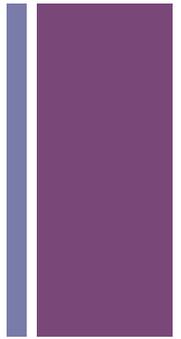


Exercise for mobility and wellness in FSHD

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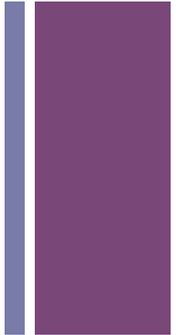
+ Welcome



- 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

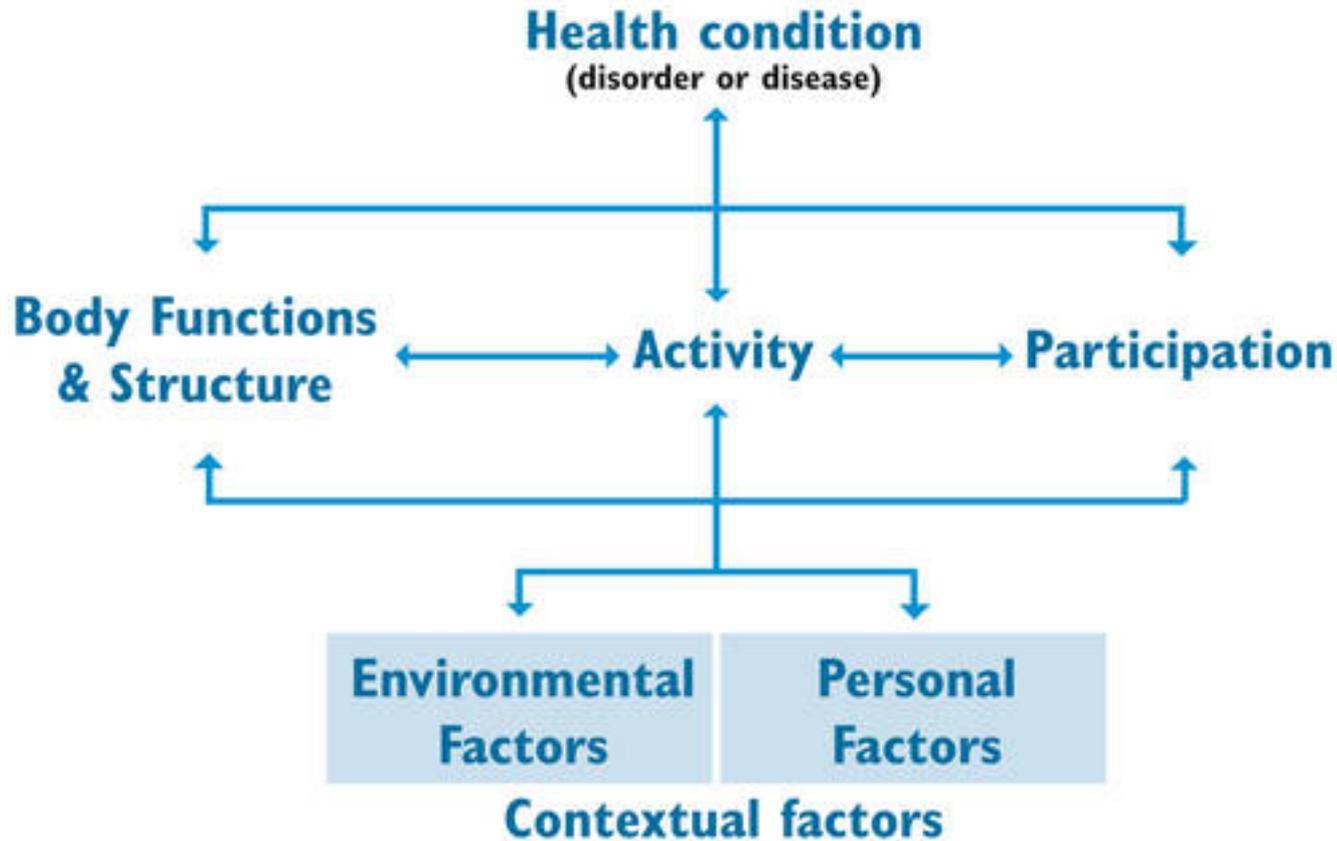
- Health is a state of complete physical, mental and social well being and not merely the absence of disease or infirmity.
- Wellness is an active process of becoming aware of and making choices toward a healthy and fulfilling life.

health

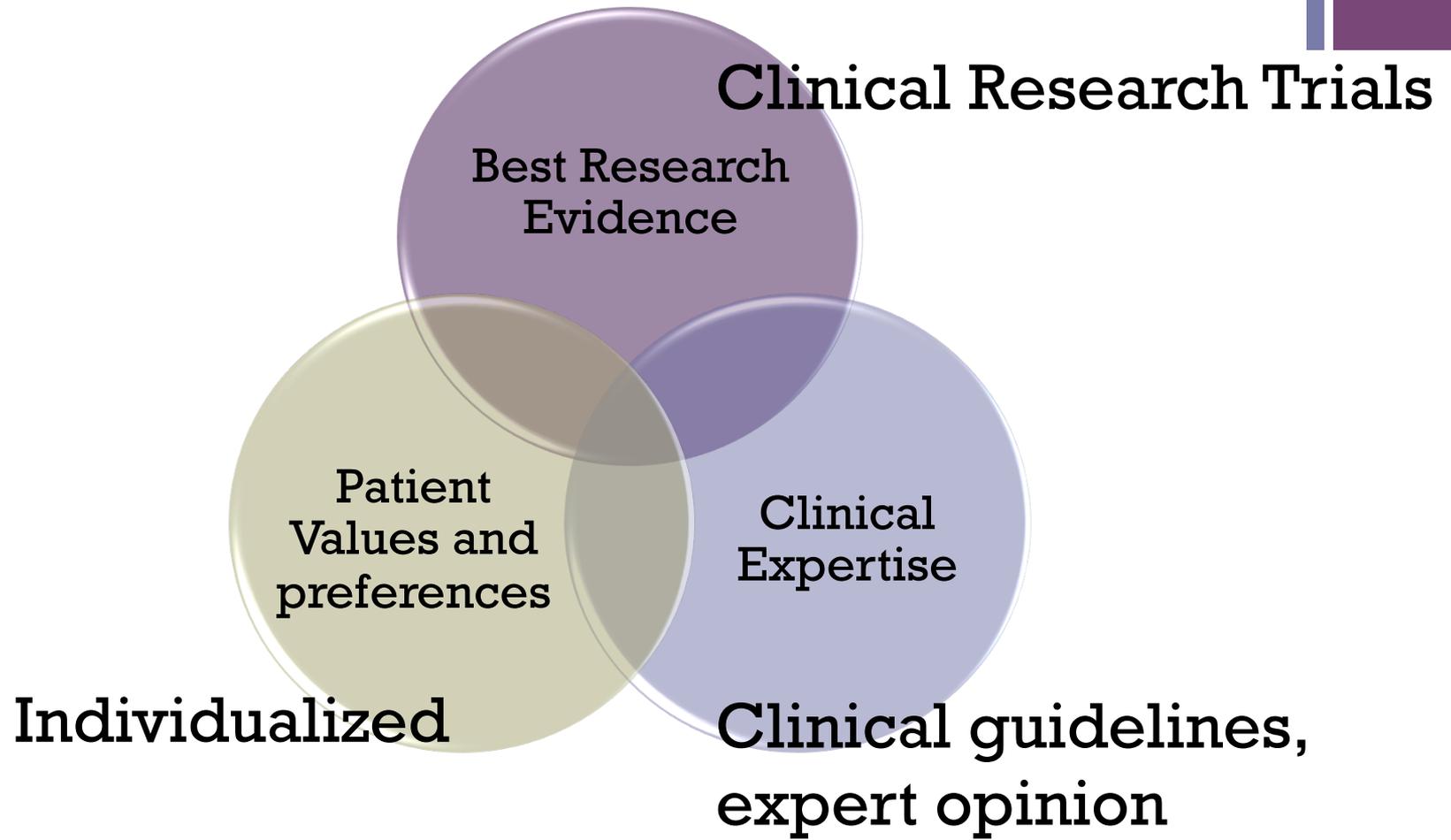
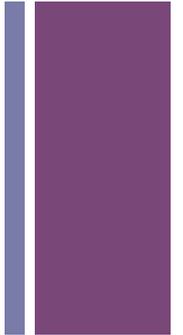
fitness

wellness

+ What are some of your barriers to exercise?



+ So what can we do?



+ Research Evidence

Best
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

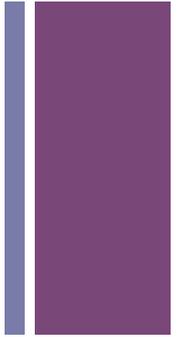




Exercise Evidence



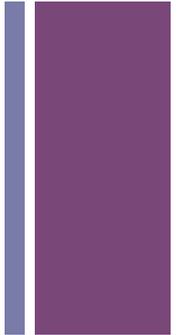
Best
Research
Evidence



- “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

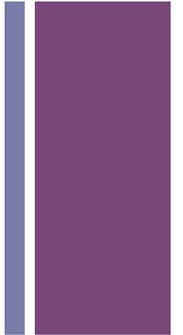


- Moderate exercise is safe!
 - Aerobic and strengthening
- Aerobic exercise can improve fitness.
- Exercise and CBT can improve fatigue





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



Clinical
Expertise

+ 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

ENDLESS ABILITIES

+ When to seek help

- New to starting exercise
- Pain
- Rapid decline or change in status

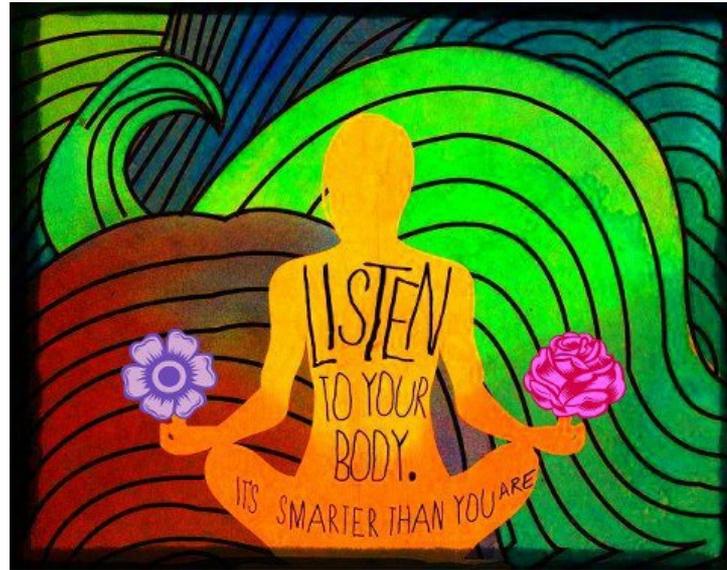


Patient
Values and
preferences



Delicate Balance: listen to your body

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



Patient
Values and
preferences



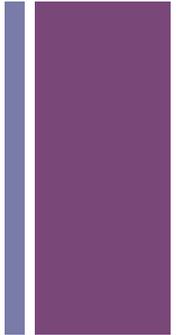
Getting Started

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



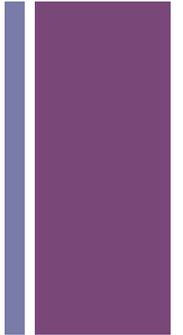
Patient
Values and
preferences

+ Question and Answer



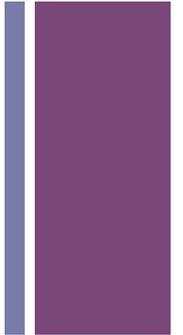
**Patient
Values and
preferences**

+ Exercise sampling



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

+ Heart Rate Reserve



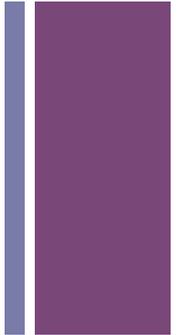
The Karvonen Formula

- Find your Resting Heart Rate (RHR)
- Find your Predicted Maximal Heart Rate (HR max)
 - $\text{HR max} = 220 - \text{age}$
- Find your Heart Rate Reserve (HRR)
 - $\text{HRR} = \text{HR max} - \text{RHR}$

+ Borg Scale

Borg RPE Scale

6		How you feel when lying in bed or sitting in a chair relaxed. Little or no effort.
7	Very, very light	
8		
9	Very light	
10		
11	Fairly light	
12		Target range: How you should feel with exercise or activity.
13	Somewhat hard	
14		
15	Hard	
16		
17	Very hard	How you felt with the hardest work you have ever done.
18		



Thank you!

