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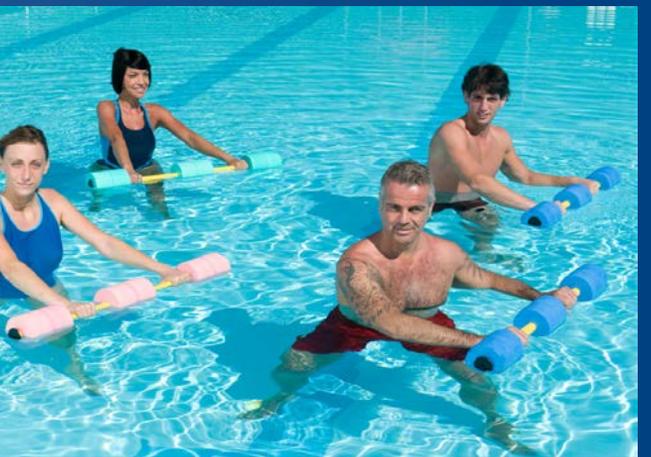
Erdheim Chester Disease (ECD) and Exercise

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Objectives

- Define Exercise
- Discuss how to initiate an exercise program
- Review guidelines that every exercise program should have

How do you define “Exercise”?



Physical Activity vs Exercise

- Physical Activity
 - Activities of Daily Life
 - Pleasure walking
 - Occupational
 - Household chores
 - Energy Expenditure that burns calories
- Exercise
 - Brisk walking
 - Treadmill
 - Cycling
 - Weight training
 - Swimming
 - Jumping rope

Exercise

- **Planned:** regular scheduled intervals
- **Structured:** prescribed amount of time with a set amount of repetition
- **Goals:** The objective of improving or maintaining physical fitness

How to get started?

Discuss your individual medical problems with your health care provider to establish what is safe for you

Initiation of Exercise Plan

- Licensed physical therapy consult
- Certified sports medicine exercise physiologist
- Join a gym and work with a personal trainer
- Once routine is established and tolerated, the internet can be helpful

Benefits of Exercise

- Improves circulation
- Weight control
- Improves cholesterol levels
- Prevents and manages HTN
- Prevents bone loss
- Boosts energy level
- Releases tension
- Improves insomnia
- Improves self image
- Helps manage stress
- Counters anxiety and depression
- Increases strength

Exercise Data in ECD



We can borrow knowledge from other diseases?

- Chronic pain
- Cancer patients
- Myositis
- Chronic fatigue

Goals specific to ECD

- Prevent further deconditioning
- Gain strength and stamina
- Help prevent/improve depression and elevate mood
- Decrease inflammation

Considerations

- May have initial fatigue; avoid exhaustion
- Medication side effects
- Disease symptoms can effect choice of exercises
- Exercises can include familiar activities
- Start at low levels
- Don't get discouraged if you have a "poor" workout

Costs

- Time and energy
- Cost of equipment if working out at home
- Gym membership fees
- Insurance copays and deductibles for Formal training and/or PT

Exercise and Medications

- Medications for ECD
- Medications for additional medical problems
- Medications can have mixed effects

Components of Exercise Program

- Warm-up
- Strength/Resistance and cardiovascular training
- Cool down and stretching

Initial Assessment to Guide Exercise Program

- Establish resistance strength
 - 1 repetition max weight
 - 10 repetition max weight
 - Cut back to 50 % of 10 repetition max
 - On scale of 0-10 work out should be about a 5
- Know that you've worked out but no muscle weakness next day

Continued Assessment

- Healthy population may reassess weight/resistance every 4-6 weeks
- ECD patients should reassess every 12-16 weeks
- Strengthening is range specific
- Using good form important over increasing weight/resistance

Tips for workout

- Intensity, Duration, and Frequency do matter
- Multiple small frequent workouts better than a “power weekend”
- Have several workout routines for variety

Use Motivational Tactics

- Utilize distractions if helpful
- Work out with a care provider or friend for accountability
- Record workout details to track improvement

Conclusions

- Exercise can be a part of every patient's day
- Safety of exercise should be discussed with health professionals before starting
- Outcomes may be slower; don't get discouraged. Plan reassessment is important
- Find creative ways to get motivated!