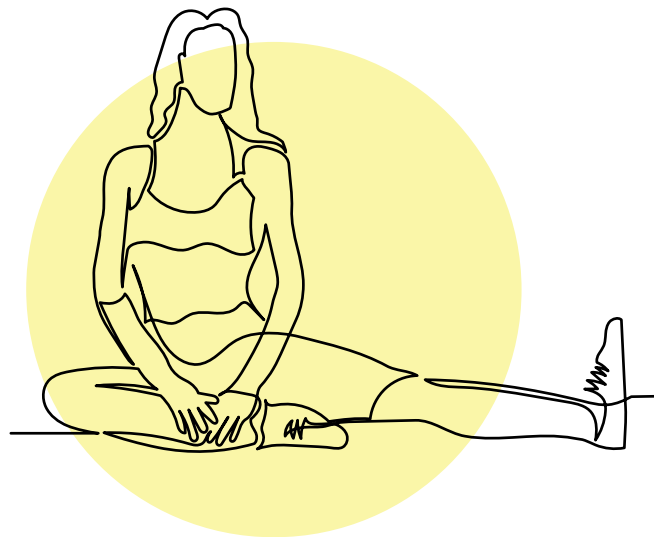
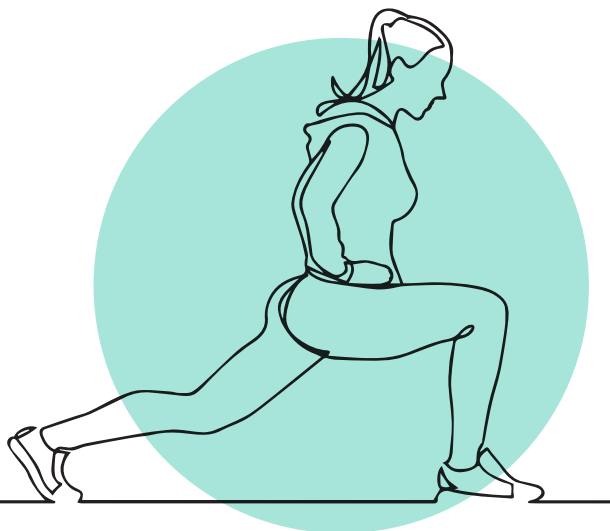


# Exercise Guide for People Living with Myotonic Dystrophy

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The Myotonic Dystrophy Foundation (MDF) is the world's largest myotonic dystrophy-only patient advocacy organization. Our programs include funding critical research, providing comprehensive resources and support to affected individuals, advocating with government agencies to enhance the drug development pipeline, increase research funding, and improve patient services.

*Disclaimer: This guide was created to help educate you about exercise. This guide does not replace any advice from your doctor or physical therapist and is meant to be educational only. Always consult your doctor or physical therapist before making any significant changes to your exercise regimen.*

**A publication of the Myotonic Dystrophy Foundation (MDF)**

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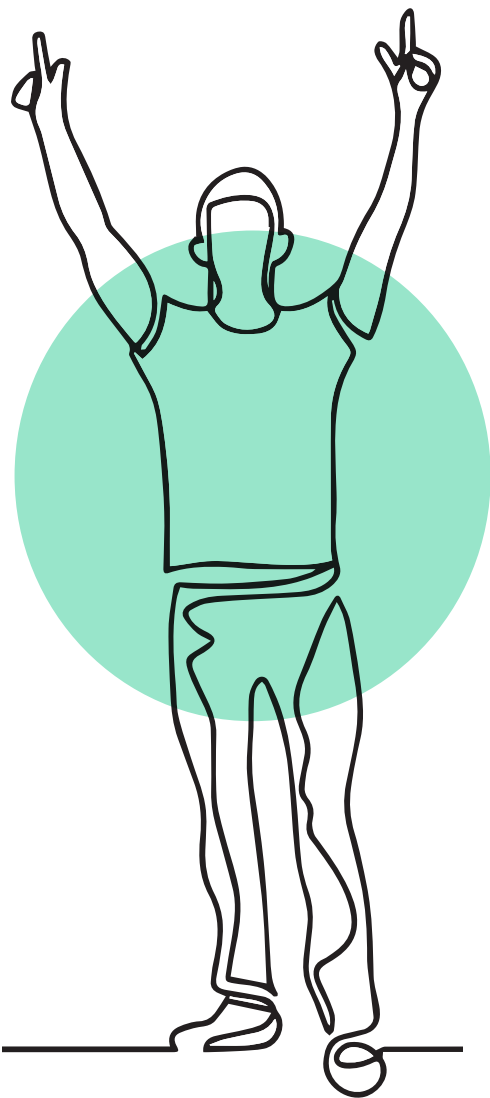
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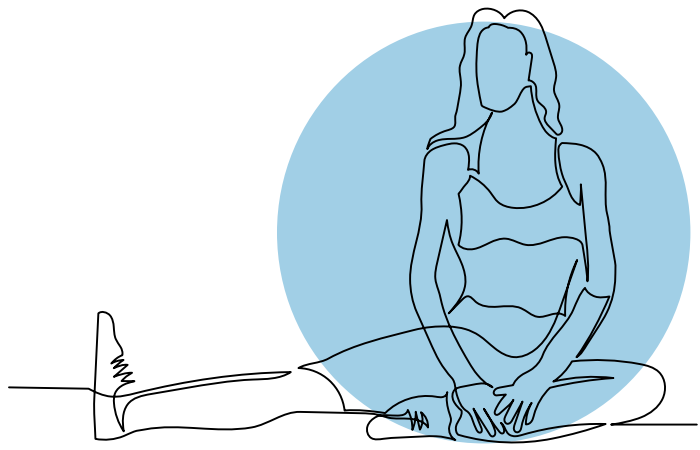
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# Exercise Guide for People Living with Myotonic Dystrophy

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This guide for exercise should be used with recommendations from your health care providers. All individuals should talk to their health care providers before starting a new exercise program. Physical therapists can help design exercise programs that are individualized to meet a person's specific needs while taking into consideration other comorbidities related to myotonic dystrophy. If you have access to a physical therapist, consult them before starting an exercise program. This document is intended to guide you on how to exercise on your own and will help you get started.

Studies show that moderate exercise is safe and may be effective for individuals with myotonic dystrophy.<sup>1-4</sup> Even though exercise does not cure myotonic dystrophy, it can help optimize function and maintain strength.

## Benefits of Exercise

### General Benefits of Exercise<sup>5, 6</sup>

- These benefits are relevant for all individuals including those with myotonic dystrophy.
- Reduces blood pressure, prevents obesity, reduces risk of osteoporosis, heart disease, arthritis, Type 2 Diabetes Mellitus and some forms of cancer.<sup>5-7</sup>
- Reduces the risk of falling.<sup>7</sup>
- Helps reduce anxiety, depression and pain.<sup>8-11</sup>
- Lowers the risk of cognitive<sup>11, 12</sup> decline and dementia.<sup>13, 14</sup>
- Improves mental health and energy levels.<sup>15</sup>

### Benefits of Exercise for Individuals with Myotonic Dystrophy

- Exercise creates a response that changes metabolism and energy used by the muscle fibers that have an impact on muscle force production.<sup>16</sup>
- Strength loss occurs slowly over time ranging from 11% to 55% compared to those without DM.<sup>17, 18</sup>
- Strengthening exercises can counter muscle loss/atrophy.<sup>3, 19</sup>
- Physical training increases muscle fiber size with no negative effect on the tissue.<sup>4, 20</sup>

## Types of Exercise

Exercise programs should include 4 types of exercises:

1. Flexibility/Stretching/Range of Motion
2. Aerobic/Cardiovascular
3. Resistive/Strengthening
4. Balance Training

## Flexibility/Stretching/Range of Motion

### What is Range Of Motion (ROM)?

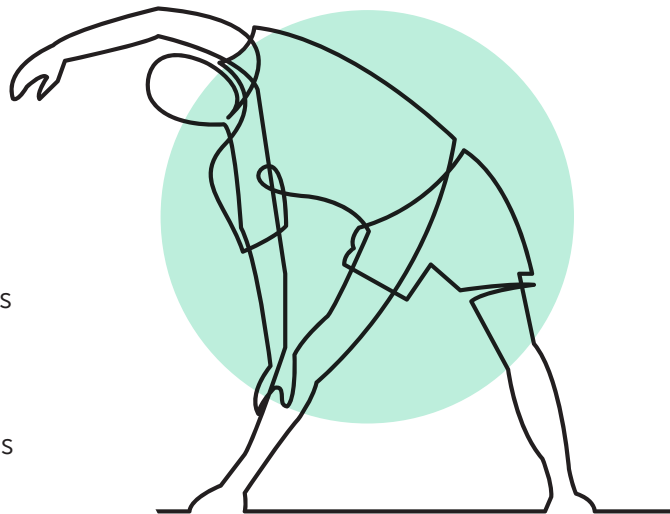
- ROM is the entire range that a joint is able to move. This may be done through passive ROM (joint is moved by someone else), active ROM (joint is moved by your own muscle strength), or active assisted ROM (joint is moved by a combination of your own muscle strength and assistance from someone else or a device).
- Muscle strength is required to actively move throughout the ROM, but some people may have limitations at different parts of the full ROM, due to tight muscles and tendons.

### What is stretching?

- Stretching increases flexibility and extensibility of the muscles and tendons. Stretches should be held for 60 seconds or 2-3 X 30 seconds. Stretching requires a joint be moved through your range of motion.

### Benefits of stretching

- Stretching reduces tightness and muscle imbalances. If you do not have the muscle strength to move the joint throughout the entire range of motion, the joints and muscles and tendons shorten and may stiffen, reducing the range of motion over time.
- For example, with weak ankle muscles, you may not be able to flex your foot up, which may lead to more difficulty walking and increased tripping. Stretching your calf muscle and Achilles tendon (muscles at the back of your ankle), keeps the ankle joint flexible and the tendon from shortening over time. Decreased ankle range of motion may lead to more difficulty walking including tripping.
- Increases circulation and nutrition to muscle fibers.
- Improves function and efficiency of muscles. The more flexible joints are, the less energy is required to move, thus improving muscle performance and function.
- Decreases the risk of injury.
- Helps to manage stress.
- May reduce post exercise soreness.
- May reduce backpain; tight hamstrings and hip flexors contribute to increased stress on the lower back.
- Stretching videos:  
<https://cinrgresearch.org/publications/stretch-out/>
- Low back pain stretches:  
[https://www.youtube.com/watch?v=ebIZmhf2u\\_A](https://www.youtube.com/watch?v=ebIZmhf2u_A)
- Head/neck posture exercises:  
<https://www.youtube.com/watch?v=DB6RNxThAxU>
- Massage has also been used to decrease pain and tightness. Studies have shown that it improves muscle repair and relax muscles after exercise.<sup>28, 29</sup> Massage therapy can also help relax muscles:  
<https://www.physio.co.uk/treatments/massage/massage-for-client-groups/massage-in-neurological-disorders.php>



## Stretching strategies

- Stretching is a form of exercise where the muscle and tendon are moved throughout the range of motion of a joint. Move through the full ROM of the joint in different positions. Gravity can make it difficult for weak muscles to move through ROM, so for weaker muscles, consider performing ROM exercises when lying down or in other positions that minimize the effect of gravity.
- Perform active assisted ROM stretches. If your muscles are not strong enough to move your arm over your head or through the entire ROM, use a sling/spring device or another person to assist your shoulder through the ROM.
- Use gentle, prolonged stretches at the end of the ROM.
- Try low impact yoga, such as gentle yoga or chair yoga.



## Aerobic/Cardiovascular Exercise

### What is aerobic exercise?

- Aerobic exercise increases the heart rate and respiratory rate (breathing). Consult with your physician before starting or increasing aerobic activity.
  - Aerobic activity should be performed at moderate intensity. You should be able to talk, but not sing.
  - Individuals with DM tend to be less active than peers in regards to completing the recommended amount of moderate intensity exercise per week.<sup>21</sup> We want to provide resources and ideas to support a more active lifestyle.

### General recommendations for weekly physical activity from the Physical Activity Guidelines for Americans:

- 2.5 to 5 hours per week of moderate intensity physical activity *OR*
- 1 hour and 15 min to 2.5 hours per week of vigorous physical activity.<sup>22</sup>

### Strategies to increase aerobic activity

- Remember to work with your physician and physical therapist before increasing aerobic activity to ensure safe progression.
- Progression of exercises should be based on monitoring intensity of exercise (*refer to table on page 11*).
- Activity suggestions:
  - Household tasks such as vacuuming and raking
  - Walking briskly or jogging
  - Bicycling (outside or inside with a stationary bike)
  - Elliptical machine
  - Dancing
  - Water exercise

## Resistive/Strengthening Exercise

### What are resistive or strengthening exercises?

- Resistive exercises are activities that make your muscles contract in order to increase strength and endurance.
- Engage in resistive/strengthening activities two times per week at moderate intensity; 8-12 repetitions per major muscle group.<sup>22</sup>

## Types of strengthening

- Strength training requires a mind and muscle connection to train your muscles and nerves to communicate to improve movement.
- Choices may vary depending on your amount of strength and may vary for different joints. Individuals with DM often have more weakness in the wrists and ankles than other parts of the body.
- Utilize active assisted strengthening for joints that aren't strong enough to move through the full ROM. Consider assistance from a caregiver, trainer, or sling/spring device, if you have access.

## Types of resistance to use in strengthening exercises

- Body weight
- Weights or weight machines
- Elastic bands
- Water

## Balance Training

### What is balance training?

- Balance training is a combination of exercises that challenge your sensory systems and strengthen the muscles that keep you upright, including your core, trunk and legs. Balance training improves stability and helps prevent falls.
- Balance training should be specific to your risks and needs. Consult with a physical therapist for individualized balance evaluation and treatment.

### Benefits of balance training

- Improves mobility and decreases fall risk.<sup>23</sup>
- Individuals with DM are at a higher risk for falls due to calf and hip weakness, which decreases reaction time to prevent falls.<sup>24</sup>
  - Fall risk is similar to the elderly population.<sup>25</sup>
  - The ankle muscles are affected in DM1 which impacts the ability to use ankle strategies to regain balance and/or prevent falls. Weakness in the muscles that flex the foot also leads to an increased risk of tripping and falling.

### Strategies for balance training

- Balance training should be a multi-factor approach addressing strength, coordination, vision and cognition.
- An example is the The Otago Exercise Program, which includes 17 exercises of strengthening, balance, forward/backward walking, and balance on a single leg.<sup>28-30</sup> <https://givefit.org/balance-better-landing>
- Try tai chi: <https://www.youtube.com/watch?v=vHBR5MZmEsY>
- Try yoga, like chair yoga:  
<https://www.youtube.com/watch?v=9rNxHZGREks>  
<https://www.youtube.com/watch?v=-Ts01MC2mlo>  
<https://www.youtube.com/watch?v=2oT3PJ-22RI>  
<https://www.youtube.com/watch?v=0xbCfTHz3mU>
- Balance training should include dual task activities, such as controlling posture while carrying an object, reaching for objects, and visual distractions.





# Special Considerations for Myotonic Dystrophy

Individuals with DM may have difficulty with common exercises due to specific areas of weakness. For example, individuals with DM often have neck weakness; thus sit ups may be difficult. Modifications may include using upper limbs to support the neck, crunches, performing modified plank activities as well as other types of core exercises. Activities such as running or jumping may also be challenging due to ankle weakness. If this is the case for you, consider performing cardiovascular exercises where your feet are secured such as on an exercise bike or an elliptical. Holding onto weights or other types of resistance equipment may also be difficult due to hand weakness, therefore, you may want to consider using weights around your wrist or weightlifting hooks/grips. Using the aquatic environment for cardiovascular or resistive exercise may allow you to do activities that are more challenging to perform on land. Options for adaptive exercise equipment are listed below.

<https://www.theptdc.com/disability-fitness>

<https://www.sportaid.com/exercise-equipment/>



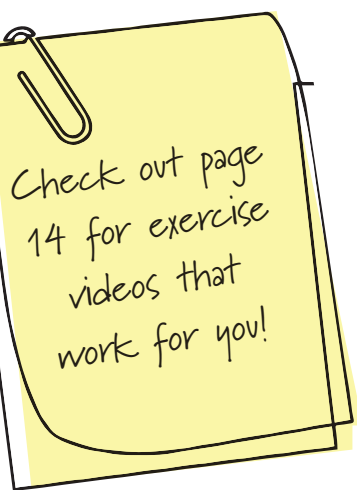
## How To Get Started With Exercise

- You can get started with exercise on your own, but talk to your physician before doing so to make sure exercise is safe for you, especially if you have any cardiac or pulmonary difficulties. You should consult with a physical therapist who has knowledge about myotonic dystrophy or neuromuscular disease for an evaluation prior to starting an exercise program. You may receive the most benefit from working with a physical therapist in collaboration with a personal training to ensure safe progression of exercises. You may consider seeing a dietician to answer any questions related to your exercise goals. Best results are from a combination of diet and exercise.
- You can find a local physical therapist (<https://aptaapps.apta.org/APTAPTDDirectory/FindAPTDirectory.aspx>) or a specialized exercise personal trainer (<https://www.acefitness.org/education-and-resources/lifestyle/find-ace-pro/>) who understands your needs, will help you feel more confident about your home exercise program, and will show you how to safely progress.
- Make exercise FUN!
  - Discuss your exercise goals with your personal trainers and physical therapists.
  - Review areas that you want to improve upon in your exercise program.
  - Let them know what you like to do for fun so they can help you be creative about exercise.
  - Find friends to exercise with and to help keep you motivated.
  - Join classes to learn something new! Consider dancing, boxing, swimming, yoga, tai chi, Zumba, and hiking groups.

<https://www.youtube.com/watch?v=JqIRGLPIJ7A>

<https://www.youtube.com/watch?v=gqaUXBnss4Q>

<https://www.youtube.com/watch?v=Zb2wkHyUAQQ>





# Monitoring Exercise

- Exercise intensity is a way to measure how hard you exercise. Exercise intensity is important to monitor to determine your level of work during exercise. When starting exercise, we recommend also starting an exercise calendar/journal, meaning a record of your activity on a calendar (see page 12 in the appendix for an example).
- The most direct way to measure exercise intensity is through VO<sub>2</sub> measurement, which is a way to evaluate your exercise capacity by measuring how much oxygen you take in per minute of exercise. This may be assessed at your clinic via referral by your physician or available at some fitness clubs at a cost. <https://www.whyexercise.com/VO2-Max.html>
- You can also measure exercise intensity at home through the simpler methods described below and on page 11.<sup>30</sup>
  - Heart Rate (HR): Measure by calculating your target heart rate
  - Rate of Perceived Exertion (RPE)
  - Talk Test (TT)

## FITT Principles

**FITT stands for Frequency, Intensity, Time and Type.**

- FITT principles are a way to monitor your exercise program and further exercise routines.<sup>5, 30</sup>
- Your exercise program should consist of a combination of aerobic/cardiovascular activity, strength/resistance, and flexibility.
- **Frequency:** How often you are doing the exercise.
  - Frequency allows you to find a balance between the different types of exercise you are doing and rest time for healing.
- **Intensity:** Amount of effort or physiological work required for the exercise.
  - Intensity may be measured via heart rate, Rate of Perceived Exertion or talk test.
  - You can monitor intensity by increasing weightlifting repetitions if you aren't tired, or adding more time to your walk and swinging your arms.
- **Time:** How long you performed the exercise.
- **Type:** What kind of exercise you did; strength, cardio, flexibility or a combination.
- Example of a FITT based exercise calendar is in the appendix on page 12.

### PHYSICAL ACTIVITY GUIDELINES FROM THE U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES (2<sup>nd</sup> ed; 2018)<sup>22</sup>

[https://health.gov/sites/default/files/2019-09/Physical\\_Activity\\_Guidelines\\_2nd\\_edition.pdf](https://health.gov/sites/default/files/2019-09/Physical_Activity_Guidelines_2nd_edition.pdf)

**Adults with chronic conditions or disabilities should do at least:**

- **Aerobic Activity:** Activities should be spread throughout the week.
  - 150 minutes (2.5 hours) to 300 minutes (5 hours) a week of moderate-intensity aerobic activity.
- **OR**
- 75 minutes (1.25 hours) to 150 minutes (2.5 hours) a week of vigorous-intensity aerobic activity.
- **Muscle Strengthening:** Moderate or greater intensity and that involve all major muscle groups on two or more days a week.

When adults with chronic conditions or disabilities are not able to meet the guidelines, they should engage in **ANY** activity within their limitations and **should avoid inactivity**.

## Finding Motivation

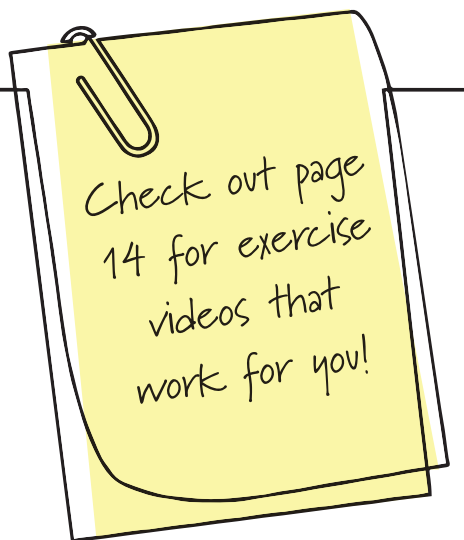
- Participation in physical activity and exercise requires motivation. Choose activities that are of personal interest and are fun.<sup>31</sup>
- Because DM may have a cognitive component that impacts adherence and motivation, it is important to find activities that fit your social interests.
- A study that combined Cognitive Behavior Therapy (CBT) and exercise in DM demonstrated that those who received CBT had increased physical activity, decreased fatigue, and increased function as measured by the distance walked on the 6 Minute Walk Test.<sup>32</sup>
- Motivation and fun are the biggest indicators to exercise adherence.<sup>33</sup>
- Realistic goals are important!

## Tricks to Get Started and Staying Motivated

- Give yourself a break. ANY amount of exercise is better than none.
- The biggest barrier to starting an exercise program is JUST GETTING STARTED!
- Start slow and set exercise goals. Start with 5 minutes, then 10 minutes, then increase.
- Consider a quick home workout: <http://twominutemoves.com/workouts>
- If exercise feels too hard at first, ease off. Enjoying the activity is vital to sticking with it. You should feel good at the end of your exercise session, it's positive reinforcement!
  - When exercise is hard, remind yourself aloud how great you are doing! Smile! This may sound cheesy, but it works. Positive self-talk is critical to success!
- You're already moving in the right direction with your desire to exercise, keep up the good work.

## Other Ways to Increase Motivation

- Consistency is key!
- Schedule exercise into your daily schedule, make it a priority.
- Monitor your workout with an exercise calendar.
- Buddy up with a family member or friend and keep each other accountable.
- Participate in an exercise class online, on the television, or an active video game.
- Set goals, track your progress, and REWARD yourself.
- Commit to at least 10 minutes of physical activity per day because consistency is key to exercise adherence. The hardest part about exercise is getting started. Often, once you start physical activity, you will be able to keep going.



# Technology and Exercise Aids

Technology is changing the way we exercise from virtual classes to wearable devices. Types of technology that involve exercise are listed below and more information about fitness apps, trackers and websites can be found in the appendix on page 15.

## Active video games:

- Such as Dance Dance Revolution, Wii, WiiFit, Xerbike.
- Active video games may have an impact on increased energy expenditure and health outcomes.<sup>34</sup>

## Activity trackers:<sup>35</sup>

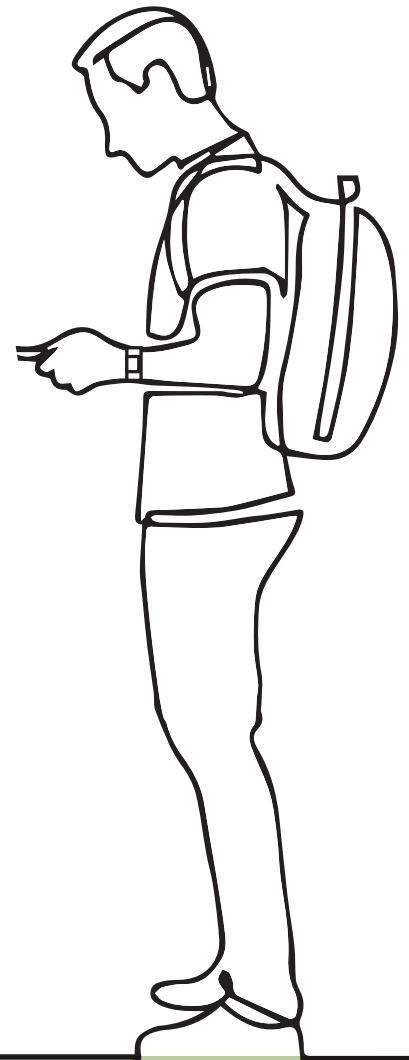
- Such as Smartwatches, Fitbit, and Garmin.
- Use activity trackers that can track movement in three planes; walking, dancing and other movements in many planes.
- Activity trackers are small enough to be worn on your hand, arm or leg to track all types of activity.
- Some activity tracker devices also help to promote good posture.

## Web-based or App Exercise Programs:<sup>36</sup>

- Different web and app-based exercise programs allow you to join exercise groups and make exercise fun and social.
- Consider apps that combine diet and exercise tracking such as MyFitnessPal.
- Many apps link other apps together to give you a whole picture of your activity.
- Apps help with adhering to an exercise program and tracking progress.

## Heart rate monitors:<sup>37</sup>

- Such as Polar, Apple Watch, and Fitbit.
- Heart rate monitors are a good way to track activity, estimate energy expenditure, and provide activity data.
- Heart rate monitors may be able to provide safe parameters to exercise. You should consult with your physical therapist (if you have one) and Physician to define heart rate parameters that are individualized to you.





## Putting it all Together



- If you are starting a new exercise program, check with your physician and health care team before starting.
- Try different physical activities until you find something that you enjoy.
- Incorporate different types of exercise into your regimen; activity doesn't need to be done together or on the same days.
- Start slowly and increase gradually.
  - Any activity is good activity! Start with 10 minutes/day.
  - Add a brief (5-10 minute) warmup to your chosen exercise, such as stretching or walking.
  - Make exercise a habit. It is better to get into an exercise routine by doing short but consistent sessions.
- Use strategies to increase your success.
- Track your progress and reward yourself!

# Glossary of Exercise Terms<sup>43</sup>

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**Active exercise:** Exercise that a person does using his or her own strength.

**Aerobic exercise:** Exercise that involves or improves oxygen utilization by requiring the heart and lungs to work harder. Aerobic exercises involve low to moderate intense activities performed for extended periods of time. Examples are walking, running, swimming and cycling.

**Anaerobic exercise:** Exercise that does not involve or improve oxygen utilization; example weightlifting.

**Cardiomyopathy:** Degeneration of the heart muscle, occurs in some people with DM.

**Conditioning:** Training to perform better for a long period of time; usually done through aerobic exercise, such as walking, swimming, etc.

**Coordination:** The ability to integrate muscle movements to perform specific functions, such as walking, running, or manipulation of small objects; hand-eye coordination is the ability to integrate what one sees with subsequent muscle action.

**Contraction:** What muscles do when they're active; refers to protein filaments actin and myosin sliding over each other.

**Contracture:** Permanent shortening of a muscle or tendon, resulting in a permanent "freezing" of a joint in a certain position; occurs when muscle weakness or spasticity prevents normal range of motion over a long period of time.

**Elliptical trainer:** Stationary exercise device that stimulates walking and running without causing the joints to be subjected to much force.

**Exercise:** Muscle exertion (use) involving expenditure of energy.

**Fitness:** The ability of the circulatory and respiratory systems to supply nutrients to skeletal muscles during sustained energy expenditure (exercise) and the ability of muscles to respond.

**Interval training:** Repetitions of exercise interrupted by periods of rest and low activity.

**Maximal:** Full-out; exercising maximally means exercising as hard and as fast as one possibly can.

**Oxygen consumption:** The amount of oxygen taken in during exercise or at rest; can be determined directly by measuring exercise intake and carbon dioxide exhalation through a metabolic mask or can be approximated indirectly by measuring heart rate.

**Passive exercise:** Exercise that a person does without any exertion; like having someone else move one's limbs in range-of-motion exercise; benefits are improved circulation, movement, comfort, flexibility.

**Personal trainer:** A fitness professional who develops and implements an individualized approach to physical fitness, generally working one-on-one with a client.

**Physiatrist:** A physician who specializes in maximizing functional abilities and quality of life for people with physical impairments; the specialty is called physical medicine and rehabilitation.

**Physical therapist:** Health care professional who helps individuals develop, maintain and/or restore maximum movement and functional ability.

**Range-of-motion exercise:** Exercise that involves putting a joint through its normal range of motion (as far as it can go in any direction); can be done actively or passively.

**Resistance exercise:** A form of exercise in which each effort is performed against a specific opposing force generation by resistance, for example, resistance to be lifted, pushed, squeezed, stretch or bent; sometimes used interchangeably with strength training.

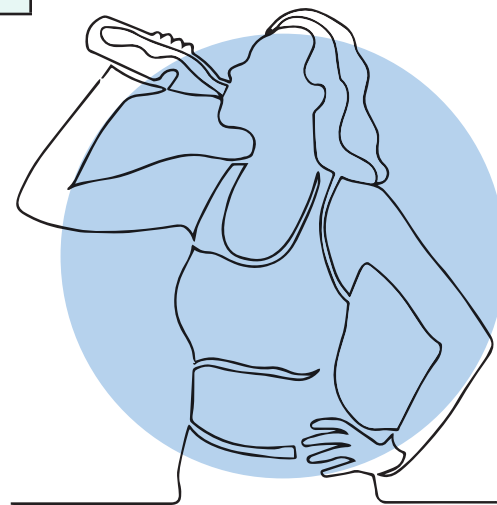
**Treadmill:** Piece of indoor sporting equipment used to allow for the motions of running or walking while staying in one place.

## Strengthening Intensity Based on Training Zones<sup>29</sup> (\*\* = target zone)

Zone Training	Type of Training	Resistance
1-3 repetitions	Muscle power	Very heavy
3-7 repetitions	Muscle strength	Heavy
<b>**8-12 repetitions</b>	<b>Strength and endurance</b>	<b>Moderate</b>
13-25 repetitions	Endurance	Light

## Exercise Intensity Based on Rate of Perceived Exertion and Heart Rate Maximum<sup>29</sup> (\*\* = target zone)

Intensity Level	RPE (Based on a 0-10 scale)	Heart Rate Maximum, %
Light	RPE < 5	50-63%
<b>**Moderate</b>	<b>RPE = 5-6</b>	<b>64-76%</b>
Vigorous	RPE > 7	77-93%



## Ways To Measure How Hard You Are Exercising<sup>28</sup>

Method	Method	Equipment
<b>Heart Rate (HR)</b>  <i>*cardiac conditions will have modified target HR</i>	<ul style="list-style-type: none"> <li>Maximum HR= 220 – Age</li> <li>Target HR= Max HR x .65-.80 (typically for moderate intensity; but also may be training dependent)</li> <li>Beta blockers may affect HR, making it difficult to monitor HR intensity.                             <ul style="list-style-type: none"> <li>Irregular cardiac rhythms may impact HR monitor accuracy.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Heart rate monitor</li> <li>Take your pulse (not ideal because you have to stop activity to measure)</li> </ul>
<b>Rate of Perceived Exertion (RPE)</b>	<ul style="list-style-type: none"> <li>RPE Scale: 0-10 based on how hard you feel you are working.</li> <li>Effort should be based on: HR, breathing, muscle fatigue, sweating, and discomfort. Be honest about how you feel.</li> </ul>	<ul style="list-style-type: none"> <li>Borg Scale<sup>32</sup> (6-20 scale)</li> <li>Omni Scale<sup>33</sup> (0-10 scale)</li> </ul>
<b>Talk Test (TT)</b>	<ul style="list-style-type: none"> <li>Measures “ventilatory threshold” of moderate activity.                             <ul style="list-style-type: none"> <li>Ventilatory threshold is the point where you are breathing faster than the oxygen you consume.</li> </ul> </li> <li>You should be able to speak 3-5 words comfortably.</li> </ul>	<ul style="list-style-type: none"> <li>None</li> </ul>

# FITT Based Exercise Calendar

FITT Principles: Frequency, Intensity, Time, Type													
Day	Exercise	How long?	Reps: sets	How hard am I working: Intensity									
Monday ____/____/____	<input type="checkbox"/> Cardio_____			1	2	3	4	5	6	7	8	9	10
	<input type="checkbox"/> Strength_____												
Tuesday ____/____/____	<input type="checkbox"/> Cardio_____			1	2	3	4	5	6	7	8	9	10
	<input type="checkbox"/> Strength_____												
Wednesday ____/____/____	<input type="checkbox"/> Cardio_____			1	2	3	4	5	6	7	8	9	10
	<input type="checkbox"/> Strength_____												
Thursday ____/____/____	<input type="checkbox"/> Cardio_____			1	2	3	4	5	6	7	8	9	10
	<input type="checkbox"/> Strength_____												
Friday ____/____/____	<input type="checkbox"/> Cardio_____			1	2	3	4	5	6	7	8	9	10
	<input type="checkbox"/> Strength_____												
Saturday ____/____/____	<input type="checkbox"/> Cardio_____			1	2	3	4	5	6	7	8	9	10
	<input type="checkbox"/> Strength_____												
Sunday ____/____/____	<input type="checkbox"/> Cardio_____			1	2	3	4	5	6	7	8	9	10
	<input type="checkbox"/> Strength_____												



## Exercise Presentations

### Exercise and Myotonic Dystrophy

1. <https://www.myotonic.org/sites/default/files/pages/files/Eichinger-Exercise-2019.pdf>
2. <https://www.myotonic.org/digital-academy/exercise-nutrition-speech-2019-myotonic-annual-conference>

In this presentation from the 2019 MDF Annual Conference, Katy Eichinger, PhD, DPT, from the University of Rochester reviews current research and strategies for managing DM symptoms with exercise.

### Staying Strong: DM & Exercise

1. <https://www.myotonic.org/digital-academy/staying-strong-dm-exercise-panel-2015-myotonic-annual-conference>
2. [https://www.myotonic.org/sites/default/files/pages/files/Katy-Eichinger\\_Staying-Strong-DM-and-Exercise\\_2018-Conference.pdf](https://www.myotonic.org/sites/default/files/pages/files/Katy-Eichinger_Staying-Strong-DM-and-Exercise_2018-Conference.pdf)

In these presentations from the 2018 and 2015 MDF Annual Conferences, a panel of physical therapy professionals and people living with DM discuss ways to stay physically fit.

### Cognitive behavioral therapy with optional graded exercise therapy in patients with severe fatigue with myotonic dystrophy type 1: a multicenter, single-blind, randomized trial.

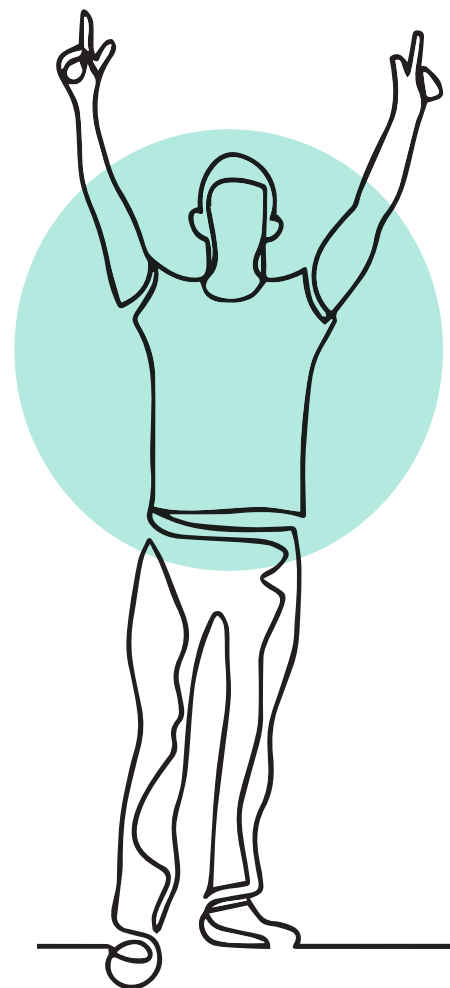
1. <https://www.ncbi.nlm.nih.gov/pubmed/29934199>
2. <https://www.myotonic.org/optimistic-view-dm1>

This study looked at whether cognitive behavioral therapy optionally combined with graded exercise compared with standard care alone improved the health status of patients with DM1.

### Understanding Falls in DM Patients

1. <https://www.myotonic.org/understanding-falls-dm-patients>

This research study found that DM1 and DM2 patients both exhibited an increased frequency of falls, and examines the risk factors, circumstances and consequences of falls in DM.



## Web Resources

1. Go 4 Life: <https://go4life.nia.nih.gov/>
2. My Health Finder: <https://health.gov/myhealthfinder/topics/everyday-healthy-living/physical-activity>
3. Move Your Way
  - Adults: [https://health.gov/sites/default/files/2019-11/PAG\\_MYW\\_Adult\\_FS.pdf](https://health.gov/sites/default/files/2019-11/PAG_MYW_Adult_FS.pdf)
  - Older adults: [https://health.gov/sites/default/files/2019-11/PAG\\_MYW\\_OlderAdults\\_FS.pdf](https://health.gov/sites/default/files/2019-11/PAG_MYW_OlderAdults_FS.pdf)
4. Physical Activity: Strategies and Resources (CDC): <https://www.cdc.gov/nccdphp/dnpao/state-local-programs/physicalactivity.html>



## Exercise Videos

### Balance

<https://www.youtube.com/watch?v=4PgR8l4n7jY>  
<https://www.youtube.com/watch?v=f717XLH5trQ>  
<https://www.youtube.com/watch?v=coxxRzKLV3E>  
<https://givefit.org/balance-better-landing>

### Bed mobility

<https://www.youtube.com/watch?v=nVRh1rbdiQA>

### Breathing exercises

<https://kristinmcgee.com/breathing-exercises-chair-yoga-practice>  
<https://www.youtube.com/watch?v=KEAjRNF48jl>

### Buttocks exercises

Bridging: [https://www.youtube.com/watch?v=tM3h1p\\_3gtU&feature=emb\\_title](https://www.youtube.com/watch?v=tM3h1p_3gtU&feature=emb_title)

### Calf and ankle chair exercises

[https://www.youtube.com/watch?v=gpaKiYJ\\_g-M](https://www.youtube.com/watch?v=gpaKiYJ_g-M)  
[https://www.youtube.com/watch?v=Xm4TYtALUIs&feature=emb\\_rel\\_end](https://www.youtube.com/watch?v=Xm4TYtALUIs&feature=emb_rel_end)  
<https://www.youtube.com/watch?v=N8NAREhkA44>

### Chair exercises

<https://www.youtube.com/watch?v=eK6xH5qqcTw>  
<https://www.verywellfit.com/chair-exercises-for-seniors-4161267>  
<https://californiamobility.com/21-chair-exercises-for-seniors-visual-guide/>  
<https://www.youtube.com/watch?v=ZwJ9pGxJKGc>

### Getting up from the floor

[https://www.youtube.com/watch?v=Q9VsxIE\\_iQU](https://www.youtube.com/watch?v=Q9VsxIE_iQU)  
[https://www.youtube.com/watch?time\\_continue=72&v=lwVhl04v0E4&feature=emb\\_logo](https://www.youtube.com/watch?time_continue=72&v=lwVhl04v0E4&feature=emb_logo)  
<https://www.youtube.com/watch?v=4Z0wqZqDN0A>

### Home workout

<http://twominutemoves.com/workouts>



### Low back pain stretches

[https://www.youtube.com/watch?v=ebIZmhf2u\\_A](https://www.youtube.com/watch?v=ebIZmhf2u_A)  
<https://www.youtube.com/watch?v=6C-wfV27bzl>  
<https://www.youtube.com/watch?v=6C-wfV27bzl>

### Seated arm workouts

<https://www.youtube.com/watch?v=EVQcgYQyzz0>

### Squats

[https://www.youtube.com/watch?v=oyoqbWs\\_y78](https://www.youtube.com/watch?v=oyoqbWs_y78)

### Stretching

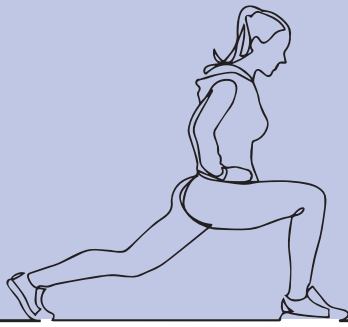
<https://cinrgresearch.org/publications/stretch-out/>

### Trunk stabilization/core stability

Start with doing in chair  
<https://skillsforaction.com/assess-sitting-core-strength-stability-child>  
Plank: <https://www.youtube.com/watch?v=TxvNkmjdhMM>  
<https://myrehabconnection.com/trunk-stability-exercise-progressions/>

### Upper body and trunk exercises

<https://www.youtube.com/watch?v=qZgM1UCiTMU>



## Fitness Apps, Websites and Trackers

	Link	Features	Cost
App	<a href="https://www.mapmyfitness.com">https://www.mapmyfitness.com</a>	Tracks different types of exercise: running, walking, cycling, swimming	Free
App	<a href="https://myfitnesspal.com">https://myfitnesspal.com</a>	Integrates exercise and diet tracker	Free
App	<a href="http://www.onepeloton.com">www.onepeloton.com</a>	Has online workouts such as meditation, yoga, strength, cardio, running apps with motivating instructors	Monthly fee
App	<a href="https://ifitnesstracker.com">https://ifitnesstracker.com</a>	Access to 300+ exercises and track progress	Free on app store
App	<a href="https://sworkit.com">https://sworkit.com</a>	Personal trainer app for all levels	Monthly fee
Smartwatch Tracker	<a href="http://www.fitbit.com">www.fitbit.com</a>	Tracks activities, heart rate and nudges you to move throughout the day	Purchase device
Smartwatch	<a href="http://www.apple.com/watch">www.apple.com/watch</a>	Tracks activity, heart rate and activity levels that could be preset to remind you to move throughout the day	Purchase device
App	<a href="https://www.apple.com/ios/health/">https://www.apple.com/ios/health/</a>	Tracks activity, heart rate and activity levels that could be preset to remind you to move throughout the day	Purchase device

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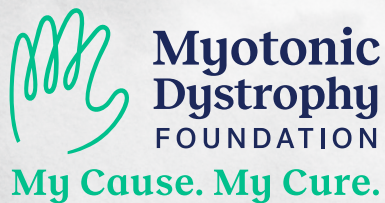
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The mission of the Myotonic Dystrophy Foundation is to enhance the quality of life of people living with myotonic dystrophy and accelerate research focused on treatments and a cure.



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