

STAYING ACTIVE AT HOME WITH FSHD

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USC Division of Biokinesiology and Physical Therapy **re+active** wellness and PT studio

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JULIE HERSHBERG PT, DPT, NCS

Passionate Neuro PT + USC Instructor



- re+active PT in CA (2 clinics, 18 people on our team)
- Schmidt Movement Disorders Fellowship (Year 5)
- LOVE all neuro! But especially rare diseases
- My other loves: my family, dogs, being outside and in the ocean



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WELCOME

- Today
 - Review research findings and clinical evidence for exercise in FSHD
 - Discuss practical applications for exercise and mobility to stay active at home
 - Question and answer on exercise and mobility

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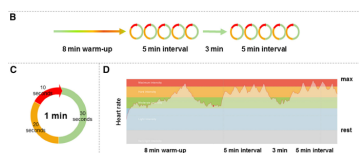
WHAT DOES THE RESEARCH SAY?

- High Intensity Interval Training
- Home Based Aerobic and Interval Training
- Aerobic Exercise and Cognitive Behavioral Training

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RESEARCH EVIDENCE

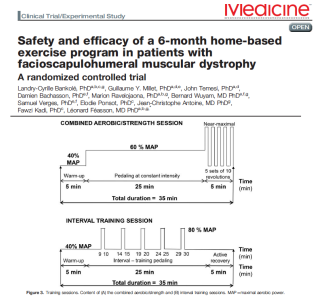
- High Intensity Interval Training (Andersen et al, 2017)
 - Stationary bike at home and 1x/wk at clinic
 - 8 weeks: 3x/wk for 21 minutes
- Outcomes:
 - No muscle damage
 - Improved fitness
 - Unchanged 5xSTS, 6MWT and muscle strength



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RESEARCH EVIDENCE

- Home based exercise program (Bankolé et al, 2016)
 - 35 min, 3x/wk, 24 weeks
 - 2 sessions aerobic, 1 session interval
 - Strengthening, high intensity and low intensity aerobic on bike
 - Supervised then independent
- Outcomes
 - No change in QOL
 - Less fatigue
 - Improved VO2max
 - Increased quad muscle strength, endurance and muscle fiber cross section area
 - Great adherence at home!



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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
- "This study provides Class II evidence that for patients with FSHD type 1, both AET and CBT decrease the rate of fatty infiltration in muscles." Janessen et al, 2016



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RESEARCH EVIDENCE SUMMARY

- Moderate and intense interval exercise is safe and beneficial!
 - Aerobic and strengthening via cycling
 - Improved strength, muscle, fatigue
- Aerobic exercise can improve fitness
- Exercise and CBT can improve fatigue
- Accessible at home

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SO WHAT CAN YOU DO AT HOME?

- Aerobic/ Cardiovascular
 - Bike
 - Recumbent bike
 - Anything to get your HR up!
- Strengthening
 - Alternative positions to go through ROM
 - Bands
- Flexibility/ ROM
 - Not overstretching
 - ROM to maintain joint mobility
 - Self Massage



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EASY EQUIPMENT

- Bands for strength
- Weights
- Foam roll
- Tennis balls
- Stretch strap
- Massage tools
- Abdominal Bracing
- Nordic Poles



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TO TRY NOW AND AT HOME

Pelvic Tilts



Instructions:

Scout your bottom to the edge of whatever surface your sitting on
Feet flat on the floor if possible
Tighten your stomach muscles and imagine that your tucking your tail bone underneath you
This makes your lower back round (picture 1)
Then relax your stomach muscles and allow your low back to arch (picture 2)
Alternate between these two positions 10 times

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Calf Stretch



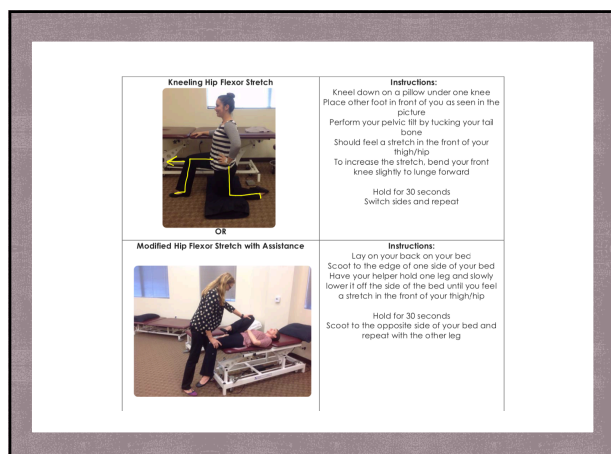
Instructions:
Standing at a wall, place one foot behind the other keeping your toes facing the wall
Bend your front knee
Only so much that the heel of the back foot remains in contact with the ground
Hold for 30 seconds
Switch feet and repeat

Standing Heel Raises

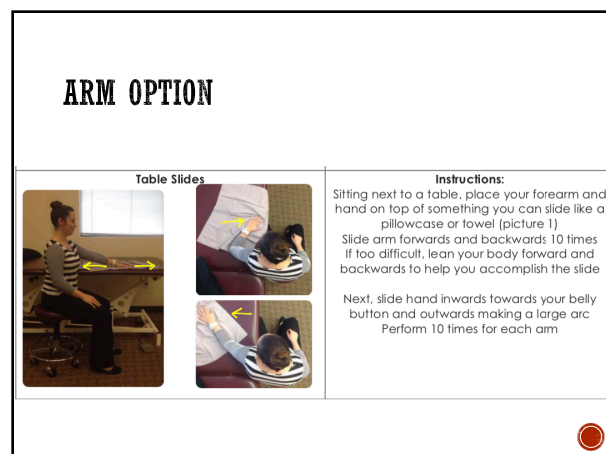


Instructions:
Standing at a counter or stable surface
Feet hip width apart
Hands on counter
Press your toes into the ground and bring your heels off the ground
Can use as much help through your arms as you need
Perform 10 repetitions slowly

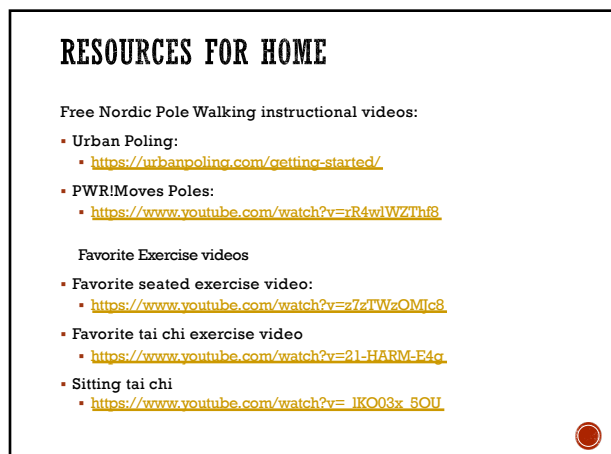
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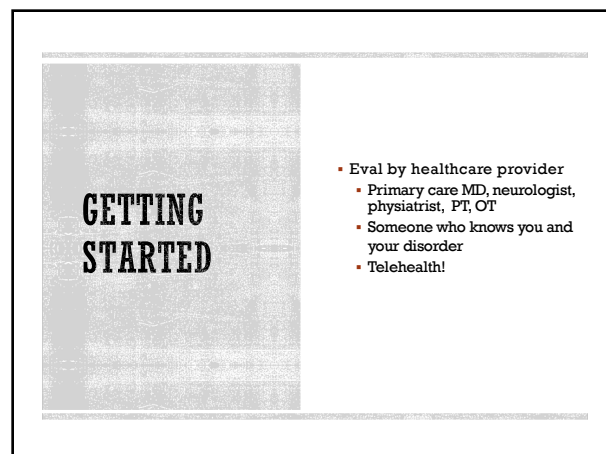
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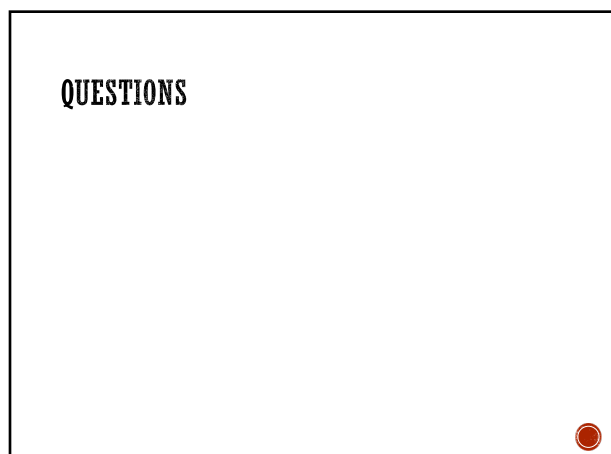
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