Maximising function and quality of life for people with HD

Delivering holistic management of psychiatric, cognitive and motor deficits for people with Huntington’s disease

📍 St Andrew’s Northampton
Delivering person-centred care for people with Huntington’s disease

At St Andrew’s we have a deep understanding of the physical, emotional and psychological impact of living with Huntington’s disease (HD). Our specialist teams focus on maximising functional ability and quality of life, across a dedicated HD pathway from secure to locked environments.

For over 150 years we have supported patients with prominent neuropsychiatric or cognitive symptoms, in addition to their movement disorders. More recently we have developed pathways and therapies designed specifically for people with HD, to deliver person-centred care tailored to the needs of the individual, through all stages of the condition.

Our services at a glance:

We provide tailored pathways focusing on three core treatment components; neuropsychiatry, cognitive deficits and physical / motor deficits, including:

- in-patient service for adults aged 18+ at any stage of HD
- adapted environments and specialist equipment
- admission for full and comprehensive time-limited assessments
- highly specialised HD professionals form ward-based MDTs
- specialist input including dieticians, GP and podiatry

- ability to manage complex and challenging behaviour
- HD active care wards designed to maximise functional ability
- therapies and activities to enhance patient quality of life
- secure services for forensic admissions
- dedicated social workers to support placement transitions
- Harper HD unit voted ‘Ward of the Year’ 2014/15*

*St Andrew’s Healthcare awards
What is HD?

Huntington’s disease (HD) is a genetic neurological condition which affects the central nervous system and usually develops when individuals are in their thirties to fifties. In the UK in 2015 there are an estimated 8,000 people living with HD. When symptoms appear in individuals under the age of 20, the condition is known as Juvenile Onset HD, and this happens in about 10% of affected individuals.

HD is caused by a faulty gene on chromosome 4, which produces a protein called mutant Huntingtin. Each child with a parent with HD has a 50:50 chance of inheriting the condition and a test can be performed to determine whether the faulty gene is present. The presence of the mutant Huntingtin protein increases the rate of cell death in the brain, which in turn, affects physical and psychological functioning. Rates of deterioration vary among individuals.

Although psychiatric disorder is not an inevitable consequence of HD, the prevalence of psychiatric symptoms is significantly higher than in the general population, and must be considered.

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Description</th>
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<tbody>
<tr>
<td>38%</td>
<td>Clinically defined mood disorder estimated as high as 38%, with 22% meeting criteria for major depression*</td>
</tr>
<tr>
<td>45%</td>
<td>Irritability is present in approximately 45% of all patients**</td>
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<tr>
<td>22%</td>
<td>Aggression is present in an estimated 22% of patients*</td>
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<tr>
<td>11%</td>
<td>Up to 11% of HD patients demonstrate recognised psychotic symptoms*</td>
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<tr>
<td>x7</td>
<td>Suicide rates are 7-12 times higher than the general population*</td>
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<tr>
<td>4.8</td>
<td>Up to 4.8% of HD patients develop bipolar affective disorder*</td>
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*Psychiatric and behavioural manifestations of Huntington’s disease, Sameer Jauhar, Stuart Ritchie, Advances in Psychiatric Treatment Apr 2010, 16 (3) 168-175; DOI: 10.1192/apt.bp.107.005371


Understanding the effects of HD

Physical symptoms include ‘chorea’ or random, jerky movements, as well as impaired gross motor control and rigidity. People may experience problems with swallowing, speaking and nutritional intake as a consequence. Psychological problems can be even more debilitating and can include anxiety, depression, mood swings and aggression, impulsiveness including inappropriate or hypersexual behaviour, difficulties with attention and in rarer cases psychosis.

A relentlessly positive approach to working with extreme behaviour.

(Reinforce Appropriate, Implosion Disruptive)

RAIDing gives a relentlessly positive philosophy for working with extreme behaviour and is especially relevant to working in secure and semi-secure environments. RAIDing provides a positive approach to be proud of, developing appropriate ‘green’ behaviour so that it simply overwhelms the problem behaviours in question. Importantly though, RAIDing also tells you what to do when problem behaviour happens.

St Andrew’s was the first UK healthcare provider to achieve the RAID® Centre of Excellence Award from the Association of Psychological Therapies (APT), reflecting the quality of provision for HD patients within the neuropsychiatry service.

For more information on RAID® visit www.raid.co.uk
Understanding and meeting the specific needs of HD patients

Our approach recognises the unique behaviours and physical presentations that accompany the disease and helps us to take the optimal route to improving care.

HD symptoms can sometimes present in ways which are not immediately clear to the healthcare professional, and can also vary widely between individuals. Our specialists are expert in the management of the physical, emotional and thinking deficits that distinguish HD from other progressive neurological conditions, and understand the best way to support each patient.

Chloe’s story

On arrival at St Andrew’s Chloe, a 28-year-old with Huntington’s disease, was visibly overwhelmed and anxious at being in yet another hospital after a string of unsuccessful placements.

She presented with verbal and physical aggression and was at risk of self-harm, requiring enhanced nursing observations. She would refuse to engage with staff in her planned occupational therapies and routinely refused meals.

From an early point staff aimed to reduce Chloe’s frequent withdrawal into her own bedroom, and to understand the causes of escalating behaviour that would result in her slamming doors and throwing property. Getting to know Chloe was therefore a primary objective and staff worked with her to start building her ‘Life Story’ book – an on-going journal providing the opportunity for Chloe to reminisce about her past and for staff to gain a fuller understanding about her life, promoting the person-centred approach adopted by St Andrew’s.

Staff also incorporated the RAID® principles and agreed with Chloe a goal of being calm and motivated to engage in activities. This would start each day by encouraging and incentivising Chloe to rise from her bed and helping her to get ready. The multi-disciplinary team provided an activity timetable that promoted positive actions and gave Chloe a schedule to work towards. Key to helping her to achieve her goals was the use of distraction techniques to pre-empt disruptive behaviour, by using her Life Story to understand what she liked and disliked.

Changes in Chloe’s behaviour were measured through the Overt Aggression Scale – Modified for Neurorehabilitation (OAS-MNR). This showed that over the period of her admission her aggressive behaviours quickly reduced from more than 50 incidents per week down to less than 10. She was proud of her progression and staff recorded consistently high levels of RAID® ‘green’ behaviour. She would rise each day and eat meals without prompting, became far more talkative and would participate in therapy groups. Over time Chloe became more motivated to try new activities, including horse-riding, bowls and pet therapy and she showed high levels of wellbeing (recorded using tools developed by the Bradford Dementia Group).

St Andrew’s HD social worker and discharge team worked closely with Chloe’s local services team to ensure a smooth transition back to a community setting near to her family. By providing the new placement with a full care plan, and the insight gained by the MDT in to Chloe as a person, Chloe was able to quickly settle in to her new environment.

“Life story books are an on-going journal of a person’s life, which put the personal history, interests, likes and dislikes of our patients at the heart of their care. One advantage of using a life story book is that it helps aid communication and encourages interaction.”

Vincent Harding
Assistant Psychologist
The effects of HD are wide-ranging and change how people think, feel, speak, move, swallow, and eat. 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:

**Cognitive**
- The processes that manage how people think, plan and interact
  - creating bespoke strategies for care
  - planning the wrap-around specialist therapies and treatment
  - occupational therapy to support daily living
  - Formulation-guided interventions
  - graded access in to community
  - assessment of road safety awareness
  - guidelines for continuing support as ability decreases

**Emotional**
- The mood and behavioural changes that affect/reflect how people feel
  - creating a timetable of activities and outings to support treatment
  - supporting emotional needs through the progression of the disease
  - Life story work to truly understand the person’s likes and dislikes
  - Mindfulness meditation
  - emotional management guidelines for patients and staff
  - supporting interpersonal skills / relationships
  - baseline assessments of cognitive function

**Physical**
- The motor functions, particularly those controlling movement and eating
  - review of equipment and seating, with access to specialist equipment and assistive technology
  - involvement of community specialists such as GP and podiatry services
  - access to acute medical services and more complex medical investigations such as videofluoroscopy or PEG fitting

**Neuropsychiatry and Clinical Psychology**
- Supporting emotional and behavioural issues
  - recognising, assessing and managing the symptoms of HD
  - tailoring the nursing and specialist care to each individual
  - creating a timetable of activities and outings to support treatment
  - supporting emotional needs through the progression of the disease
  - “Expert medication management will alleviate symptoms of mental illness that frequently occur in HD alongside the movement disorder.”

**Occupational Therapy and Physiotherapy**
- Optimising health and quality of life
  - physiotherapy, speech and language therapies
  - management of dysphagia through individual dietary assessments and plans
  - dysarthria therapy to support speech and communication
  - occupational therapy to support daily living
  - physiotherapy focus on movement, mobility and posture

**The importance of specialist care**

The effects of HD are wide-ranging and change how people think, feel, speak, move, swallow, and eat. 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.
As the disease progresses the person may require increasing levels of care and input from a variety of specialist services. We consider these needs from the moment of admission.

Each patient is surrounded by a comprehensive group of in-patient and community specialists to ensure they receive the most appropriate, tailored care:

- Skilled medical care is provided by a Consultant Psychiatrist, GP service, Dentist, Pharmacist, Podiatrist, and our team of dedicated and experienced nursing staff. There are also links to the local Clinical Genetics department.
- Psychological support, including detailed continuous assessment and advice in relation to challenging behaviour and assessment of cognitive abilities, is provided by the Consultant Neuropsychologist.
- Our Speech and Language Therapist, Dietician and Dentist provide advice on swallowing, food and re-texturing, and are assisted by videofluoroscopy from the local radiology department.
- Occupational Therapists and Physiotherapists are key members of the team, and aim to maintain and maximise functional abilities and quality of life. They provide wheelchair, seating and mobility assessments and regular sessions both on the St Andrew’s site and in the community.
- Our HD Social Workers maintain vital links with families, encouraging participation in treatment plans where possible. Detailed assessment of communication needs and capacity issues as well as counselling where appropriate is also undertaken by the team.
Unique environments for unique needs

Our environments meet the unique physical and therapeutic needs of patients with HD and reflect our warm, positive and empathic approach.

We have created safe, comfortable, structured but flexible units for our patients, which can provide a homely environment to optimise independence, quality of life, respect and choice. We are also able to admit patients to secure facilities where appropriate.

Wide corridors, door-frames and wet-rooms ensure that therapy and living areas are fully accessible for those requiring disabled access. Spacious recreation areas and safe enclosed gardens allow patients the freedom to access facilities, while over 100 acres of landscaped gardens provide interesting venues to explore during family visits.

Specialist equipment such as CareFlex™ chairs allow patients to be mobile and provide safe transitions between areas, helping to prevent falls.

A variety of additional activities are available, with easy access to the local town centre on foot, or within a short bus / car ride. We also provide the following activities on-site;

- gymnasium
- swimming pool
- jacuzzi
- sheltered workshops
- library
- activity centre and cafés.

“...The risk of choking is very high, particularly as some people eat too fast and forget to chew. Find a quiet area for them to eat in, and always keep a close eye on them.”

Dietician

Food preparation and grading helps to prevent choking and dysphagia, while special moulds ensure presentation is always considered.
Our integrated HD care pathway

Our HD units are bright, spacious and offer accessible accommodation with fit-for-purpose furniture and equipment. Harper HD ward has recently enjoyed a refurbishment, with the expansion of the ward to include an orangery where patients can gather for recreational activities and events, and which opens on to the enclosed secure garden featuring a water-fountain.

**Rose Ward:** a 17-bed medium secure male unit within the neuropsychiatry pathway.

**Tallis Ward:** a 14-bed admission ward within the neuropsychiatry pathway, for highly challenging patients requiring stabilisation and assessment.

**Allitsen High Dependency HD Ward:** a 5-bed locked admission unit for males with challenging and complex behavioural and physical healthcare needs.

**Walton HD Ward:** a 14-bed admission ward for active complex males with significant but reducing risk, supporting daily living skills and maximising cognitive and physical function.

**Allitsen HD Ward:** a 9-bed ward focusing on neuro-palliation for males with deteriorating cognitive, behavioural and physical health, to optimise quality of life.

**Harper HD Ward:** an 11-bed ward focusing on neuro-palliation for females with deteriorating cognitive, behavioural and physical health to optimise quality of life.

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**Getting in touch**

For more information about our **HD services**

or to make a referral:

**t:** 0800 434 6690 (text relay calls welcome)

**e:** enquiries@standrew.co.uk

**w:** standrewshealthcare.co.uk/neuropsychiatry