Exercise for mobility and wellness in FSHD

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Welcome

Today
- Review latest research findings and clinical evidence for exercise in FSHD
- Discuss practical applications for exercise and mobility
- Question and answer on exercise and mobility
- Exercise demonstration/practice.
What is health and wellness?

World Health Organization

- Health is a state of complete physical, mental and social well being and not merely the absence of disease or infirmity.

- Wellness is an active process of becoming aware of and making choices toward a healthy and fulfilling life.
What are some of your barriers to exercise?
So what can we do?

- Clinical Research Trials
- Best Research Evidence
- Clinical Expertise
- Patient Values and preferences
- Individualized Clinical guidelines, expert opinion
Research Evidence

- FACTS-2 FSHD trial 2014
  - Aerobic exercise
    - 50-65% HR reserve, 12-14 on Borg
    - 40 sessions
  - Cognitive Behavioral Therapy
    - Min 3 sessions
    - Fatigue, pain, sleep
  - Outcomes
    - Less Fatigue (CIS-fatigue)
    - Lasting effects
Exercise Evidence

- “Aerobic training is safe and can improve fitness effectively in patients with FSHD; No evidence that exercise is harmful” Olsen, 2005

- “There is level II evidence (likely to be effective) for strengthening exercises in combination with aerobic exercises for patients with muscle disorders”, Cup, 2007

- “Moderate intensity strength training appears not to do harm but there is insufficient evidence to conclude it offers benefit” Cochrane review, 2013
Research Evidence Summary

- Moderate exercise is safe!
  - Aerobic and strengthening

- Aerobic exercise can improve fitness.

- Exercise and CBT can improve fatigue
CDC Recommendations: Aerobic activity

- 2 hours and 30 minutes (150 minutes per week)
- 30 minutes per day for 5 days
- 10 minutes at a time is ok!

Moderate intensity: carry on a conversation
- Brisk walking
- Raking
- Mowing
- Cycling
- Dancing
CDC Recommendations: Strengthening

- 2 or more days per week
- All major muscle groups: legs, hips, abs, back, shoulders, arms

- Method
  - body weight
  - free weights
  - elastic bands
  - Aquatic
FSH Specific Recommendations

- **Aquatics**
- **Aerobic/ Cardiovascular**
  - Bike
  - Recumbent bike
  - Supported treadmill training
- **Strengthening**
  - Alternative positions to go through ROM
  - If you cannot move the body part against gravity (<3/5)
    - Daily activity
    - Individual guidance
- **Flexibility/ ROM**
  - Not overstretching
  - ROM to maintain joint mobility
FSH Specific Recommendations

- Recreational activities

ADAPT: LIVE ENDLESS ABILITIES
When to seek help

- New to starting exercise
- Pain
- Rapid decline or change in status
Delicate Balance: listen to your body

- Secondary Disuse
- Note overall activity level
  - Fitness tracking
- Overdoing
- Learn to listen to your body
Getting Started

- Eval by healthcare provider
  - Primary care MD, neurologist, physiatrist, PT, OT
  - Someone who knows you and your disorder

- Regular monitoring and adjustments

- Self monitoring
Patient Values and Preferences
Exercise sampling

- Self-monitoring, fatigue
- Movement Awareness/ Pilates
- Nordic Pole Walking
- Range of motion/ Gravity eliminated exercises
Heart Rate Reserve

The Karvonen Formula

- Find your Resting Heart Rate (RHR)
- Find your Predicted Maximal Heart Rate (HR max)
  - HR max = 220 - age
- Find your Heart Rate Reserve (HRR)
  - HRR = HR max - RHR
# Borg Scale

## Borg RPE Scale

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
<th>Interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>Very, very light</td>
<td>How you feel when lying in bed or sitting in a chair relaxed. Little or no effort.</td>
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<tr>
<td>7</td>
<td></td>
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<tr>
<td>8</td>
<td>Very light</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Fairly light</td>
<td></td>
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<tr>
<td>11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Somewhat hard</td>
<td>Target range: How you should feel with exercise or activity.</td>
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<tr>
<td>13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Hard</td>
<td></td>
</tr>
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<td>15</td>
<td></td>
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</tr>
<tr>
<td>16</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>Very hard</td>
<td>How you felt with the hardest work you have ever done.</td>
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<tr>
<td>18</td>
<td></td>
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Thank you!