Huntington’s disease:
A quick reference guide
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**
Because I have HD...

To summarise, people with HD:

- might be worried about the future
- remember their lives before HD, they were once more independent, lived a more ‘typical’ lifestyle 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.

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 into 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 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, specifically these 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.

Understanding the effects of HD; supporting healthcare professionals

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- European Huntington’s Disease Network (EHDN), website www.euro-hd.net
- HDBuzz, website www.en.hdbuzz.net
- The HD Lighthouse, website www.hdlf.org
- NHS Choices, website www.nhs.uk/conditions/huntingtons-disease

Registered Charity Number 1104951

For more information about our HD service or to make a referral:

t: 0800 434 6690
e: enquiries@standrew.co.uk
w: standrewshealthcare.co.uk

Registered Charity Number 296453

For more information about HD or to speak with a HDA adviser:

t: 0151 331 5444
e: info@hda.org.uk
w: hda.org.uk
The importance of specialist care
Specialist care planning will optimise quality of life.

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.

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 speech for family visits
- supporting interpersonal skills / relationships

Managing Physical / Motor deficits:
- physical therapy
- speech and language therapies
- management of dystonia through individual dietary assessments
- dysphonia 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

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.
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Specialist care planning will optimise quality of life.

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Managing Physical / Motor deficits:

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The importance of specialist care

Specialist care planning will optimise quality of life.
Because I have HD...

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
• 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’ lifestyle 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.

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.

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• Cognitive
• Emotional
• Physical
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.
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These effects can be broadly grouped into three key elements of change, all of which affect how people with HD behave and influence how we should consider their needs:

1. Understanding the effects of HD;
2. Supporting healthcare professionals;
3. Getting in touch.

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