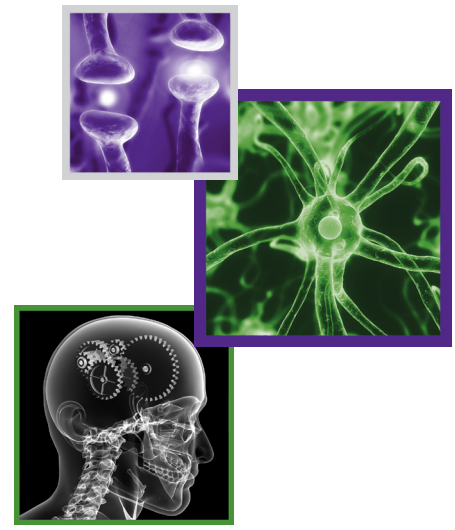
SPECIAL REPORT

Oral feeding in Huntington's disease: a guideline document for speech and language therapists



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Practice Points

- Speech and language therapy has an important role in the management of Huntington's disease.
- Management of oral feeding difficulties in Huntington's disease is a challenge but implementation of a systematic program of intervention can improve swallow safety and efficiency and reduce the occurrence of pneumonia.
- Early referral to speech and language therapy is recognized as good practice. It facilitates accumulation of baseline data, which aid clinical decision making on timely assessment and/or intervention. This is crucial in Huntington's disease because of the multiple factors involved, including cognitive and behavioral changes.
- In early-stage disease the individual with Huntington's disease may have no symptoms of dysphagia but speech and language therapists may still have a role in the provision of information and advice.
- In mid-stage disease there is wide variability in the presentation of oral feeding difficulties and regular assessment and review is required to identify changes and their impact.
- There is significant overlap in presenting oral feeding difficulties in the mid and late stages and as the disease progresses the challenge of maintaining adequate nutrition and hydration becomes greater due to the complexities involved.
- The speech and language therapist will contribute to the discussions and multidisciplinary decision making regarding non-oral feeding/supported feeding. Decisions should involve the individual and significant carers, the discussions having been introduced whilst the individual's cognitive abilities allowed full participation.

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SUMMARY Speech and language therapy has an important role in the management of Huntington's disease (HD). Swallowing difficulties affect most individuals with HD. Throughout the disease process these difficulties require management with timely and effective therapeutic intervention. Currently there are no European guidelines for the assessment and management of swallowing impairments in HD. The European Huntington's Disease Network (EHDN) Standards of Care Speech and Language Therapy Working Group has brought together expert speech and language therapists from across Europe to produce guidelines to improve the management of swallowing disorders for individuals with Huntington's disease. The guidelines were developed with the aim of promoting timely and appropriate assessment of the swallowing process and focused management throughout all stages of the disease. Literature was systematically searched in an attempt to ensure that the recommendations are based on sound evidence. Where evidence was lacking, specific guidance is based on expert consensus. The provision of care varies widely between countries in Europe and the implementation of those guidelines should improve the quality of care delivered to individuals with HD.

Huntington's disease (HD) is a mainly adult-onset, familial disorder that can affect both men and women [1]. Symptom onset usually occurs by the age of 40 years, but this can be very variable. Age of onset is related to the size of the mutation, which is an unstable expansion of a CAG sequence in the gene [2]. The classical triad of clinical signs and symptoms include a movement disorder, cognitive impairment and behavioral changes. These features cause complex management problems. Described by George Huntington in 1873, this disease continues to devastate families and perplex the clinicians who care for them.

Changes in eating and drinking in HD are impacted by physical, cognitive and affective factors. Management of oral feeding needs to take account of these, as well as the more traditional approach, which may have a narrower focus on oral and pharyngeal dysfunction. The guidelines presented here adopt this more holistic approach.

Dysphagia is a common problem in HD [3,4]. As the disease progresses the swallowing function can become greatly impaired, raising the risks of aspiration and associated bronchopulmonary infections, airway obstruction, dehydration and malnutrition. Dysphagia and aspiration are cited as common triggers for complications leading to death in the later stages of HD [5]. Management of swallowing difficulties in HD is a challenge but implementation of a systematic program of diagnosis and management of dysphagia can improve swallow safety and efficiency and reduce the occurrence of pneumonia. Some studies support the implementation of interventional programs in managing dysphagia in HD and report favorable results with some improvements reported to have persisted for as much as 3 years [4,6,7]. In general, there is a paucity of high level evidence to support the management of dysphagia in HD, with case study and expert opinion levels forming the main body of literature [8]. However, the Standards of Care Working Group has produced a consensus view reflecting the opinions of experts working in this field and using available evidence from the literature. It is hoped this will enable others to provide optimum intervention and care to the HD patient and their family.

Aims

The aims of this guideline are:

- To assist practitioners in reducing the risks of aspiration and airway obstruction and in applying appropriate methods to support food and fluid intake;
- To inform the optimal, individualized management of swallowing disorder in HD in order to enable uniformity of care internationally and to document speech and language therapy practice, and the different approaches around Europe to the management of HD;
- To review scientific literature to identify evidence-based practice in managing oral feeding difficulties in HD;
- To establish expert opinion and consensus regarding usefulness and efficacy of interventions;
- To make recommendations on effective practice, based on the literature, clinical data and expert opinion available, therefore, promoting standard methodologies.

Stages of HD

There have been several attempts to define the stages of progression of HD [9,10]. Current research may provide further options [10]. For these guidelines recommendations have been made for three stages of the disease; early, mid and late.

■ Early stage

Early disease cannot be defined as the time of diagnosis since diagnosis can be made at variable times. Most individuals present with early neurological and psychiatric features that may have started to cause difficulties at work and home.

■ Mid stage

Mid-stage disease is reached when the affected person has to cease work, or at least change employment to a post that is less challenging. Executive function declines and some cognitive deficit may be demonstrated. Involuntary movements are obvious but individuals may still be able to feed themselves.

■ Late stage

Late-stage disease occurs when employment becomes impossible, the individual is no longer able to live independently, self-care ceases and cognitive decline is obvious. Some patients maintain the ability to feed themselves to a late stage, but swallowing difficulties and involuntary movements create increasing difficulties.

Methods

■ Role of the European Huntington's Disease Network

The European Huntington's Disease Network (EHDN) was formed in 2003, to provide a platform for clinicians and families to work together to find a cure for HD, and to coordinate research. Working groups were created to address various themes, such as Standards of Care. Care of HD varies widely throughout the world, and there are many HD management clinics worldwide. Some follow guidelines for care provision that they themselves have devised, but there is a scarcity of peer-reviewed evidence for any standard of care in HD.

We present a guideline for care of the speech and language therapy aspects of HD. The literature has been reviewed, and an expert consensus view for management of this aspect of care of HD has evolved. We expect this to enable others to provide best care for the HD patient, their family and their carers. We also expect these guidelines to evolve as evidence emerges, and we will welcome this.

■ Literature review

A systematic literature search was performed electronically using OVID Medline (1988–2009), OVID Embase (1988–2009) and EBSCO Cinahl (1988–2009) to identify evidence within the themes of communication, language problems, dysarthria and dysphagia in HD. A search strategy was developed in collaboration with the members of the Standards of Care Speech Language Therapist (SLT) Group. The literature search was updated during the development of the guideline. All relevant publications were identified and categorized to evidence statements according to the Scottish Intercollegiate Guidelines Network (SIGN 50). Owing to the lack of scientific evidence recommendations were also formulated based upon clinical experience and expert consensus from within the EHDN Standards of Care SLT group.

Key priorities in assessment, management & treatment of swallowing disorders in HD

■ Referral

Early referral to Speech and Language Therapy is recommended and recognized as good practice in the management of long-term neurological conditions [11]. This facilitates the accumulation of baseline clinical data and aids clinical decision making on timely assessment and/or interventions. It is crucial in managing dysphagia in HD because of the multiple factors involved, including cognitive and behavioral changes. SLT referrals should be discussed as early as the person is identified at being at risk of developing the disease, as it is recognized that there is a group who will want to seek early support and information. There may be significant anxieties based on family experiences.

Objectives of referral

The Standards of Care Working Group in Speech and Language Therapy agreed that the following objectives are important to the person with HD and their family on being referred to speech and language therapy services:

- Seeking and receiving information
- Assessment of swallowing safety and identification of current risks

- Opportunity to discuss future management and options
- Receiving pertinent advice on relevant areas: appetite changes, dietary modifications and on strategies for optimizing swallow safety
- Reduction of patient and family/carers anxieties on swallowing problems
- Opportunity to begin forming an effective relationship with the appropriate professionals

Assessment

Pre-assessment information

Information should be gathered in accordance with standards recommended by SLT professional bodies as with other patient groups referred for dysphagia assessment [12]:

- Medical history
- Current medications
- Dietary history
- Feeding/swallowing history
- Patient-specific information

Some of this information should be obtained if possible from other members of the multidisciplinary team prior to patient interview. If possible partner/carers should also be interviewed to obtain a detailed history of the general course of the disease and current status. It is agreed that information gathered only from the patient, particularly as the disease progresses, may not provide a sufficiently adequate profile. This information will assist in determining the type, scope and timing of further assessments.

Clinical assessment

The clinical assessment gives information about the presence, nature and severity of dysphagia [13]. This should define the physiological dysfunction and its effect on patient's activity and participation, identify the requirement for further investigation, examine the effectiveness of particular interventional strategies and facilitate the development of a management plan. In assessing the patient with HD it is recommended that the SLT considers gathering information on the following areas, all of which can have particular relevance in HD **(Box 1)**.

The SLT should use the information gathered to determine the ongoing assessment procedure and to determine the safety of food trials. It is recognized that in early stage patients will usually be taking full oral diet. The SLT should also observe the following factors, which are likely to have particular relevance in assessing and managing dysphagia in HD:

Box 1. Recommendation for clinical speech and language therapy assessment in Huntington's disease.

- Oro-facial examination, including cranial nerve assessment
- Generalized motor skills, including co-ordination, posture and tone
- Respiratory status
- Secretion management
- Oral hygiene and dental health
- Effects of emotional status, mood and behavior
- Cognitive status/factors
- Alertness levels
- Communication status
- Nutrition and hydration
- Ability to participate and co-operate

- Mealtime routines
- Positioning
- Bolus size
- Utensils/assistive devices
- Environment
- Supervision

A number of swallowing assessments are available (e.g., Northwestern Dysphagia Screening Check Sheet [14]) and some have been developed with specific attention to Huntington's Disease, for example, Yorkston and colleagues [3] and Basmagi [Unpublished Data]. These can plot baseline information and serve as a monitoring tool for further assessment as the disease progresses. Standardized testing, for example, Timed Water Swallow Test [15] can also be used as a measure of presence or absence of dysphagia in the early stages of the disease.

Observation of a meal intake in the home environment is considered beneficial to provide information, which may be obscured/ameliorated in a clinic-based examination of the swallow. This may include adverse and positive effects of environment (seating, distractions, and cutlery), rate of intake and possible effects of fatigue.

Instrumental assessment

Studies with other neurological populations have shown that the bedside clinical examination

lacks specificity and sensitivity in identification of aspiration [16]. In other progressive conditions, such as motor neuron disease/amyotrophic lateral sclerosis, instrumental assessment is recommended to answer specific questions [17]. Videofluoroscopic evaluation of swallowing is an instrumental dynamic assessment of swallowing involving visualization of the structure and functions of the oral, pharyngeal and upper esophageal stages. It allows assessment of the presence and cause of aspiration and residue. It facilitates the experimentation of techniques, textures, postures and manoeuvres in order to improve the safety and effectiveness of the swallow [101]. Videofluoroscopy examination to provide both, assessment and interventional information is reported by Hamaka and colleagues [7]. Their study underlined some of the improvements in swallow achieved through altering bolus sizes and consistencies. Kagel and Leopold [4,6] demonstrated improvements in swallow using modified head and body postures using videofluoroscopy assessment. There are some cases where videofluoroscopy may not be an appropriate tool. For example, if in the SLT's judgment, the instrumental examination would not change the clinical management of the patient or the patient is unable to cooperate or participate [101].

Fiberoptic endoscopic evaluation of swallowing is an alternative instrumental assessment method. However, this technique is not widely used with patients with HD as it does not allow visualization of the oral stage and choreic movements can make the examination difficult.

Instrumental tools

Pulse oximetry and cervical auscultation are instrumental tools that have been used to assist in evaluating swallow function in other neurological dysphagic populations but the evidence on the reliability of these is inconsistent [18,19].

Management

Early stage

In the early stages of the disease the patient with HD may have no symptoms of dysphagia. Patients and/or family may identify the following:

- Pharyngeal lodging
- Occasional coughing on eating/drinking
- Slight difficulties in mastication and reduction in lingual control

The SLT should note whether there are any specific requirements noted in the referral and that with genetic conditions such as HD affected individuals and their families are likely to have past experiences, which may mean they seek support early. Any program of intervention that is introduced should be systematically and regularly reviewed and should always take account of the individual's own circumstances and wishes. In the early stages both general and specific advice can be appropriate. Therapeutic interventions in the form of oral/respiratory/phonatory exercises may also be introduced if appropriate at this time.

Management approaches in early-stage HD

- Raise awareness of swallowing (both normal swallow and potential areas of difficulty) and advise on self-monitoring techniques;
- Advise on mood changes and that the presence of anxiety or depression can affect the person's appetite. Stress may also trigger choreic change and affect the swallow process;
- Advise on reducing anxieties on fear of choking/drooling as well as on the embarrassment of making a mess whilst eating;
- Advise on reducing distractions and creating a relaxed environment during mealtimes;
- Advise on conserving energy before and during mealtimes;
- Advise on potentially difficult foods and textures [4,20,21];
- Advise on posture and positional changes, specifically identified for HD in the literature [4] and also for dysphagia in other conditions [21];
- The SLT should identify and agree which interventions receive priority at any stage in time.

Mid stage

Mid-stage HD can coincide with the first signs of swallowing difficulty and/or much more prevalent signs, having a greater impact on the individual's nutritional and medical status **(Box 2)** [4,6,7,23].

Management approaches in mid-stage HD

- Assessment and re-assessment should be a regular feature during this stage in the disease and will include bedside clinical evaluation, imaging and biofeedback assessments as appropriate;
- Safe swallowing recommendations and information to HD individuals and their family/carers should be presented in both verbal and written format. Limitations should be explicit;
- Consideration should be given to training, in particular involving family and carers. Caregivers need to be able to facilitate optimally safe and pleasurable eating and drinking. In other dysphagic populations (including learning disability), patient and carer adherence to recommendations has been shown to be influenced by their understanding of the condition, and this can be improved by SLT training [24,27];
- Recommendations for a safe swallowing/eating and drinking plan may also be presented in picture/accessible information format to facilitate the eating/swallowing routine;
- Information should be provided on how to support the individual with HD safely, on how to implement the eating and drinking plan and also to identify when further input from the SLT is required;
- Therapeutic intervention to maintain and/or improve oro-motor function within agreed optimal timeframes may be implemented. These may include breathing exercises, oral and chewing exercises and individualizing swallow sequence, for example, cough postswallow [6];
- Consideration should be given to the individual's level of cognition, alertness, receptive abilities and behaviors so that the interventional plan is aimed at optimum circumstances;
- The SLT should make recommendations to modify food and liquid consistencies, textures and temperatures as well as the viscosity in order to achieve improved swallow safety [4]. The modifications should link directly to the ongoing systematic assessment in order to increase the safety and efficiency of the swallow;
- The placement of the bolus, its size and the pacing of the feeding are also important in managing the safety and efficiency of the swallow. It is recognized that some individuals with HD will overfill the mouth increasing the risk of choking and forward spillage;
- The SLT should advise on posture and positioning to achieve optimum body and trunk position to support safe swallow function. This should include chin tuck positions to protect the airway and may include strategies to minimize hyperextension of the neck and trunk to minimize swallow effort and assist in pharyngeal clearance [4,22]. Joint working with colleagues in physiotherapy is recommended to achieve optimal positioning;
- Adaptive feeding equipment should be considered [4] and it is recommended that the SLT work with colleagues in occupational therapy to provide appropriate equipment;
- The SLT should advise on optimizing the individual's environment as this can have a significant influence on the mealtime and the aim should be to make it a safe and pleasurable experience. Social interaction, distraction and noise levels should be considered [26];
- The SLT will contribute to the discussions and multidisciplinary decision making regarding nonoral feeding/support feeding. This discussion and decision regarding the provision of nutrition and hydration by a non-oral route should include the individual with HD and their significant carers [27]. Discussion should be introduced while the patient's

Box 2. Swallowing features in mid-stage Huntington's disease.

- Hyperextension of neck and trunk
- Reduced mastication and lingual control
- Darting lingual chorea
- Drooling – spillage from mouth
- Tachyphagia/premature transfer particularly of liquids
- Intraoral retention following initial transfer
- Delayed and repetitive swallow
- Prolonged laryngeal elevation
- Coughing on liquids
- Choking on foods and liquids
- Reduced/disrupted breath control during the swallow
- Phonation during swallowing
- Belching
- Aerophagia
- Vomiting

cognitive abilities allow full participation and decisions should be clearly documented.

- It is agreed that the cough reflex is often well preserved in HD and the protection afforded to the airway means oral feeding is often possible until the advanced stages of the disease.

End stage

It is agreed that there is significant overlap of presenting symptoms of oral feeding difficulties in HD in the mid and late stages. As the disease progresses, the challenge of maintaining adequate nutrition and hydration becomes greater due to the complexities involved (Box 3).

Several of these areas have been shown to influence risk of aspiration pneumonia, for example, dependence on others for feeding [28] and oral hygiene [29].

Management approaches in late-stage HD

- Dietary modifications, the use of compensatory swallowing techniques, the manipulation of head or body postures and manoeuvres to support safe and efficient swallowing should continue. All of these factors must be reviewed regularly;
- Therapy techniques such as exercises or strategies to facilitate or stimulate the swallow should continue;
- Good oral hygiene should be maintained. This should ensure pathogenic organisms are not allowed to proliferate in the mouth and should reduce the risk of aspiration pneumonia [29];
- Training packages ranging from raising awareness of good practice to specific training in all aspects of dysphagia should be considered vital at this stage. All caregivers should possess the knowledge and skills to feed/support the feeding of patients with dysphagia safely;
- All caregivers should be in receipt of specific instructions on:
  - Food placement
  - Dietary modifications
  - Positioning and postures
  - Management of behavioral and environmental factors
  - Management of choking
- Regular monitoring of the individual with HD's weight, hydration, nutrition and occurrences of aspiration pneumonia is key at this stage in the disease;
- Increased risk relating to all or any of these areas should initiate multidisciplinary discussion regarding alternatives in future management;
- If this discussion has taken place with the individual with HD at an earlier stage when the ability to understand the options and the implications was clear, then the management decision should comply with the patient's wishes and rights.

Box 3. Complex aspects of late-stage Huntington's disease.

- Cognitive difficulties
- Communication difficulties
- Behavioral changes
- Mood disorder
- Appetite changes
- Weight loss/gain
- Increased aspiration risks
- Medication
- Oral health/dentition
- Feeding dependency
- Non-oral feeding/support feeding

Conclusion

This guidance document on the management of oral feeding in HD has been developed using a systematic review of all the available evidence as well as expert consensus on best clinical practice.

The guidance considers the progression of the disease over time and the importance of the involvement of Speech and Language Therapy Services to support food and fluid intake and manage changes in the safety and efficiency of the swallowing function. It underlines the need for flexibility and responsiveness in addressing the changing clinical picture of the affected individual and the value of involving the family and care givers in the exchange of information and in particular interventions to minimize the devastating effects of the disease.

These clinical guidelines are an important tool in attempting to provide equity and quality of service provision and are also work in progress which will require review and revision as new research becomes available.

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