit	14.1	1.32	1.20	0.19
Feeling different from other people	42.2	1.11	1.15	0.47
Foot deformity	25.5	1.60	1.42	0.41
Lowered self worth	30.1	.98	1.12	0.29
Feet that turn out	14.8	1.30	1.42	0.19
<b>Difficulty thinking</b>	<b>66.7</b>	<b>1.99</b>	<b>1.22</b>	<b>1.33</b>
Memory deficits	45.3	1.66	1.27	0.75
Problems concentrating	75.7	1.73	1.24	1.31
Trouble finding the right word	61.9	1.29	1.26	0.80
Need for increased planning for activities	55.6	1.54	1.43	0.86
Decreased motivation	47.8	1.91	1.38	0.91
Tires with mental tasks	65.7	1.84	1.33	1.21
Decreased ability to think fast	70.1	1.81	1.45	1.27
Difficulty with math	72.4	2.40	1.35	1.74
Problems reading	58.2	1.87	1.39	1.09
Being in a dream-like state	45.1	1.18	1.23	0.53
Trouble organizing activities or tasks	68.7	1.94	1.55	1.33
Increased time to complete a task	71.6	2.05	1.45	1.47
Difficulty with comprehension	68.9	1.76	1.39	1.22
Reduced decision making abilities	68.4	1.91	1.44	1.31
Inability to focus	74.1	1.81	1.35	1.34
Easily confused	53.7	1.76	1.36	0.95
Learning difficulties	83.3	2.34	1.47	1.95
Visual spatial difficulties	45.4	1.88	1.37	0.85
Literal/concrete thinking	59.2	2.08	1.41	1.23
Repetitive speech	55.7	1.86	1.46	1.04
Mental retardation	40.3	2.28	1.42	0.92
Decreased attention span	70.1	1.73	1.38	1.22

<b>Decreased satisfaction in social situations</b>	<b>61.3</b>	<b>1.92</b>	<b>1.34</b>	<b>1.18</b>
Inability to do things he or she used to do	35.8	1.67	1.42	0.60
Decreased ability to participate in activities	54.0	2.00	1.43	1.08
Perceived burden to family members	23.5	1.22	1.41	0.29
Lack of understanding by others	65.0	1.57	1.37	1.02
Increased family stress	44.9	1.59	1.38	0.71
Negative perceptions by others	40.7	1.29	1.27	0.53
Lack of available information about myotonic dystrophy	28.9	1.44	1.60	0.42
Perception of being lazy	57.7	1.43	1.31	0.83
Difficulty being in crowds	42.3	1.86	1.33	0.79
Impaired interactions with friends	57.7	2.18	1.31	1.26
Dissatisfaction with social interactions	41.5	2.11	1.38	0.88
The perception by others that myotonic dystrophy is contagious	7.4	1.40	1.51	0.10
Decreased acceptance by others	52.9	1.67	1.29	0.88
Desire to hide conditions from others	29.4	1.73	1.45	0.51
Reduced enjoyment with activities	34.6	1.65	1.34	0.57
Decreased ability to play with friends	55.6	1.96	1.42	1.09
Impaired interaction with unaffected sibling	28.1	1.67	1.27	0.47
Inappropriate social responses	50.7	1.59	1.28	0.81
Not able to participate in age appropriate activities	70.5	2.11	1.51	1.49
Behavioral problems affecting school or work performance	41.0	1.82	1.36	0.75
<b>Fatigue</b>	<b>78.6</b>	<b>1.86</b>	<b>1.26</b>	<b>1.46</b>
Physical fatigue	78.3	1.89	1.29	1.48
Poor endurance	75.9	1.83	1.27	1.39
Whole body weakness	65.0	1.84	1.38	1.20
Decreased energy	70.1	1.93	1.37	1.35
Prolonged recovery time after physical activities	58.7	1.77	1.34	1.04
Muscle fatigue	73.0	1.86	1.36	1.36
Lethargy	52.2	1.85	1.37	0.96
Decreased lower extremity stamina	65.9	1.81	1.43	1.20
Decreased activity level	61.5	2.02	1.33	1.25
Breathing difficulties	31.9	1.05	1.24	0.33
Tired muscles	67.9	1.66	1.32	1.12
Irritable towards the end of the day	48.6	1.61	1.24	0.78
<b>Impaired performance in social situations</b>	<b>70.7</b>	<b>2.04</b>	<b>1.43</b>	<b>1.44</b>
Reliance of family members	80.9	2.30	1.48	1.86
Limitations on what one can do physically	75.9	2.06	1.46	1.56
Issues at work or school	59.1	1.92	1.34	1.14
Having to adapt to disease related restrictions	54.5	1.77	1.44	0.96
Need for job training program	32.3	2.29	1.38	0.74
Lack of job secondary to disability	34.4	2.86	1.29	0.99
Decreased independence	59.0	2.20	1.46	1.30
Impaired social interactions	63.6	2.13	1.37	1.36
Difficulty interacting with family	34.6	1.34	1.17	0.46

Limited activities secondary to weakness	58.8	1.77	1.31	1.04
Difficulty interacting with friends	60.6	1.95	1.37	1.18
The avoidance of social situations	46.3	1.94	1.40	0.90
Financial issues associated with your disability	38.0	2.33	1.46	0.88
Decreased ability to see friends	47.3	2.23	1.45	1.05
Difficulty making friends	61.4	2.37	1.36	1.46
Inability to go out	45.5	2.32	1.41	1.05
Reliance on friends	37.5	1.46	1.49	0.55
Inability to take care of oneself	54.8	2.20	1.49	1.21
Inability to provide childcare	29.5	2.76	1.57	0.82
The need for special education	69.4	2.41	1.50	1.67
The need for close parental/caregiver supervision	64.2	2.34	1.51	1.50
Inability to take family trips	27.9	1.50	1.48	0.42
Being the last child picked for games	38.9	2.18	1.44	0.85
The need for physical, occupational, or speech therapy	68.4	2.29	1.42	1.57
<b>Impaired sleep or daytime sleepiness</b>	<b>70.2</b>	<b>1.85</b>	<b>1.39</b>	<b>1.30</b>
Daytime sleepiness	71.0	1.57	1.32	1.12
Excessive sleep requirements	66.9	1.80	1.49	1.20
Breathing problems at night	31.4	1.70	1.42	0.53
Difficulty sleeping due to choking on saliva	21.5	1.21	1.29	0.26
Difficulty falling asleep at night	36.0	2.02	1.44	0.73
Fear of safety secondary to excessive sleepiness	12.0	1.13	1.41	0.14
Morning headaches	12.6	1.35	1.12	0.17
Restless sleep	32.4	1.50	1.25	0.49
<b>Pain</b>	<b>50.0</b>	<b>1.39</b>	<b>1.14</b>	<b>0.70</b>
Pain all over	23.7	1.28	1.02	0.30
Chest pain	21.3	.93	1.16	0.20
Leg pain	37.2	1.28	1.17	0.47
Hip pain	22.8	1.07	1.06	0.24
Neck pain	28.1	1.34	1.19	0.38
Sore and achy muscles	44.1	1.15	1.21	0.51
Back pain	34.6	1.45	1.16	0.50
Limited activity due to pain	24.8	1.33	1.14	0.33
Foot pain	30.4	1.17	1.28	0.36
Headache	20.6	1.14	1.11	0.24
Arm pain	20.7	1.18	1.06	0.24
Shoulder pain	25.2	1.18	1.03	0.30
Muscle pain after exertion	41.8	1.57	1.29	0.66
Pain from wearing a brace	21.7	1.71	1.15	0.37
<b>Problems with your vision, hearing or sense of smell</b>	<b>49.3</b>	<b>1.32</b>	<b>1.17</b>	<b>0.65</b>
Cataracts	18.8	1.08	1.41	0.20
Difficulty focusing eyes	23.2	.91	1.03	0.21
Visual loss	27.3	.87	0.99	0.24
Poor night vision	20.3	.96	0.88	0.20
Increased tearing	24.1	.73	0.94	0.18

Inability to close eyes	24.1	.82	1.13	0.20
Eye irritation	19.4	.70	0.87	0.14
Having crossed eyes	12.2	1.29	1.40	0.16
<b>Communication issues</b>	<b>81.8</b>	<b>1.92</b>	<b>1.32</b>	<b>1.57</b>
Slurred speech	68.6	2.03	1.46	1.39
Quiet voice	39.3	1.83	1.33	0.72
Impaired speech	73.6	2.16	1.54	1.59
Difficulty communicating with others	76.4	2.05	1.46	1.56
Difficulty writing	75.7	2.10	1.43	1.59
Impaired facial expression	64.7	1.76	1.41	1.14
Poor handwriting	79.0	2.16	1.45	1.70
Poor pronunciation	74.8	2.07	1.41	1.55
Drooping eyelids	49.3	1.33	1.33	0.66
Not wanting to talk because of voice	19.1	1.89	1.37	0.36
49 k) Having to repeat oneself often	68.4	1.83	1.43	1.25
Inability to smile	41.0	1.42	1.38	0.58
Inability to whistle	53.6	1.68	1.60	0.90
Facial weakness	70.7	1.46	1.42	1.03
Inability to wink	43.8	1.33	1.60	0.58
Embarrassment while talking in public	28.9	1.28	1.23	0.37
Being non-verbal	23.4	2.28	1.49	0.53
Unable to maintain conversation due to attention span	34.6	1.26	1.26	0.43
Slow speech	37.0	1.52	1.37	0.56
The need for sign language to communicate	19.3	1.78	1.65	0.34
<b>Difficultly with medication side effects</b>	<b>20.9</b>	<b>1.11</b>	<b>1.10</b>	<b>0.23</b>