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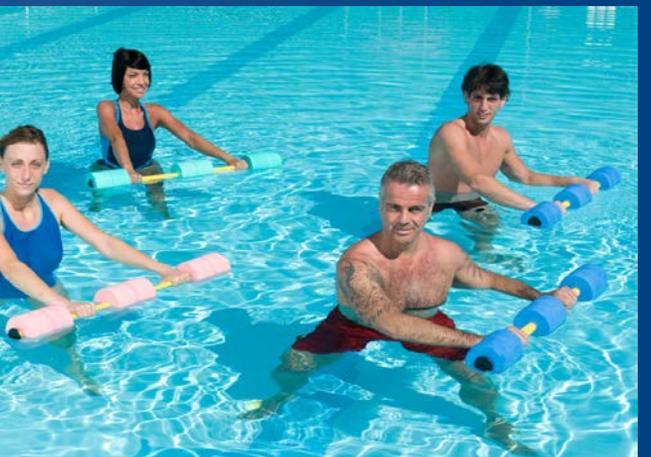
# Erdheim Chester Disease (ECD) and Exercise

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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!