

Southern Derbyshire Huntington's Disease Service

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Background & Service Development

Huntington's disease (HD) is an inherited condition causing **cognitive**, **behavioural** and **physical** impairments. Each offspring of someone with the gene has a 50% chance of developing symptoms.

Our service was set up in 1995, at a time when the Regional Clinical Genetics provided limited follow-up support for some families and psychiatric input was limited to crisis response.

Service Description We serve families resident in the Derby area (pop. approx 600,000). A Consultant in Rehabilitation Medicine and a Huntington's Disease Association Regional Care Adviser support around 30 individuals and families at any one time through clinics and outreach to homes and nursing homes.

At-risk individuals seeking pre-symptomatic DNA testing attend pre-counselling sessions with the Clinical Genetics Nurse Counsellor and the Consultant. This enables flexible support to be provided from the earliest possible stage.

The Southcroft team, providing intensive community support to people with complex disabilities, has played a vital role in enabling HD clients to remain in at home.

Innovation Our service provides a degree of continuity which may be unique in the UK. A key aspect of the service is a system of regular communication with social services teams.

People affected by HD typically seek ^{1,2,3,4} :

- **Continuity** of support for those at risk as well as for those affected
- Maximal **autonomy** and participation
- Assistance with mobility, and management of **physical** impairments
- Ability to live in a familiar **community** as long as possible
- **Preventive** strategies (eg fire risk due to smoking; prevention of malnutrition)
- **Avoidance** of acute psychiatric admissions
- **Family** support



Maintaining a package of support for the family is a complex, unpredictable, multidisciplinary task.

We are grateful to the Huntington's Disease Association for supporting this service

1. Sulaiman S Learning to Live with Huntington's Disease. Jessica Kingsley, 2007
2. Ward CD, Dennis, NR. Huntington's disease. In Greenwood, Barnes, McMillan, Ward (Eds) Handbook of Neurological Rehabilitation Hove East Sussex and New York. Psychology Press 2003 Chap 40
3. Marriott H The Selfish Pig's Guide to Caring. Polperro Heritage Press, 2003
4. National Service Framework for Long-Term Conditions (2005)
5. Ward CD, Phillips MF, Smith S, Moran M. Multidisciplinary Approaches in Progressive Neurological Disease: Can we do better? Neurology in Practice J Neurol Neurosurg and Psychiatry Suppl 2003; 74: 8iv-12iv