



Huntington's
Disease
Association



Physiotherapy for people living with Huntington's disease

EHDN EUROPEAN
HUNTINGTON'S
DISEASE
NETWORK

Advancing Research, Conducting Trials, Improving Care

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The information in this guideline is primarily from the Quinn et al. (2020) clinical recommendations on physiotherapy for Huntington's disease, and we thank everybody who developed these recommendations (see 'Acknowledgements' below).



Community reviewer

Allan Adams

Introduction

Physiotherapy assessments and treatments are essential to optimise function and prevent secondary problems in people with Huntington's disease. Early referrals are important to capitalise on the person's ability to gain the benefits of lifelong activity and exercise, and develop personalised plans to delay the onset of disability. In the middle stage of Huntington's disease, physiotherapists use functional task training and exercise to manage the problems of poor balance, muscle weakness and gait problems. In the later stage, physiotherapists aim to prevent complications and maintain function and quality of life, working alongside healthcare professionals and caregivers.

The recommendations in this guideline are divided into Grade A (strong) and Grade B (weak) recommendations, depending on the evidence to support them. The guidelines also include action statements based on expert consensus. The criteria used to determine this are explained in the clinical recommendations (Quinn et al. 2020).

Multi-disciplinary care

The complex nature of Huntington's disease means that it is essential to provide multi-disciplinary team care.

Neurologists, psychiatrists, psychologists, physiotherapists, occupational therapists, speech and language therapists, dieticians, nursing and social workers should all be involved in providing assessment and treatment.

Grade A recommendations

Aerobic exercise combined with strengthening exercises

Physiotherapists should prescribe aerobic exercise (moderate intensity, 55%–90% heart rate maximum) paired with upper and lower body strengthening 3 times per week for a minimum of 12 weeks to improve fitness and to stabilise or improve motor function. This could be achieved through a gym or home-based progressive exercise programme.

The recommended assessment is the 6-minute walk test of fitness using predicted or actual VO_2 max.

Gait training

Physiotherapists should prescribe one-on-one supervised gait training to improve spatiotemporal measures of gait (e.g. walking speed, stride length, step length). This could be achieved through supervised task-specific training of walking and transfers, and advice on walking aids.

The recommended assessment is the Timed Up and Go test or Tinetti Mobility Test.

Grade B recommendations

Balance exercises

Physiotherapists may prescribe individualised exercises, including balance exercises, delivered at a moderate frequency and intensity to improve balance and balance confidence. This could be achieved through task-specific balance training.

The recommended assessment is the Berg Balance Scale.

Breathing exercises

Physiotherapists may provide regular breathing exercises, including inspiratory and expiratory training, to improve respiratory muscle strength and cough effectiveness. This could be achieved by breathing exercises with and without resistance.

The recommended assessment is the 6-minute walk test. Peak Cough Flow can also be used.

Expert consensus

Expert consensus provides the basis for the following action statements, in the absence of research evidence.

Secondary musculoskeletal and postural changes

Physiotherapists may prescribe an individually tailored programme to improve postural control and may use positioning devices to optimise posture.

This could be achieved by postural stability and transfer training tailored to the stage of disease.

The recommended assessment is the Berg Balance Scale, Tinetti Mobility Test or SF-36.

Limited active movement

Ensure that care plans for people with limited active movement and end-stage disease include appropriate positioning and seating, active movement, respiratory exercise and education.

Provide training to caregivers on strategies for maintaining appropriate ongoing activity and participation for as long as possible. This is an important focus for the physiotherapy team as part of end-stage care. This could be achieved by supporting activities of daily living, fall prevention, environmental modifications and seating adaptations. The recommended assessment is SF-36.

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Resources

Huntington's Disease Association resources

For professionals

The Huntington's Disease Association offers a range of resources to support professionals working with people affected by Huntington's disease.

You can find our resources at www.hda.org.uk

Explore the professionals webpage using the search bar to find specific resources. Search "resources".

Join our professional-only mailing list to receive updates on events, webinars, and new resources tailored to your needs. You can sign up at <https://www.hda.org.uk/professionals-and-training/>

Guide to exercises and activities

Our guide to exercises and activities for people with Huntington's disease ('Keeping Active with Huntington's') is available [here](#).

A physical activity plan is important for people with Huntington's, and the earlier people start this, the better. This is a resource that can be used by any professional or caregiver. It includes information on safety, advice and how to plan physical activity and exercises to help someone with Huntington's disease stay physically active.

Support for children and young people

Find information on our Huntington's Disease Youth Engagement Service (HDYES) by searching for "HDYES" on the website.

Other resources for healthcare professionals

The following resources from the European Huntington's Disease Network



(EHDN) are useful to healthcare professionals:

- EHDN physiotherapy working group. Available [here](#).
- Huntington's disease balance and gait training fact sheet. Available [here](#).
- Huntington's disease exercise and resistance training fact sheet. Available [here](#).
- Huntington's disease cognitive, emotional and behavioural issues fact sheet. Available [here](#).

The following resources from Physiopedia are useful for physiotherapists assessing a person with Huntington's disease.

- Six Minute Walk Test. Available [here](#).
- Timed Up and Go Test. Available [here](#).
- Tinetti Test. Available [here](#).
- Berg Balance Scale. Available [here](#).

Other resources for people affected by Huntington's disease

The following resources from the EHDN are useful to people affected by Huntington's disease:

- Huntington's disease balance and walking training. Available [here](#).
- Huntington's disease exercise and resistance training. Available [here](#).
- Huntington's disease cognitive, emotional and behavioural issues fact sheet. Available [here](#).
- Huntington's disease residential care reference guide. Available [here](#).

References

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Notes

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Get in touch

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