Myotonic Dystrophy Foundation Meeting 2013

Activity and Exercise Recommendations for Individuals with Myotonic Dystrophy

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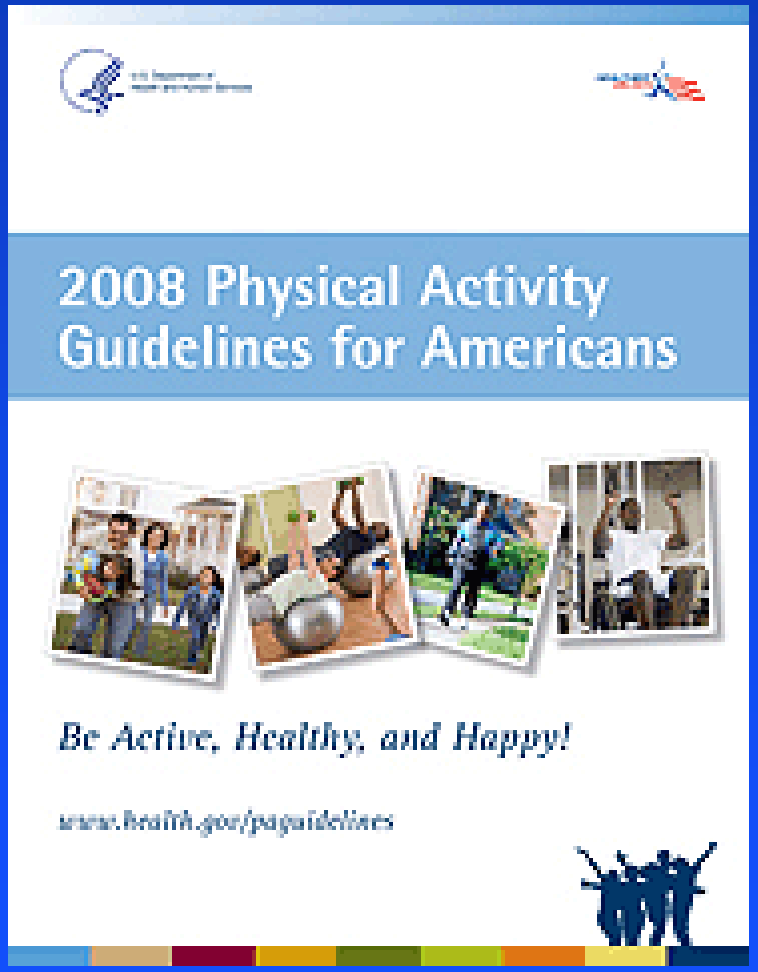
Physical Activity and Health

The Benefits of Physical Activity

- Helps control weight
- Reduces risk of cardiovascular disease
- Reduces risk for type 2 diabetes
- Reduces risk of some cancers
- Strengthens bones and muscles
- Improves mental health and mood
- Improves ability to do daily activities
- Increases chance of living longer

2008 Physical Activity Guidelines for Americans



http://www.health.gov/paguidelines/guidelines/default.aspx

Recommendations from 2008 Guidelines

Adults need at least

- 2 hrs and 30 minutes (150 minutes) of moderate intensity aerobic activity every week
- Spread your activity out during the week
  30 minutes x 5 days = 150 minutes
- Break it up into smaller chunks of time during the day. 10 minutes at a time is fine
- Moderate intensity activities are activities where you can still carry on a conversation such as brisk walking, raking, mowing, cycling, line dancing

Recommendations from 2008 Guidelines

Adults need at least

- 2 or more days a week of muscle strengthening activities that work all major muscle groups (legs, hips, abdomen, back, shoulders and arms).
- You can use body weight, free weights, elastic bands, aquatherapy or equipment for resistance.

Current Recommendations for Individuals with DM

- Aerobic/cardiovascular exercise
- Resistance/strength training
- Flexibility/range of motion
- Balance training
- Weight bearing

Evidence for Current Recommendations in DM

- "Moderate intensity strength training appears not to harm muscles in people with DM" *Cochrane,2010*
- "There is level II evidence (likely to be effective) for strengthening exercises in combination with aerobic exercises for patients with muscle disorders" *Cup, 2007*
- "Aerobic training is safe and can improve fitness effectively in patients with myotonic dystrophy" *Orngreen, 2005*

Factors Affecting Individual Recommendations

- Age
  (pediatric/adult)
- Clinical profile
  (phenotype/current status)
- Personal profile
  (work, family role, interests,
  financial/environmental/social barriers, facilitators)

Implementation

- Evaluation by healthcare provider
- Recommendations from health care provider
- Regular monitoring and adjustments as necessary by provider
- Self monitoring

(Providers may include primary care provider, neuromuscular specialist or rehabilitation specialist)

Recommendations

- Pick activities that you enjoy, work with a partner – spouse, parent, child, friend, co-worker if you can.
- Start with short sessions 1-2 days/week and gradually build up to 30 minute sessions 5 days/week.
- Give the routine a try for at least 3 months, it takes that long to see benefits! Do not get discouraged.

Physical Activity Profile and Barriers to Physical Activity in Individuals with Myotonic Dystrophy

Eichinger KJ, Dekdebrun J, Dilek N, Chen D, Pandya S

- Survey performed at EMPOWER 2011 meeting
- Findings presented at World Muscle Society meeting 2013

Background

- Individuals with myotonic dystrophy (DM) are less active than healthy individuals, which may result in secondary complications and decreased functional abilities (Wiles, et al., 2007)
- Information regarding participation in physical activities and exercise has not been reported for individuals with DM in the USA

Methods

- Individuals attending the Empower 2011 Patient and Family Conference, held in Clearwater, FL and sponsored by the Myotonic Dystrophy Foundation, were invited to participate in this study
- Participants were asked to complete a demographic/clinical profile, the Barriers to Physical Activity and Disability Survey (BPADS) and the International Physical Activity Questionnaire (IPAQ)
- Physical activity was reported as the number of days and time spent (10 minute increments) over the past 7 days

Results

Subjects

- 107 participants (53% male) with DM (65% DM1)
- Mean age = 45.7 years (20-77)
- Mean age of onset
  - DM1= 28.5 years (12-70); DM2= 33.4 years (7-64)

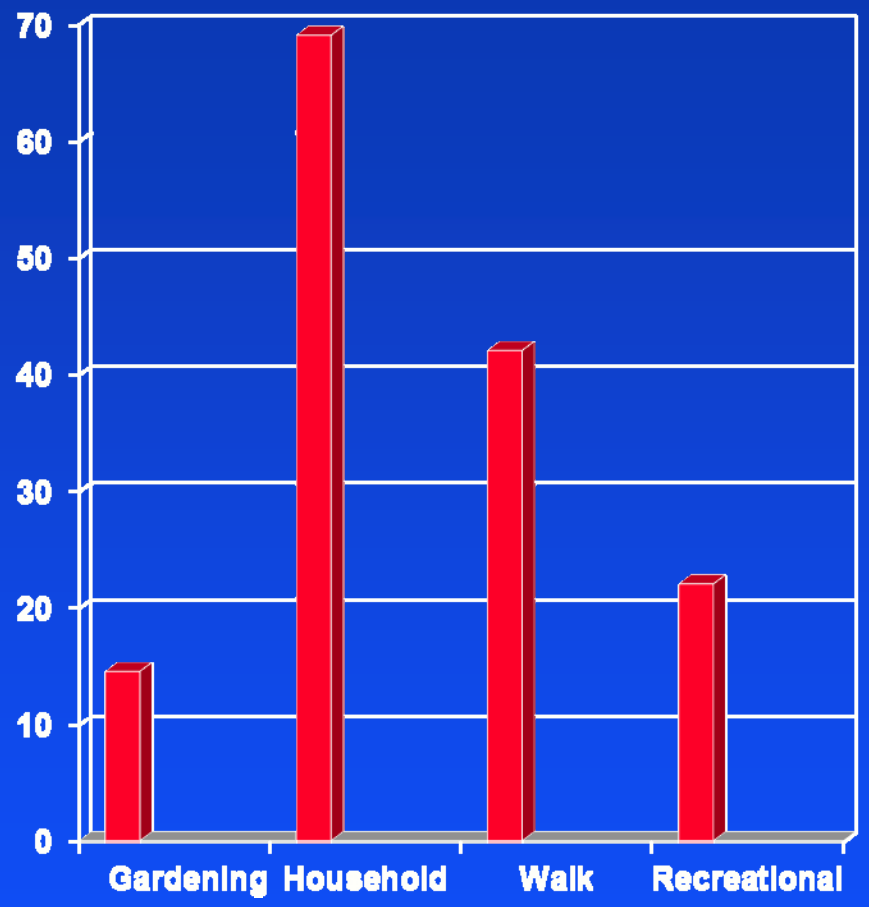
Results

Current Clinical Problems	N(%)
Ankle weakness	48 (44.9)
Leg weakness	62 (57.9)
Finger and hand weakness	79 (73.8)
Arm weakness	49 (45.8)
Myotonia	59 (55.1)
Pain	47 (43.9)
Fatigue	73 (68.2)
Daytime sleepiness	71 (66.4)
Gastrointestinal (stomach) problems	71 (66.4)
Cardiac (heart) problems	32 (29.9)
Pulmonary (breathing) problems	17 (15.9)
Neurocognitive problems	25(23.4)

Results

Barriers to Exercise	N(%)
Cost of the exercise program	30 (28.0)
Lack of transportation	11 (10.3)
Lack of time	31 (29.0)
Lack of interest	24 (22.4)
Lack of energy	54 (50.5)
Lack of motivation	50 (46.7)
Exercise is boring/monotonous	23 (21.5)
Exercise will not improve my condition	18 (16.8)
Exercise will make my condition worse	14 (13.1)
Exercising is too difficult	14 (13.1)
Health concerns prevent me from exercising	11 (10.3)
Pain prevents me from exercising	19 (17.8)
Feel uncomfortable or self-conscious in a fitness center	28 (26.2)

Results



The percentage of individuals who performed moderate intensity level physical activity on at least 1 day in the categories of gardening, household work, walking, and recreational activities.

Results

- The time spent sitting was reported to be 7.5 hours on average per day

Recommendations

- Recent findings suggest prolonged sitting is deleterious
- Recommend moving for 10 minutes every hour

References

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- National Center on Health, Physical Activity and Disability http://www.nchpad.org