The Importance of Physical Activity for People with HD

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Huntington’s disease Pathology

- Huntington’s disease: neurodegenerative disorder causing progressive neurological dysfunction and brain cell death leading to cognitive, psychiatric and motor symptoms.

- The gene is also widely expressed outside the central nervous system and there are several signs of the disease affecting bodily organs other than the brain.

- Pathology of the brain and other organs run in parallel.

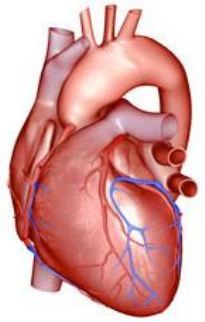
Central Pathology

- Degeneration of brain cells in the basal ganglia causing impairments of motor skills, chorea, dystonia, ataxia.
- Spinal cord atrophy

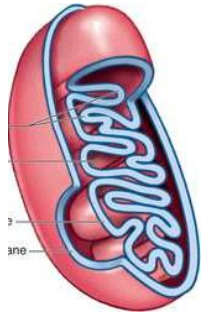
Peripheral Pathology

Decreased pulmonary function

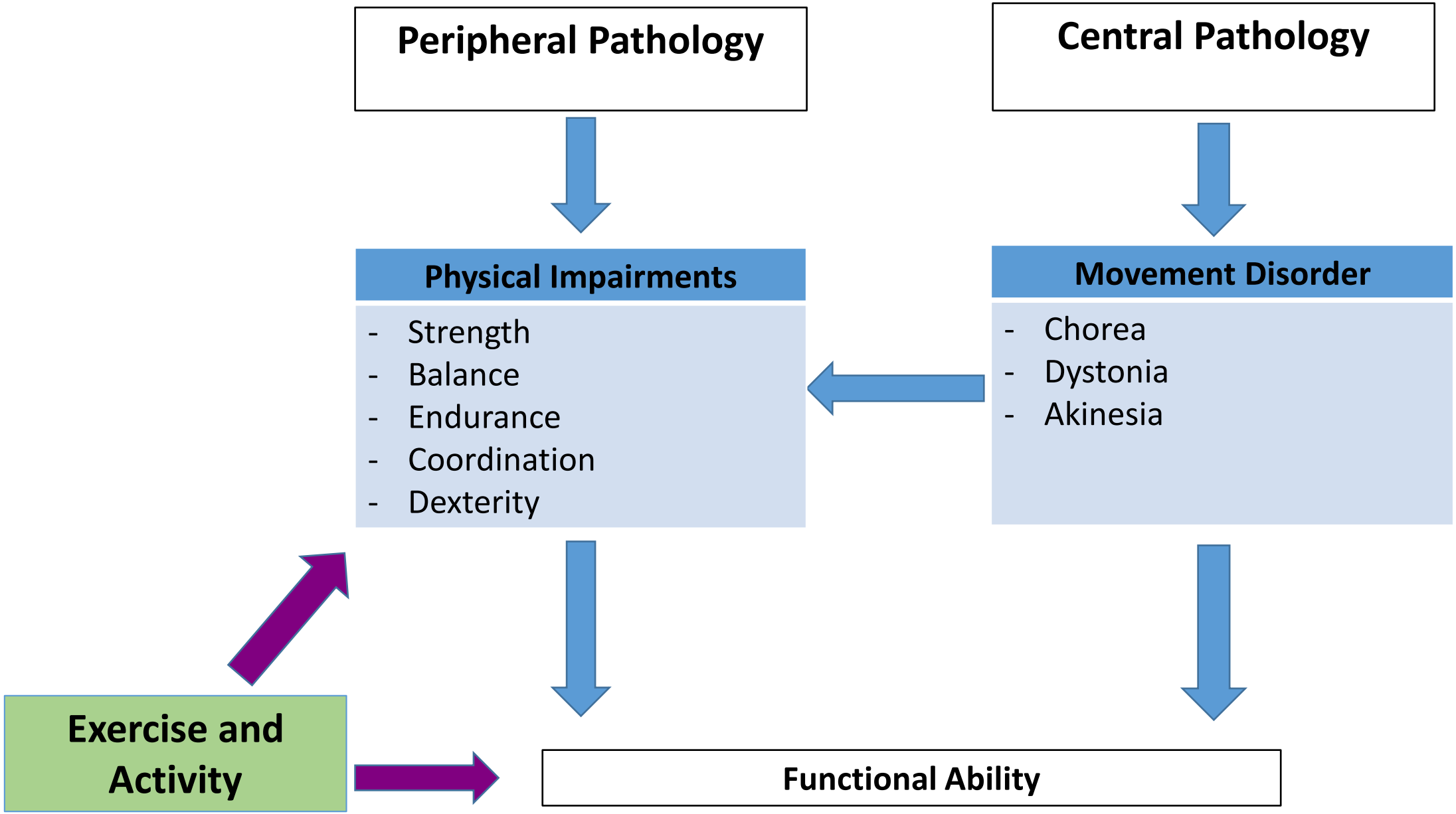
Skeletal muscle atrophy leading to reduced work capacity and muscle strength.



Impairment of cardiac function. Causative factor in mortality.



Mitochondrial dysfunction in presymptomatic and symptomatic HD


Peripheral Pathology
Central Pathology
Physical Impairments
- Strength
- Balance
- Endurance
- Coordination
- Dexterity
Movement Disorder
- Chorea
- Dystonia
- Akinesia
Exercise and Activity
Functional Ability

Research has shown the following Benefits of Activity for People with HD

- Improvement of walking speed (Kloos et al 2013; Khalil et al 2013, Pirra et al 2013)
- Improved cardiovascular function and endurance (Frese et al,2016)
- Improvement in balance (Pirra et al 2013; Khalil et al, 2013))
- Improved function and activities of daily living (Khalil et al, 2013; Zinzi et al, 2007)
- Improved cognitive function (Wallace et al, 2016; Cruickshank et al, 2015)
- Reduced anxiety and depression (Pirra et al 2013)

Physical Activity and Exercise

- **Physical activity**: activity that is part of ones daily life involving bodily movements

- **Structured exercise:** activity that is planned, structured and purposive to improve physical fitness

Current Physical Activity Guidelines: adults (18-64) and older adults (+65)

- At least 150 minutes of moderate aerobic physical activity throughout the week or 75 minutes of vigorous intensity activity spread across the week or combinations of both moderate and vigorous intensity activity.
- Aerobic activity should be performed in bouts of at least 10 minutes duration.
- Strength training for major muscle groups at least twice a week.
- Balance exercise

Reducing Sedentary Behaviours

- Meeting physical activity guidelines alone does not counteract the effect of a sedentary lifestyle (Hamilton et al, 2008).

- Need to minimise sedentary behaviours.

- Spend less time sitting and more time active in our daily lives.

Types of Activity

Type of Activity	Examples
Moderate intensity aerobic activity: - Increase heart rate and breathing rate - Increased body heat	Brisk walking, cycling, dancing, swimming/water aerobics, general gardening
Vigorous intensity aerobic activity: - Larger increase in heart rate and breathing rate - Increase sweating	Running, playing sports, walking while carrying heavy loads, fast cycling
Strength training - Use of resistance	Weights, carrying heavy loads, heavy housework
Balance training	Dancing, yoga, backwards and sideways walking, heel to toe walking, sit to stand.

Intensity of Activity

RPE Scale	Rate of Perceived Exertion
10	**Max Effort Activity** Feels almost impossible to keep going. Completely out of breath, unable to talk. Cannot maintain for more than a very short time.
9	**Very Hard Activity** Very difficult to maintain exercise intensity. Can barely breath and speak only a few words
7-8	**Vigorous Activity** Borderline uncomfortable. Short of breath, can speak a sentence.
4-6	**Moderate Activity** Breathing heavily, can hold short conversation. Still somewhat comfortable, but becoming noticeably more challenging.
2-3	**Light Activity** Feels like you can maintain for hours. Easy to breathe and carry a conversation
1	**Very Light Activity** Hardly any exertion, but more than sleeping, watching TV, etc

Modified Borg Rating of Perceived Exertion Scale

Watch for the following symptoms of over exertion

- Shortness of breath
- Excessive fatigue
- Dizziness
- An increase in HD symptoms such as involuntary movements

Adjusting an Exercise Programme

- Guidelines will need to be adjusted for each individual based on their specific health needs and abilities

- Because HD is progressive, it is important to re-assess an exercise programme regularly to make sure it continues to suit the person's needs and functional abilities.

Promoting Engagement with Activity

- Poor adherence to exercise/activity may often affect people with HD. Poor motivation and apathy is a common feature of HD.

Motivational Strategies

Choice	Goal setting	Feedback
• Exercise type • Location	• Realistic • Achievable	• Constructive • Encouragement

Promoting Engagement with Activity

- Routine and structure

- Care giver support (Khalil et al 2012)
  - Help with exercise performance due to physical limitation
  - Verbal cuing and feedback to support performance due to cognitive limitation
  - Poor carer-patient relationship can affect adherence.

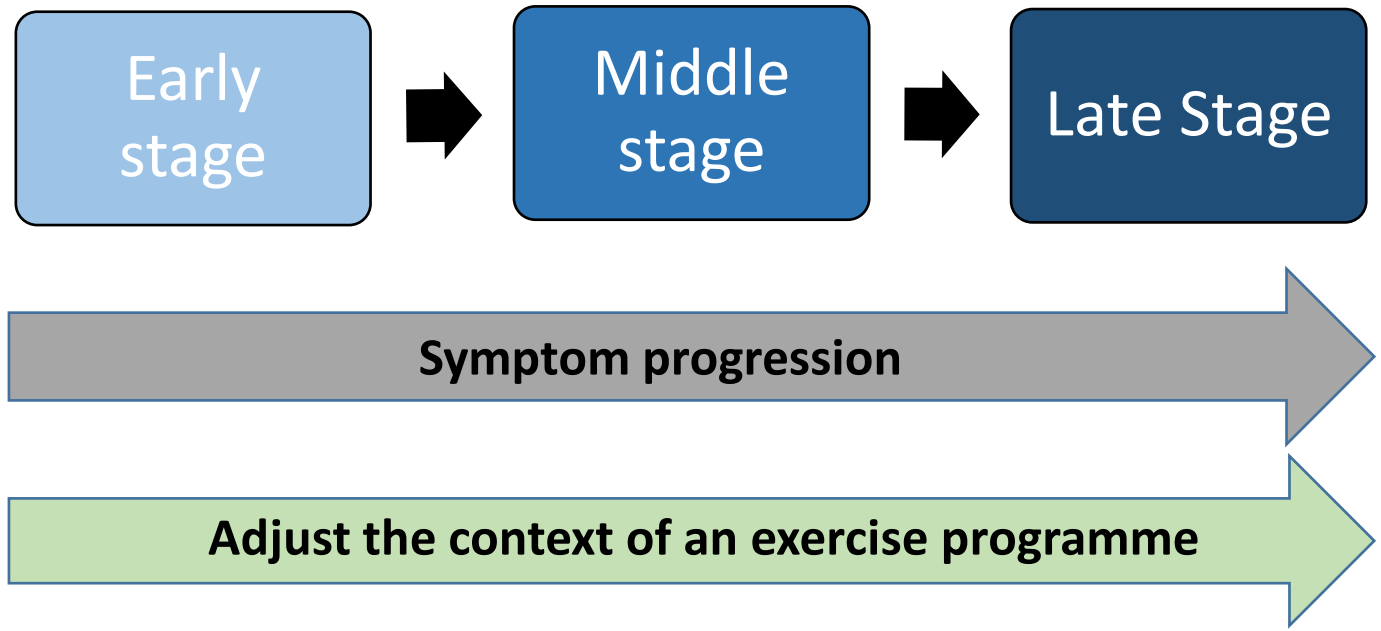
- Exercise setting

Exercise Setting Pros and Cons

Home based exercise programme	Group/Gym based exercise programme
Convenient, no travel	Less convenient, travel required
Flexibility of time	Time specific
Equipment limited; person may lose interest	More equipment variety
Little social interaction	Lots of social interaction
Private	Public

Barriers to Activity: Safety Issues

- In early/premanifest stages of HD when there is relatively few impairments, safety issues may not be as prevalent. As a person progresses to the mid/late stages, symptoms such as balance difficulties or behavioural and cognitive issues may increase.



Barriers to Activity: Safety Issues

1. **Environment**
   - Ensure slip/trip hazards removed
   - Low noise levels or competing distractions to enable full concentration.

2. **Need for supervision**
   - Safe and effective performance may require a carer to supervise sessions, providing physical assistance and/or providing verbal prompting and feedback.
   - A person will not receive same level of supervision in group setting.

3. **Use of equipment**
   - Consider use of equipment that can reduce risk of falls or harm from falls. e.g. walking aids, or protective clothing as appropriate.
   - Seek assessment from appropriate health professionals as equipment may also act to increase falls/injury risk.

Barriers to Activity: Safety Issues

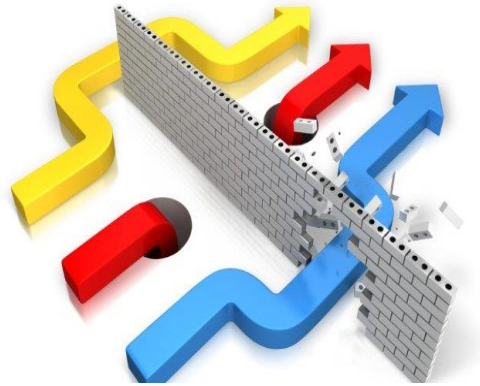
4. Content of an Exercise Programme

- People with cognitive impairments may find it difficult to perform activities involving multitasking . A person may benefit more from a programme that involves more singular tasks.

- Movement impairment such as chorea may restrict performance of certain activities.

- Striking the right balance between challenging a person to improve with exercise while managing risk is essential. Consider referral to physiotherapist to develop an appropriate activity programme.

Barriers to Activity: Physical Issues



1. **Fatigue**
   - Development of routine
   - A little and often approach
   - Awareness of tolerance as over doing it can cause excessive fatigue and may affect stability

2. **Pain**
   - Pain can significantly affect activity and quality of life.
   - Consult medical and/or allied health professionals to help address underlying cause.

Conclusion

- Exercise and activity is extremely important to maintain physical fitness, function and quality of life.

- All movement and activity is beneficial.

- As disease progresses, we can adapt exercise programmes to enable a person to participate safely and effectively

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