



# Huntington's disease at Exemplar Health Care

*every day better*

Approximately  
**7,800**  
people in the UK  
are living with HD

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Huntington's disease is a complex illness that requires specialist knowledge to ensure people receive the right care. The HDA is working closely with Exemplar to improve skills and care to ensure those with the illness have the best quality of life possible.”

Cath Stanley – Chief Executive  
Huntington's Disease Association

Exemplar's nurse-led specialist teams effectively manage the symptoms of Huntington's disease to improve the lives of those living with the condition.

At Exemplar we strive to achieve the best possible outcomes for individuals through our caring and effective person-centred approach. Care plans are created and reviewed together with families and professionals, ensuring a person's changing support needs are met.

At Exemplar, people living with HD are supported to live a fulfilling life with regular social activities and hobbies. Our care home teams consider a person's concentration span and tendency to fatigue when planning meaningful activities which make a real difference to life. We focus on restoring people's choices wherever possible, ensuring those living with HD feel valued and happy.

From changes in mood, lack of drive and behaviours that challenge to difficulties with speech, swallowing and involuntary movements, our experienced nursing teams work to reduce the impact of a person's symptoms. Communication difficulties are overcome with support from community speech and language therapists, with assistive technologies and equipment for managing communication, safety and comfort, including communication aids, which are identified and put in place. Special care is given to food, with high calorie diets used effectively to prevent weight loss and modified diets developed to reduce the risks associated with swallowing.

## Management of complex behaviours

Our specialist teams work to understand why someone is demonstrating behaviours that challenge, and reduce their impact by addressing the triggers. In this way we:

- **reduce feelings of frustration by responding quickly to requests**
- **leave extra time for comprehension and completion of tasks**
- **encourage independence by offering assistance, without taking over**
- **avoid confrontation by distracting attention and using de-escalation techniques**
- **encourage choices and alternatives, and allow considered risk taking.**



## Supporting families

We understand that Huntington's disease has a major impact on families. Our open-door policy means friends and family are welcome to visit and be part of daily life. We also offer a supportive place for loved ones to talk over their concerns.

Exemplar's purpose-built homes are welcoming, caring environments.

All our homes and extended pathways of care have;

- **Personalised bedrooms with ensuite wet rooms**
- **Close links with HD consultants and community therapists**



## Innovating for better care

Some Exemplar homes bring together NHS specialist consultant neurologists, psychologists, GPs and Huntington's Disease Association experts at quarterly in-home HD clinics.

Hosting clinics at Exemplar homes avoids changes in routine and the frustration of long hospital waits. Service users benefit from expert consultant care in a familiar environment.

Extended pathways of care are available at several Exemplar homes. These individual houses and flats allow individuals to live independently while still accessing care and support when needed.

## Case study

Valerie came to Exemplar with very challenging behaviour and severe self-neglect. In addition to Huntington's disease, Valerie was severely underweight, had underlying mental health needs including agoraphobia and had isolated herself from friends and family.

Exemplar worked with funders to develop a care plan for Valerie, focussing on methods to manage her behaviour so personal care could be carried out. It was initially determined that Valerie was entering the end stage of her illness and would need end of life care.

Gradually we developed a therapeutic relationship with Valerie. It became understood that her agoraphobia was based on feelings of embarrassment about her appearance. Slowly, we introduced self-care activities and a breakthrough came when Valerie requested a shower, hair wash and blow dry. As Valerie progressed and

her health stabilised, she began eating meals with others, with a diet of food she could eat without help.

The team encouraged Valerie to expand her surroundings and she began spending time in the garden. Now happy with her appearance, it became clear that Valerie's fear of the outside world was due to fear of falling and embarrassment about her unsteady gait. One morning, Valerie agreed to visit another Exemplar home in a wheelchair. Now, Valerie enjoys 1:1 drives and local shopping trips with a member of the team.

Valerie's story demonstrates how an understanding of HD, appropriate interventions to decrease challenging behaviour and fulfilling activities can result in enormous improvements to a person's well being. Twelve years after Valerie came to Exemplar for end of life care, she lives in the same home enjoying a true quality of life.

## Placements with Exemplar



We carry out a comprehensive process to fully understand individual needs and identify support requirements

Funders will receive a full report of our assessment and costs for review

If a placement is agreed, we develop a care plan in conjunction with families, specialists and the individual, discuss goals and identify a named nurse and key worker

Throughout a placement, we hold regular reviews, and where appropriate, work to develop future pathways of care

**Make a referral or enquire about a placement**

**01709 565777**

**referrals@exemplarhc.com**

**www.exemplarhc.com**

