

SCHEDULE 2 – THE SERVICES

A. Service Specifications

Service Specification No.	11J/0207
Service	Huntington's Disease Association Annual Grant
Commissioner Lead	Long Term Conditions, Frailty and End of Life Clinical Delivery Group, Dorset CCG
Provider Lead	Funding and Liaison Officer - Statutory Authorities, Huntington's Disease Association
Period	1 April 2017 – 31 March 2020
Date of Review	December 2019

1. Population Needs

1.1 National/local context and evidence base

The National Service Framework (NSF) for Long Term Conditions (2005) states amongst its Quality Requirements that:

- 'People with neurological conditions can experience a wide range of complex physical, sensory, cognitive, psychological, emotional, behavioural and social difficulties, with a broad range of needs. An integrated approach to assessment of care and support needs and to the delivery of services is key to improving the quality of life of people with long-term neurological conditions.'
- 'People with long-term neurological conditions have improved health outcomes and a better quality of life when they are able to access prompt and ongoing advice and support from practitioners with dedicated neurological expertise, such as specialist nurses. This can cover: managing their medicines; management of specific symptoms; help to understand their condition and its current and future management. Specialist advice and treatment can be cost neutral and may reduce admissions and length of stay and improve well-being.'

The number of people in the Dorset total population of 766,000 is very low. The prevalence of Huntington's Disease in the South West of England is 13.5 per 1,000 which equates to around 675 people (information is taken from the South West Alliance of Neurological Organisations Directory July 2009).

A total of **463** people with Huntington's Disease (HD), at risk of HD, their families and their carers were supported by the Specialist Huntington's Disease Advisor in Dorset from April – October 2015 including Improved quality of life for **71** individuals with the symptoms of Huntington's Disease and **44** Carers.

2. Outcomes

2.1 NHS Outcomes Framework Domains & Indicators

Domain 1	Preventing people from dying prematurely	
Domain 2	Enhancing quality of life for people with long-term conditions	✓
Domain 3	Helping people to recover from episodes of ill-health or following injury	
Domain 4	Ensuring people have a positive experience of care	
Domain 5	Treating and caring for people in safe environment and protecting them from avoidable harm	

3. Scope

3.1 Aims and objectives of service

- To provide a highly Specialist Huntington's Disease Advisor (SHDA) who is available to patients according to need
- To provide help and support for patients in NHS Dorset CCG with Huntington's Disease
- To provide advice and support for families

3.2 Service description/care pathway

The role of the SHDA can vary from client to client but in essence centres on advice, prevention, palliative support to the service user and professionals and bereavement support to families.

- Provide specialist information and training to health, social care, agency and nursing home staff on different aspects of Huntington's Disease e.g. managing challenging behaviour
- Facilitate specialist information and training to healthcare professionals on End of Life Care, Power of Attorney, Advanced Care Planning
- Supports service users and their families and professionals in delivering End of Life Care
- Attendance at Community Neurology Steering Group.
- Close working with the Dorset Community Neurology Team
- Attendance at the Huntington's Disease clinic and multidisciplinary team meetings
- Support of the Dorset Carers Group
- Support of the Dorset Branch of HDA with meetings across the county
- Personal introduction of the service to GPs on referral of their first patient.
- Distribution of the Guide to Huntington's disease for General Practitioners and Primary Health Care Teams to every practice in Dorset.
- Gather service user feedback
- Attend management protection of public meetings

3.3 Population Covered

The number of people in the Dorset total population of 766,000 is very low. The prevalence of Huntington's Disease in the South West of England is 13.5 per 1,000 which equates to around 675 people (information is taken from the South West Alliance of Neurological Organisations Directory July 2009).

3.4 Any acceptance and exclusion criteria.

The patient must be registered with an NHS Dorset Clinical Commissioning Group GP.

3.5 Interdependence with other services/providers

The SHDA works closely with the Dorset Community Neurology Team and is a member of the Community Neurology Steering Group.

The SHDA works alongside the specialist nurse and consultant at the Huntington's Disease clinic and multidisciplinary team meetings

The SHDA works closely with the Dorset Huntington's Disease Branch

4. Applicable Service Standards

4.1 Applicable local standards

The service should work towards the following NHS Dorset Clinical Commissioning Group strategic principles:

- Services designed around patients
- Care closer to home

5. Applicable quality requirements and CQUIN goals

The Provider's premises are located at:

This is an outreach post. The SHDA will liaise with clients in their place of choice; at home, by email, telephone or personal messaging.

The Provider base is;

Huntington's Disease Association
Suite 24, Liverpool Science Park
Innovation Centre 1
131 Mount Pleasant
Liverpool, L3 5TF
Tel: 0151 331 5444
E-mail: info@hda.org.uk