Huntington's Disease Association

Nutritional care for people living with Huntington's disease

EHDN EUROPEAN HUNTINGTON'S DISEASE NETWORK

Advancing Research, Conducting Trials, Improving Care

Registered Charity No. 296453

Contents:

Introduction

As Huntington's disease progresses, issues with nutrition may become more likely as cognitive and physical changes, and changes in mood, can make eating and drinking more difficult. This can lead to weight loss or malnutrition. It is also possible for weight loss to occur, despite a good appetite and a high calorie intake.

A person with Huntington's who is having uncontrollable, jerky movements (chorea) will be using up more energy than they would be without the movements. This means more protein and calories are often required to maintain weight. As the condition progresses, requirements are significantly higher compared to a person without Huntington's disease.

Changes in appetite can occur at various stages of Huntington's and can be for a variety of reasons. These include physical changes, such as difficulty with swallowing, or cognitive and behavioural changes, such as low mood or issues with executive functioning. Fear of spilling food or choking can also contribute to someone not eating. A high-protein, high-calorie, fortified diet is usually recommended for those with Huntington's disease, especially those losing weight.

Recommended standards of nutritional care

Clinicians should follow the nutritional guidelines developed by the European Huntington's Disease Network (EHDN) Standards of Care Dietitians Group.

The key recommendations are reproduced below, but it is advisable to consult the EHDN guidelines in full before providing nutritional care and management for someone with Huntington's disease.

Table 1. Nutritional challenges and recommended standards of nutritional care for individuals with early-stage disease.

Nutritional challenge / recommended level of nutritional care	Rationale for the recommendation
Early assessment of nutritional intake and status	• Severe, rapid weight loss is problematic, although not universal • An early assessment of nutritional intake is essential to the delivery of effective nutritional care • Early dietetic assessment facilitates delivery of good nutritional care in later stages of the disease when the patient becomes unable to communicate effectively
The baseline assessment should include weight, height, BMI, completion of a validated nutritional screening tool, calculation of percentage weight loss, record of usual weight. If unable to obtain weight, use alternative measurements such as mid-arm circumference	• Nutritional assessment should be carried out by a trained health professional • The nutritional status of people with Huntington's disease can deteriorate rapidly
Ensure adequate nutrient intake, including sufficient energy, protein, fluid, electrolytes, minerals, micronutrients and fibre needs (NICE, 2006), taking account of any increased nutritional needs	• Some people have higher energy requirements. People should aim for a balanced intake of fat, protein and carbohydrates to provide the additional calories to maintain weight

	• Excessive and frequent intake of simple sugars should be avoided where possible, as this may impact on dental health • If the dietary assessment indicates an inadequate intake of vitamins and minerals, a vitamin and mineral supplement should be considered
Consider impact of medication on nutritional intake and status	• Medications used in the treatment of Huntington's disease to suppress chorea may affect a person's weight and food intake. For example, some neuroleptics may cause raised triglycerides, raised glucose, dry mouth, constipation, weight gain, increased appetite
Discuss tube feeding within the multi-disciplinary team (MDT) and identify a member of the team to discuss it with the patient, focusing on potential benefits and burdens. Record the person's wishes	• Discussing tube feeding in the early stages of the disease before cognitive function diminishes and communication becomes difficult. Many people have witnessed family members experience similar issues and are aware of the impact of the advancing disease • Discussions must be patient-led; some patients will want to discuss feeding fully, but others will want to avoid or defer decision-making. Group discussions or education facilitated by the dietitian may be beneficial

Table 2. Nutritional challenges and suggested standards of nutritional care for individuals with mid-stage disease

Nutritional challenge / recommended level of nutritional care	Rationale for the recommendation
Monitor weight / weight changes should be recorded at every clinic visit If target weight not achieved / weight loss >5% re-refer to dietitian	• Nutritional goal in mid-stage is often to maintain a healthy weight (BMI: 23–25 is recommended by the group), ensuring adequacy of nutritional intake to prevent rapid weight loss NB: Caution is required for people who are overweight, as a weight-reducing diet may be inappropriate if the person is at risk of future rapid weight loss and feeding difficulties
Monitoring nutritional intake Discussion of food preferences Use of supplements or food fortification	• Difficulties with social aspects of eating may impact on nutritional intake • Poor food choices may be important to address in order to motivate behaviour change while patients are cognitively able to understand the reasons • Particular attention should be paid to any difficulties experienced as a result of advancing disease, such as problems caused by reduced mobility, dexterity, cognition, swallowing and behaviours associated with advancing Huntington's disease, such as food obsessions, food cramming, spillage, fear of choking or apathy

Food texture modification may be indicated Texture-modified diets will require fortification to increase calorific value, and nutritional supplement may be required	• Referral to a speech and language therapist (SLT) for assessment is recommended where clinically indicated • Appropriate texture of food and drink is required to minimise the risk of aspiration
Altered eating behavioural issues, for example, excessive coffee drinking, food cramming and fixations	• Drug use, excessive alcohol intake or constant smoking may impact on nutritional intake • Dietary advice and intervention should focus on practical ways to modify intake, recommending alternatives where appropriate, for example, decaffeinated coffee
Consider specific problems impacting on food intake, for example, sleep difficulties, inability to eat normal portion sizes, constipation, unawareness of importance of nutrition and eating difficulties	• Provision of individualised nutritional care plan and implementation of person-centred, appropriate solution-focused strategies to overcome nutritional difficulties

Table 3. Nutritional challenges and suggested standards of nutritional care for individuals with late-stage disease.

Nutritional challenge / recommended level of nutritional care	Rationale for the recommendation
1. In addition to the assessment outlined in mid-stage: • Texture of diet and usual oral intake • Use of supplements or food fortification • Specific difficulties with eating and drinking • Level of independence with eating and drinking • Usual bowel pattern	• Ensure good communication between members of the multi-disciplinary team (MDT) to meet patient's nutritional needs and to have a comprehensive overview of factors impacting on ability to eat and drink • Constipation can cause food refusal and / or increase risk of reflux or vomiting • Difficulties with social aspects of eating may impact on nutritional intake. Particular attention to any difficulties experienced as a result of advancing disease, such as difficulties with reduced mobility, dexterity, cognition, swallowing and behaviours associated with advancing Huntington's disease, such as food cramming, spillage or apathy
2. Care settings: on admission: • Commence food and drink record charts • Establish frequency of weighing • Observe the patient eating at a meal time	• Identify level of dietetic intervention required • Observation at meals highlights all aspects impacting on a person's ability to eat and drink a nutritionally adequate diet

• Establish a suitable target weight • Determine if advance directives exist • Establish a person's capacity	• A target weight ensures the dietitian and nursing team have clear goals regarding weight management

Source: Brotherton, A., Campos, L., Rowell, A., et al. 2010. Nutritional management of individuals with Huntington's disease: EHDN standards of care nutritional guidelines. *Journal of Neurology, Neurosurgery & Psychiatry*.

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Resources

Huntington's Disease Association Eating Well guide

Our Eating Well guide provides practical nutritional advice to help people with Huntington's disease and their caregivers cope with challenges relating to nutrition. You can read it here.

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”.

Stay informed

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/

Support for children and young people

Find information on our Huntington’s Disease Youth Engagement Service (HDYES) by searching for “HDYES” on the website.

Notes

Get in touch

For advice and support or to speak to a Specialist Huntington's disease Adviser

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