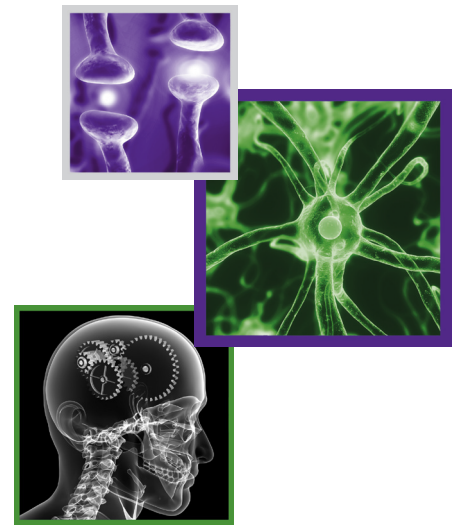
SPECIAL REPORT

Development of guidelines for occupational therapy in Huntington's disease



Clare Cook[1], Kirsty Page[2], Anne Wagstaff[2], Sheila A Simpson[3,4] & Daniela Rae[3,4]*; On behalf of the contributing members of the European Huntington's Disease Networks Standards of Care Occupational Therapist Group

Practice Points

- Occupational therapy has an important role to play in the management of occupational performance problems in Huntington's disease.
- As the disease progresses activity/occupations become increasingly compromised by physical, cognitive and neuropsychiatric changes.
- A variety of symptoms impact on the individual's occupational performance. The consensus opinion is that interventions will vary between rehabilitative, compensatory and environmental approaches while an informative and supportive approach will be used throughout the disease trajectory.
- All interventions must be timely and responsive to the changing needs of their family and caregivers.
- It is vital to understand the value and importance of involving family and caregivers in developing effective strategies to enhance occupational performance and participation.

SUMMARY This paper introduces the 'Guidelines for Occupational Therapists working with people with Huntington's disease' which is currently being developed by the European Huntington's Disease Network (EHDN) Standards of Care Occupational Therapists working group. This article aims to describe the everyday functional problems experienced by people with Huntington's disease, the role of the occupational therapist, the systematic literature review which preceded the formulation of the guidelines and use excerpts from the guideline to illustrate some of the issues raised.

Huntington's disease (HD) is an autosomal dominant genetic disease that is characterized by movement disorder, behavioral disturbances and dementia [1]. The early symptoms of the condition may go undetected for a while and the onset is slow and gradual so it can be difficult for the individual or family member to identify exactly when the symptoms started. HD can start at any age but most people develop symptoms between the ages of 35 and 55 years [2].

[1]Neuropsychiatry Deptartment, Birmingham & Solihull Mental Health Foundation Trust, Birmingham, UK
[2]Harper Unit, St Andrew's Healthcare, Northampton, UK
[3]NHS Grampian, Centre of Clinical Genetics, Aberdeen, UK
[4]University of Aberdeen, Aberdeen, AB25 2ZD, UK
*Author for correspondence: Tel.: +44 1224 552 120; d.rae@nhs.net

Future Medicine part of fsg

Current statistics suggest that the prevalence of HD is 5–7 people per 100,000 in Western countries affected by the condition [3]. In the UK, which has a population of approximately 55 million, there are approximately 5500 people with HD at any one time. This illustrates that HD is a rare disease but if the carers and family members are also counted this condition affects a larger number of people [2].

People with HD may be referred to an occupational therapist at various stages through the disease trajectory. Occupational therapy practitioners base their work on a thorough understanding of occupation and its role in health [4]. Occupation not only enables people to meet the basic biological needs for sustenance and shelter but also provides the physical activity, mental stimulation and social interaction that is needed to keep bodies, minds and communities healthy [5]. Participation in occupation also provides opportunities to develop skills, express ourselves and to form identities. Engagement in occupation encourages good health and a sense of well being [5].

Occupational therapists may work with people with HD in a variety of settings however, all occupational therapists will have common goals for these individuals. The College of Occupational Therapy defines the practice of occupational therapy as follows,

"The purpose of occupational therapy is to enable people to fulfil, or work towards fulfilling, their potential as occupational beings. Occupational therapists promote function, quality of life and the realization of potential in people who are experiencing occupational deprivation, imbalance or alienation. They believe that activity can be an effective medium for remediating dysfunction facilitating adaptation and recreating identity" [6].

All occupational therapists will assess the person with HD and planned interventions will be mostly using a rehabilitative, compensatory or environmental adaptation approach to enable the individual to manage their skill deficits due to the degenerative nature of the condition. Occupational therapists also work closely with family members to teach them how to promote function in the person affected by HD **(Table 1)**.

Table 1. Common impairments of people with Huntington's disease and their impacts on activities and participation (Standards of Care [occupational therapists] Working Group consensus statement).

Impairments	Problems with activity and participation
Physical	
Chorea	Difficulty maintaining posture and controlling limb movements impacting on all activities of daily living
Bradykinesia	Slowing of intentional movement
Dystonia	Contracting of specific muscle groups causing balance problems and increasing risk of falls
Reduced manual dexterity, poor co-ordination, reduced grip	Difficulty with manual tasks such as eating, fastening buttons, writing and, holding and operating a phone
Dysarthria	Loss of voice clarity and decreased intelligibility of speech
Dysphagia	Difficulty swallowing food and drinks – increasing the risk of choking and aspiration
Fatigue	Reduced endurance affecting all tasks. Reduced ability to maintain posture and complete activities
Cognitive impairments	
Bradyphrenia	Generalized slowing of thinking processes
Impaired executive function	Reduced problem-solving and decision-making skills
Impaired attention	Reduced concentration and ability to maintain or switch attention
Reduced motivation	Apathy, reduced interest and drive leading to social isolation
Depression	Low mood, sadness and reduced motivation
Anxiety	Fear and avoidance of situations
Dementia	Confusion and inability to maintain safety
Behavioral impairments	
Psychosis	Confusion and reduced concentration
Challenging behavior	Difficulty maintaining relationships Inability to maintain safety Reduced engagement in activity

When working with people with HD and their families it is important to provide a cohesive and multidisciplinary service. The disease affects many different aspects of the individual's abilities they will need to be assessed by appropriately trained healthcare professionals for the various difficulties they experience. Aubeeluck states [7]:

"The complex nature of Huntington's diesase makes it unlikely that any one professional will have all the skills needed to help any one individual. It is therefore of utmost importance that the service providers take a multidisciplinary approach to Huntington's disease in order to identify the best way to assist individual patients by taking into account their differing needs."

While the person with HD continues to live in their own home there can be a number of different agencies involved such as housing department, social work department, care agency workers, wheelchair services, employment services, daycare centers. It can be difficult to keep track of the people involved and their contact details. For this reason, a care co-ordination approach works well where one person acts as a key worker and will liaise with the other professionals as necessary, advocate for the service user, and introduce new professionals to the service user at appropriate times. In some teams the key worker or care co-ordinator will be the occupational therapist (Figure 1).

The aims of this paper are to describe the process of developing the Practice Guideline for Occupational Therapists working with people who have HD, to share some of the results of this process and to identify plans for future dissemination and further research into occupational therapy and HD.

Methodology

A systematic literature search was performed electronically using several databases specified by Scottish Intercollegiate Guidelines Network (SIGN) Guideline Development Handbook (SIGN 50) [8]. The levels of evidence and SIGN grading system is detailed in the appendix. SIGN was established in 1993 to develop evidence-based clinical guidelines for the National Health Service in Scotland (UK). The databases searched include; Medline, Embase, Cinahl, Amed, PsychInfo, Need, Cochrane library and an internet search (Google scholar).

Search strategy

The search strategy included articles published in English and subjects of 18 years of age plus with a confirmed diagnosis of HD.

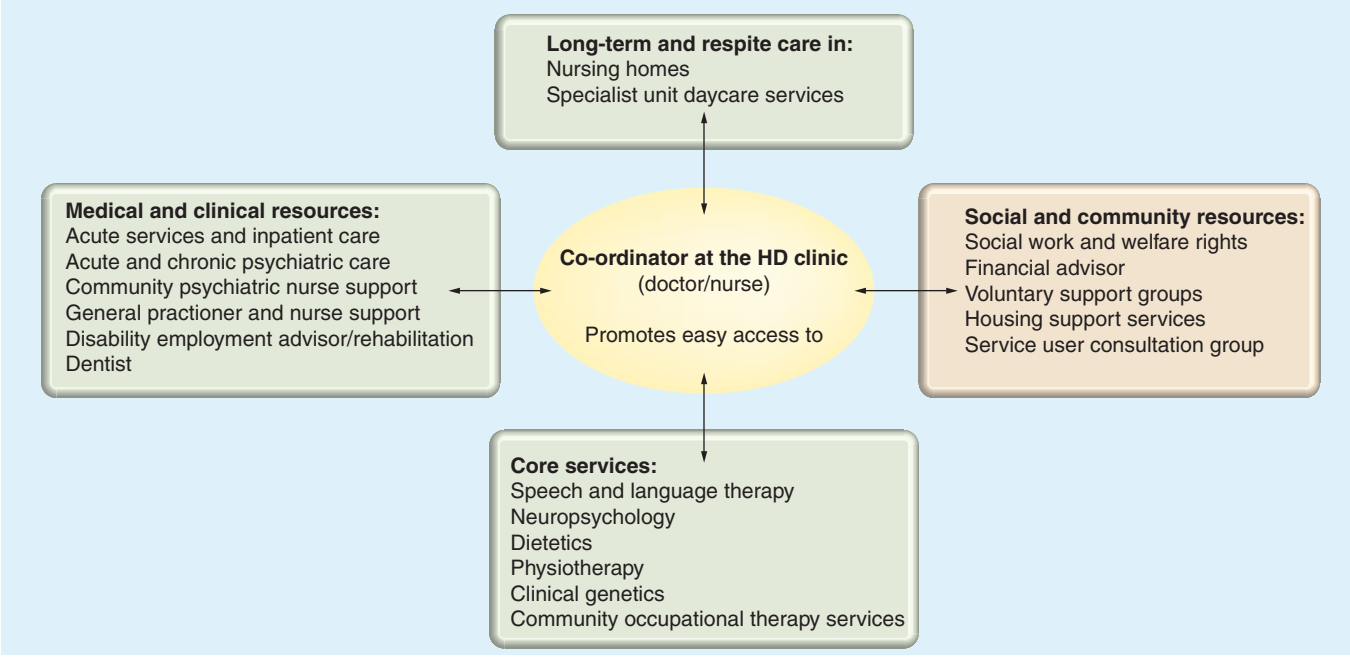


Figure 1. Standards of Care Multidisciplinary Network.
HD: Huntington's disease
Redrawn with permission from the European Huntington's Disease Networks Standards of Care Working Group.

■ **Search terms included:**

Huntington's disease, AND occupational therapy/occupation/independence/rehabilitation/activities of daily living/adaptations/home adaptation/equipment/leisure/work/employment/feeding/posture/seating/wheelchairs/splinting/sensory/multi-sensory/manual handling.

On occasion references of potentially relevant articles were also obtained from article's reference lists and followed up. This was done to seek and evaluate evidence of occupational therapy used with patients with HD, and of any specific occupational therapy interventions which form part of the practice of clinicians from the Standards of Care Group. All relevant publications were identified and categorised to evidence statements (Table 2). Due to the limited scope of the literature found, observational studies were included in the review process. Qualitative studies were also included and reviewed separately.

Table 2 shows a summary of the evidence found and categorizes it into a hierarchy of evidence according to the SIGN manual.

Owing to the apparent lack of scientific evidence recommendations were also formulated based upon clinical experience and expert consensus from within the European HD Network (EDHN) Standards of Care Occupational Therapist group.

The guidelines were commissioned by the EHDN and developed as part of the Standards of Care working group which have produced similar guidelines for physiotherapy, speech and language therapy, dietetics and dentistry.

The two initial meetings included occupational therapists from the UK, Sweden and the USA. These meetings focused on similarities in practice across these countries and discussion of areas to include within the guidelines. The guidelines were written by the main authors and then circulated via e-mail to the other group members for comment and revision. A draft of the guidelines was taken to the College of Occupational Therapy Conference 2011 for extended peer review in the UK.

Results

A draft guideline document has been produced for occupational therapists working with people from early to end stages of the disease. The guideline is divided into two main parts. Part 1 is the background section which provides an overview of HD, its etiology, diagnosis and treatments. Part 2 focuses on the actual guidelines which are divided into four sections addressing the following:

■ **Strategies for physical, cognitive and behavioral factors impacting on engagement, motivation & learning**

HD typically sees deterioration in the three areas of cognition, physical function and mood/behavior. As these affect peoples ability to function in all activities, recommendations of ways to overcome these problems is covered initially, before going on to look at facilitating engagement in specific activities of daily living.

■ **Optimizing activities**

This section focuses on the everyday activities that people with HD may find problematic and makes suggestions of ways to compensate for the skill deficits.

■ **Supporting participation**

This section concentrates on the wider skills of community living, social skills, roles and relationships which may be affected as the disease progresses. It identifies the occupational therapists role in supporting and educating people with HD and their carers.

■ **End of life care**

The final section identifies ways of planning for and managing end of life care building on the work published by the NHS National End of Life Care Programme [101].

An example from the guideline text, Part 2 (optimizing activities)

■ **Domestic skills**

Performance of domestic tasks such as meal preparation, shopping and housework are affected during the mid-to-late stages of HD. Cognitive changes relating to planning, organization and decision-making impact on the ability to manage finances and running a household. However, these tasks can be a central role within the family for some people with HD and important for them to maintain for continued self-esteem. Consideration should be given to modifying tasks for those people who wish to continue this role. For example, buying pre-prepared meals or pre-prepared vegetables, shopping online or employing a cleaner.

Declining cognitive skills and a reluctance to request assistance can result in some people

neglecting their property and failing to pay bills. If an individual with HD does not have a friend or family member who calls and reports the problem the neglect continues to increase. The person may not be able to plan, organize or initiate tasks such as cleaning, checking the dates on food or organizing household repairs. In extreme circumstances the individual can end up homeless. Other complications are dealing with bailiffs, repossession orders and finance companies. In recent years there has been much work in the UK around the implementation of the Mental Capacity Act 2005 and the safeguarding of vulnerable adults in healthcare trusts and local authorities. Gunstone (2003) studied the perceptions and experiences of mental health workers who assess and manage severe self-neglect. The findings suggest a number of 'grey areas' including a lack of definition of severe self-neglect and desensitising of mental health workers to neglect.

Where there is self-neglect, neglect of property or safeguarding issues the occupational therapist should work closely with the social worker, consultant, family and any other relevant professionals. The individual's mental capacity to decide how and when to care for themselves and their property should be assessed as well as their ability to carry out activities of daily living. If the individual lacks capacity a decision needs to be made which is the least restrictive and in their best interests (Mental Capacity Act 2005, Deprivation of Liberty Safeguards 2009 [102]). A short summary of recommendations for OT's is given in Box 1.

Conclusions

The guideline is currently being reviewed and updated following a peer review at the UK College of Occupational Therapy (COT) Conference 2011. The authors are also attempting to insure that the guidelines meet NICE evidence accreditation criteria and the COT Practice Guidelines Development criteria (COT 2011). Once the guidelines have been updated following peer review they will be submitted to the Council of Occupational Therapists in European Countries (COTEC) for endorsement.

A shortened version of the guidelines will be incorporated into a multidisciplinary handbook, which is currently being developed by the Standards of Care group. This will include guidelines from the speech and language therapists' group, dietitians' group, dentists' groups and physiotherapists' groups.

Box 1. Example of guidance for occupational therapists.

For occupational therapists aiming to promote domestic skills and abilities with people with Huntington's disease, it is recommended that:

- Small items of equipment should be assessed for and provided without delay, for example:
  - Non-slip mats may ease jar opening and prevent plates slipping
  - Wire-mesh baskets may help when draining vegetables
  - Trolley may be appropriate to assist with transferring objects
- Consideration should be given to breaking down domestic tasks into component actions to allow successful participation in some aspects of the activity.
- Consideration should be given to introducing convenience foods and internet shopping where appropriate and support to plan shopping lists.
- Carrying a meal or drink from the kitchen to the living room can be difficult to co-ordinate and increase the risk of falls. Where possible it can help to have a table and chair in the kitchen to eat and drink at. Some people manage to use a trolley. The metal type with larger wheels is preferable as it is sturdier and the larger wheels go over threshold strips more easily.
- Consideration should be given to the use of a microwave rather than a conventional cooker. If using a conventional cooker, timers can be useful to remind the person to return to the task.
- Consider reorganising food cupboards and freezer space and labeling drawers and cupboards can help people to find the items needed. Workspaces should be free of clutter and unnecessary items.
- Smoke alarms should be fitted at strategic points within the home. The local fire service will usually assist with a fire safety assessment.
- Occupational therapists should explore the need for assistance with or delegation of some or all of the household tasks such as ironing, housework, household maintenance, and management of paperwork/finances. This may involve a referral to local health and social care teams for a care package or involvement of the local authority appointee where finances are concerned.

Consensus statement – Standards of Care Group 2010.

The full guideline will be available to download from the EHDN website and it is hoped that it will also be available for download on the COT website and COTEC website.

The process of researching and writing the guidelines has highlighted the need for more high-quality research into occupational therapy and HD. Consequently, the Neuropsychiatry team in Birmingham has recently employed a research occupational therapist to investigate the validity of the Assessment of Motor and Process Skills (AMPS) [19] with people who have HD. It is hoped that this will provide evidence for the use of occupational therapy assessment in identifying specific skill deficits in people with HD and that more research into occupational therapy will develop across Europe.

Once the guidelines have been published and disseminated an evaluation will be planned for 3–5 years in accordance with the COT Practice Guidelines Development Manual.

Acknowledgements

The authors would like to acknowledge the members of EHDN Standards of Care Occupational Therapist Working Group and Gabriele Stautner for her work on the Standards of Care Diagram.

Financial & competing interests disclosure

The EHDN had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript. The authors have no other relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript apart from those disclosed.

No writing assistance was utilized in the production of this manuscript.

References

1 Naarding P, Janzing JGE, Eling P, Van der Werf S, Kremer B. Apathy is not depression in Huntington's disease. *J. Neuropsychiatry Clin. Neurosci.* 21, 266–270 (2009).

2 Quarrell O. *Huntington's Disease – The Facts*. Oxford University Press, Oxford, UK (1999).

3 Dickie V. What is occupation? In: *Willard and Spackman's Occupational Therapy (11th Edition)*. Blesedell Crepeau E, Cohn ES, Boyt Schell BA (Eds). Lippincott Williams & Wilkins, PA, USA (2009).

4 Hocking C. Contribution of occupation to health and well-being. In: *Willard and Spackman's Occupational Therapy (11th Edition)*. Blesedell Crepeau E, Cohn ES, Boyt Schell BA (Eds). Lippincott Williams & Wilkins, PA, USA (2009).

5 College of Occupational Therapy. *College of Occupational Therapists' Curriculum Guidance for Pre-Registration.* COT, London, UK (2009).

6 Aubeeluck A. A holistic and multidisciplinary approach to Huntington's disease *Management. Int. J. Ther. Rehabil.* 16(7), 360–361 (2009).

7 Scottish Intercollegiate Guidelines Network. *SIGN 50: A Guideline Developer's Handbook.* Edinburgh, UK (2008).

8 Leng TR, Woodward MJ, Stokes MJ, Swan AV, Wareing L-A, Baker R. Effects of multisensory stimulation in people with Huntington's disease: a randomized controlled pilot study. *Clin. Rehabil.* 17, 30–41 (2003).

9 Bilney B, Morris ME, Perry A. Effectiveness of physiotherapy, occupational therapy, and speech pathology for people with Huntington's disease: a systematic review. *Neurorehabil. Neural Repair* 17(1), 12–24 (2003).

10 Zinzi P, Salmaso D, De Grandis R *et al.* Effects of an intensive rehabilitation programme on patients with Huntington's disease: a pilot study. *Clin. Rehabil.* 21(7), 603–613 (2007).

11 Mason J, Andrews K, Wilson E. Late stage Huntington's disease: effect of treating specific disabilities. *Br. J. Occup. Ther.* 54(1), 4–8 (1991).

12 Blacker D, Broadhurst L, Teixeira L. The role of occupational therapy in leisure adaptation with complex neurological disability: a discussion using two case study examples. *Neurorehabilitation* 23, 313–319 (2008).

13 Fenech A, Baker M. Casual leisure and the sensory diet: a concept for improving the quality of life in neuropalliative conditions. *Neurorehabilitation* 23, 368–376 (2008).

14 Higgins DS. Huntington's disease. *Curr. Treat. Options Neurol.* 8, 236–244 (2006).

15 Myers C. The many faces of Huntington's disease part II: occupational therapy's role in improving quality of life. *Adv. Occup. Ther. Pract.* 4, 32–34 (2007).

16 Aubeeluck A. Management and therapies for HD-related dementia. *Br. J. Healthcare Manag.* 15(4), 11–16 (2009).

17 National End of Life Care Programme. *End of Life Care: The Route to Success in End of Life Care – Achieving Quality for Occupational Therapy.* (2011).

18 Gunstone S. Risk assessment and management of patients whom self-neglect: a 'grey area' for mental health workers. *J. Psychiatr. Ment. Health Nurs.* 10(3), 287–296 (2003).

19 Fisher A. *Assessment of Motor and Process Skills (Volume 2, User Manual)*. 3 Star Press Inc. (2010).

■ Websites

101 The National End of Life Care Programme. www.endoflifecareforadults.nhs.uk

102 Department of Health. The Mental Capacity Act Deprivation of Liberty safeguards. http://www.dh.gov.uk/en/SocialCare/Deliveringsocialcare/MentalCapacity/MentalCapacityActDeprivationofLibertySafeguards/index.htm

103 Department for Constitutional Affairs. Mental Capacity Act (2005) Code of Practice. (2007). http://dca.gov.uk/menincap/legis.htm#code of practice

104 Mental Capacity Act 2005: deprivation of liberty safeguard (2009). www.publicguardian.gov.uk

Contributing members

- **UK**
  - Clare Cook
  - Anne Wagstaff
  - Kirsty Page
  - Daniela Rae
  - Eleanor Winning,
  - Louise Oakley
  - Stella Cannon
  - Adrienne Scott
  - Sheila Simpson
- **Sweden**
  - Jenny Werner
  - Gunilla Croede Widsell
- **USA**
  - Katie Moser
- **Czech Republic**
  - Pavla Šašinková
  - Jirí Hruda
- **Italy**
  - Paola Zinzi
- **Portugal**
  - Helena Soares

Table 2. Summary of evidence for occupational therapy in Huntington's disease.

Evidence level	Studies
1++	**High quality meta-analyses, systematic reviews of RCTs or RCTs with a very low risk of bias.** No articles found
1+	**Well-conducted meta-analyses, systematic reviews or RCTs with a low risk of bias.** No articles found
1-	**Meta-analyses, systematic reviews, or RCTs with a high risk of bias.** ▪ Leng TR, Woodward MJ, Stokes MJ, Swan AV, Wareing LA, Baker R. Effects of multisensory stimulation in people with Huntington's disease: a randomized controlled pilot study. *Clin. Rehabil.* 17, 30–41 (2003). This was a small randomized control 2 group design involving 12 people with mid-to-late stage Huntington's disease. The treatment group experienced twice weekly 30-min sessions in a multisensory environment using visual, tactile, auditory, olfactory stimulation. The control group experienced relaxation, music and being read to. Measures of behavior and mood were performed pre- and post-session. Physiological assessments (blood pressure, heart rate and respiratory rate), behavior measures (Rehabilitation Evaluation – Hall and Baker and Behaviour and Mood disorder Disturbance Scale) and motor assessment measure (dyskinesia section of the St Hans Rating Scale) were performed during the intervention period. No significant difference was found between the treatment and control group on main outcome measures. The treatment group experienced significant within session effects, i.e., changes in stimulation & mood levels, but the effect wasn't sustained. As sessions increased a cumulative effect was seen in stimulation level and mood, suggesting a leisure, but not therapeutic, effect.
2++	**High-quality systematic review of case–control or cohort studies.** ▪ Bilney B, Morris ME, Perry A. Effectiveness of physiotherapy, occupational therapy and speech pathology for people with Huntington's disease: a systematic review. *Neurorehabil. Neural Repair* 17(1) 12–24 (2003). This systematic review searched English published electronic databases including; CINAHL 1982–2001, Embase 1984–2001, Medline 1966–2001, Cochrane 2001, Allied and Complementary Medicine 1985–2001 and PEDro database for physiotherapy trials 2001. Interventions were included if they were provided for impairments of movement, cognition or emotional status and aimed to improve the performance of activities or participation in society. Articles methodological quality was assessed and articles were graded for study type using a hierarchy of levels of evidence. Expert opinion was not included in the data analysis. The search failed to find any studies ranked as level 1, 2 or 3 evidence. Three articles were found for occupational therapy in Huntington's disease. Two were of observational single case design. Mason *et al.* (1991) found no gain in function, but concluded occupational therapy may of prevented further deterioration. The Di Scipio & Hannesson study (1971) was characterized by lack of objective valid reliable outcome measures. The review concluded there was insufficient evidence to draw treatment recommendations.
2+	**Well-conducted case–control or cohort studies with a low risk of confounding or bias and a high probability that the relationship is causal.** No articles found
2-	**Case–control or cohort studies with a high risk of confounding or bias and a significant risk that the relationship is not causal.** ▪ Zinzi P, Salmaso D, De Grandis R *et al.* Effects of an intensive rehabilitation programme on patients with Huntington's disease: a pilot study. *Clin. Rehabil.* 21(7), 603–13 (2007). This was a pilot study of an inpatient rehabilitation program, using a within subjects design. Forty patients of early- mid stages as per Unified Huntington's Disease Rating Scale (UHDRS) Total Functional Capacity (TFC) section were included and had CAG repeat of 40–54. Each had an individualized treatment program including; respiratory exercises, speech therapy, physiotherapy, occupational therapy and cognitive rehabilitation. Three weeks of intensive treatment was repeated up to three-times a year. The occupational therapy aimed to facilitate learning new strategies to perform tasks by stimulating memory, planning strategies and prolonging concentration. Occupational therapy was also involved in transfers, promoting safety in the environment and autonomy in eating, personal hygiene and dressing. The Zung Depression Scale, Mini-Mental State Examination, Barthel Index were completed before each admission period. The Tinetti Scale and Physical Performance Test (PPT) were completed on admission and on discharge. Each 3-week period of treatment resulted in highly significant ($p < 0.001$) improvements of motor performance and functional performance. No carry over effect from one admission to the next was apparent, but at the same time no motor decline and no functional decline was detected over 2 years. The authors conclude that patients maintained a constant level of function, motor and cognitive performance. However, it wasn't possible to identify the effectiveness of the individualized therapies from the study.

Table 2. Summary of evidence for occupational therapy in Huntington's disease.

Evidence level	Studies
3	**Non-analytic studies, e.g., case reports, case series.** ▪ Mason J, Andrews K, Wilson E. Late stage Huntington's disease: effect of treating specific disabilities. *Br. J. Occup. Ther.* 54(1), 4–8 (1991). A multiple baseline single-case experimental design involving four patients on a specialist Huntington's disease unit, and patients were deemed to be in the late stages. All were dependent for daily care but had considered potential to assist with some activities of daily living. Patients were randomly allocated to four Activities of Daily Living (ADL). Two were treatment ADL, two ADL acted as a control. A baseline observation period of 8 weeks, was followed by 16 weeks ADL intervention and assessment undertaken at 2 weekly intervals. 8-week follow-up assessment of performance in all four ADL. No consistent change was found in the treated ADL conditions. One patients abilities fluctuated. However, only one patient's abilities deteriorated. Concluded a possible generalized effect of occupational therapy in preventing deterioration.
4	**Expert opinion.** ▪ Blacker D, Broadhurst L, Teixeira L. The role of occupational therapy in leisure adaptation with complex neurological disability: a discussion using two case study examples. *Neurorehabilitation* 23, 313–319 (2008). The paper describes one case study of a patient with mid-stage Huntington's disease on an inpatient specialist Huntington's disease unit. The clinical features affecting function were generalized chorea affecting upper/lower limbs, fatigue, and dysarthria. The article focuses on facilitating client centered creative leisure activity. Aspects of occupational therapy involved stabilization of posture, adaptation of environment and the task and employment of low tech equipment. ▪ Fenech A, Baker M. Casual leisure and the sensory diet: a concept for improving the quality of life in neuropalliative conditions. *Neurorehabilitation* 23, 369–376 (2008). Descriptive case study of one patient with Huntington's disease with severe cognitive dysfunction. An individualized sensory diet programs encompassing all seven senses and based on detailed sensory profile is described. The patient was observed and reported to feel satisfied with leisure choices. It concludes using a sensory diet as a guide to plan casual leisure opportunities may provide way to engage patients with severe cognitive function and broaden sensory leisure experience. ▪ Aubeeluck A. Management and therapies for HD-related dementia. *Br. J. Healthcare Manag.* 15(4), 11–16 (2009). Opinion that a multidisciplinary approach optimizes effectiveness of care for the patient. Acknowledgement that occupational therapy can help with progressive physical disabilities and home adjustments. ▪ Higgins DS. Huntington's disease. *Curr. Treatment Options Neurol.* 8, 236–244 (2006). States that the potential of rehabilitation is often overlooked in symptom management. Acknowledgement that wheelchair assessment, workplace modification, driving assessments, home evaluation for safety and functional needs play a role in disease management. ▪ Aubeeluck A. A holistic and multidisciplinary approach to Huntington's disease management. *Int. J. Ther. Rehabil.* 16(7), 360–361 (2009). The article's emphasis is that Huntington's disease can be managed by focusing on management and therapy in maintaining function and reducing the effects of the disease. Quality of life for the patient can be improved with 'the implementation of an individual care-plan, based on a full assessment of the patient in the context of their disease state, their family and social environment'. Input from 'Occupational therapy and physiotherapy to help with progressive physical disabilities and home adjustments. A multidisciplinary approach is needed to manage the disease. A clear understanding of these services and 'communication between professionals and with the patient and their family is key'. ▪ Myers C. The many faces of Huntington's disease. Part II: occupational therapy's role in improving quality of life. *Adv. Occup. Ther. Practitioners* 4, 32–34 (2007). Myers acknowledges that the different stage of disease progression will change the emphasis of occupational therapy intervention. An example of occupational therapy interventions for early middle and late stages of the disease is described.