



**St Andrew's**  
HEALTHCARE

# Huntington's disease:

A quick reference guide



*Transforming lives together*

# About the Huntington's Disease Association (HDA)

The HDA is a national charity, working to improve the lives of people with HD, and raise awareness among the general public and allied health and social care professionals.

Their award winning Advisory Service is vital in providing the best package of support, offering care to the carers whilst playing a pivotal role in keeping families together.

The helpline team offers a confidential service supporting anyone affected by HD. To speak with a member of the team please call:

**0151 331 5444** or visit the website at **[hda.org.uk](http://hda.org.uk)**



# Understanding the effects of HD; supporting healthcare professionals

The effects of HD are wide-ranging and change how people think, feel, speak, move, swallow and eat. It presents typically at a time in life when most people may be establishing families and careers yet those with the disease are suddenly faced with the emotional impact of impairment and living with a disease for which there is currently no cure.

These effects can be broadly grouped in to three key elements of change, all of which affect how people with HD behave and influence how we should consider their needs:

**The three elements of HD deficit can be summarised as:**



## Cognitive

**The processes that manage how people think, plan and interact**

The cognitive disorders may be less obvious in early stages of the disease and can often be confused with other conditions, or simply attributed to forgetfulness, laziness or a general lack of awareness. As the disease progresses these become more pronounced and disabling.



## Emotional

**The mood and behavioural changes that affect /reflect how people feel**

Emotional and psychological symptoms develop as the disease progresses (and even before symptoms become evident) as people come to terms with the prospect and results of diagnosis. Living day to day with HD can wear individuals down as the debilitating effects of the disease directly impacts on mood and behaviour.



## Physical

**The motor functions, particularly those controlling movement and eating**

Physical symptoms of HD, including voluntary and involuntary movement, are perhaps the most obvious. However there are many other symptoms, from swallowing and speech difficulty to muscle rigidity, that require specialist input and care.

# 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.

# 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.



# 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.

# 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



## Neuropsychiatry and Neuropsychology:

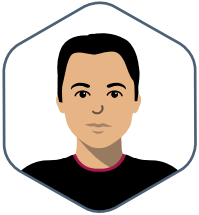
- recognising, assessing and managing the HD symptoms
- tailoring nursing and specialist care to each individual
- creating a timetable of activities / outings to support treatment
- supporting emotional needs as the disease progresses
- 'Life story' work to truly understand the person's likes and dislikes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



## Managing Physical / Motor Deficits:

- physiotherapy
- speech and language therapies
- 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
- access to specialist equipment and assistive technology
- involvement of community specialists such as GP and podiatry services
- OT focus on movement, mobility and posture

# Because I have HD...



Hi,

*I have Huntington's disease (HD) which is a brain disease that affects how I think, feel and act, so I thought I would share a few things that might help you to help me.*

## To summarise, people with HD:

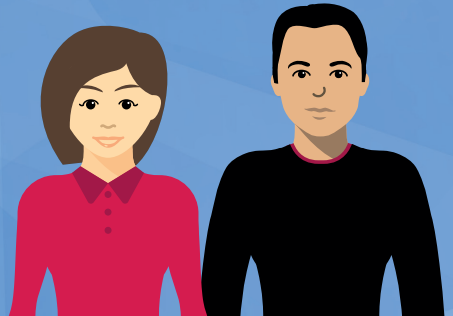
- like their own **routine**
- can only manage to concentrate and do **one thing at a time**
- need their attention to be gained before being spoken to
- need to be given sufficient **time** to process and respond to information
- require others to **actively listen** to what they say as speech becomes very effortful as HD progresses
- can get 'stuck' on thinking about particular things, meaning that they may repeat words or phrases several times
- might be **worried** about the future
- **remember their lives before HD**, they were once more independent, lived a more 'typical' life-style and made their own decisions. They don't necessarily want to change more than they have to. They still have their likes, dislikes and wishes and still enjoy things and have fun.



# 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.



## Useful links:

- Huntington's Disease Association (HDA), England & Wales, **0151 331 5444**, email [info@hda.org.uk](mailto:info@hda.org.uk), website [www.hda.org.uk](http://www.hda.org.uk)
- Scottish Huntington's Association (SHA), **0141 848 0308**, email [sha-admin@hdscotland.org](mailto:sha-admin@hdscotland.org), website [www.hdscotland.org](http://www.hdscotland.org)
- European Huntington's Disease Network (EHDN), website [www.euro-hd.net](http://www.euro-hd.net)
- HDBuzz, website [www.en.hdbuzz.net](http://www.en.hdbuzz.net)
- The HD Lighthouse, website [www.hdlf.org](http://www.hdlf.org)
- NHS Choices, website [www.nhs.uk/conditions/huntingtons-disease](http://www.nhs.uk/conditions/huntingtons-disease)

## Getting in touch



For more information about our [HD service](#) or to make a referral:

**t:** 0800 434 6690

**e:** [enquiries@standrew.co.uk](mailto:enquiries@standrew.co.uk)

**w:** [standrewshealthcare.co.uk](http://standrewshealthcare.co.uk)

**Registered Charity Number** 1104951



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**Registered Charity Number** 296453

