

# Understanding the effects of HD; supporting healthcare professionals

The effects of HD are wide-ranging and change how people think, feel, communicate, move, swallow and eat.



## Cognitive symptoms

Cognitive symptoms can affect the way people think, plan and interact and may be less obvious in early stages. They can often be confused with other conditions, or simply attributed to forgetfulness, laziness or lack of awareness. As the disease progresses the symptoms become more pronounced and disabling, and include:

- a lack of insight and initiation
- slower processing times
- a need for routine
- difficulty planning ahead and multi-tasking
- poor memory and concentration
- repetition
- lack of initiation.

## Physical symptoms

Physical symptoms including voluntary and involuntary movements can be obvious. However, there are many other symptoms including impaired gross motor control and muscle rigidity that require specialist input and care. As a consequence people may experience a range of difficulties, including:

- communication
- swallowing (Dysphagia) and nutritional intake
- weakness in facial and body muscle tone
- muscle deterioration in the throat
- lowered immune system
- incontinence.

## Emotional & psychological symptoms

Emotional symptoms include mood and behavioural changes which reflect and/or affect how the person feels. These can be considered an understandable response to the prospect and diagnosis of HD. As the condition progresses and abilities deteriorate, mood and behaviour can be impacted further. Behaviour should be seen as 'communicating a need', and other symptoms include:

- apathy
- depression
- impulsivity
- communication challenges
- frustration
- social isolation
- irrational & disinhibited behaviour
- repetitive loss & bereavement.

## The importance of specialist care

Specialist care planning will optimise quality of life.



### Managing Cognitive Deficits:

- baseline assessments of cognitive function
- creating bespoke strategies for care
- planning the wrap-around specialist therapies and treatment
- occupational therapy to support daily living
- formulation-guided interventions
- graded access to community
- assessment of personal safety awareness
- guidelines for continuing support as ability decreases
- expert medication management



### Managing Physical and Motor Deficits:

- physiotherapy
- speech and language therapies
- OT focus on movement, mobility, posture
- management of dysphagia through individual dietary assessments
- dysarthria therapy to support speech and communication
- access to complex medical investigations such as videofluoroscopy or PEG fitting
- review of equipment and seating, with access to specialist equipment and assistive technology
- involvement of specialists such as GP and podiatry services



### Neuropsychiatry and Neuropsychology:

- recognising, assessing and managing the HD symptoms
- tailoring nursing and specialist care to each individual
- creating a timetable of activities / outings to support treatment
- supporting emotional needs as the disease progresses
- 'Life story' work to truly understand the person's likes and dislikes
- mindfulness meditation
- emotional management guidelines for patients and staff
- adjustment and commitment therapy
- enhancing opportunities for family visits
- supporting interpersonal skills / relationships

## What can we do to help?

- get to know the person
- validate their thoughts and feelings
- talk to them and involve them
- treat people as individuals
- understand their background, likes and dislikes
- be warm, positive and enthusiastic
- always explain what you are doing and why
- speak in a soft, gentle tone and in a genuine manner
- provide structure but be flexible
- do one thing at a time and give people time to process and respond to information
- do not repeat or re-phrase before they respond
- anticipate their 'wants' in order to minimise potential frustrations
- understand that they are likely to need increasing levels of support, but allow them to work within their independence

Remember that people with HD have difficulty controlling their impulses because of changes in the brain, not because they are being deliberately thoughtless, uncaring, selfish, impatient or aggressive.

## Getting in touch



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