

# Huntington's Disease Association

## General Background Information

**The core activity of the HDA is our network of 24 Regional Care Advisors (RCA's)** trained staff who offer specialist care support, advice and information to families affected, directly or indirectly, by HD. The Regional Care Advisory Service is available five days a week, 52 weeks a year, with a 24-hour telephone answer service and weekend cover by arrangement.

### **Need for the Project**

Huntington's Disease is a progressively degenerative illness of the central nervous system which causes dementia and severe physical incapacity. It is the third most common hereditary neurological disease in the UK and affects more people than Motor Neurone Disease.

Juvenile Huntington's Disease (JHD) is the diagnosis given to anyone who develops symptoms of Huntington's Disease before they are 20 years old, which accounts for about 5% of all people with HD. This is a rare condition, which leaves the young people, their families and the professionals involved in their care, feeling extremely isolated.

**It is a complex disease and needs careful management of the condition which can only be provided by someone with experience of the disease.**

### **Beneficiaries of our service**

We support both men and women predominantly between the ages of 30 and 50 years who are affected by Huntington's Disease, with a prognosis of 15-20 years. Those supported include people with:

**Physical Disabilities and Sensory Impairment:** Most HD sufferers have a range of physical symptoms, including involuntary movements (chorea), loss of voluntary movements, difficulties in swallowing and speech and problems with balance and walking. With good advice and support families can better manage these symptoms.

**Learning Disabilities:** Cognitive flexibility is impaired by the condition. i.e. not being able to concentrate on more than one task and to adapt plans. The patient can become overloaded with tasks or have difficulty adapting to changing situations and respond with what seems to be unreasonable behaviour or an outburst of temper.

**Mental Health Problems:** Symptomatic HD sufferers often exhibit a range of problems, including severe depression, frustration, mood swings, psychiatric illnesses and cognitive impairment.

### **Other direct beneficiaries of our service include:**

**Carers:** They are usually spouses or relatives (many are children) who often provide personal care, such as help with dressing, feeding, and going to the toilet.

**Children at risk:** As well as providing direct care to children with Juvenile Huntington's Disease, we also safeguard non-symptomatic children, who may be the main carer, from both the emotional and physical harm that is often inflicted by an affected parent with progressive HD.

**Health and Social Care Professionals.** We provide a range of specialist training, advice and consultation to allied professionals working with symptomatic sufferers, to assist them in delivering the appropriate level of care.

**To demonstrate the value of the RCA service, the following comments were taken from a recent Service User questionnaire:**

*“From the first time and up to the present [our RCA] has been very helpful and always genuinely polite and caring towards my family.”*

*“Always felt supported and understood. Look forward to more frequent visits if possible!”*

*“The help we received was faultless and the RCA was most helpful and without her we would never have known as much about HD as we do now.”*

*“Nothing is too much trouble for her.”*

*“Very kind, considerate and helpful. Extremely prompt in communicating with care service following difficulties.”*

*“I was impressed by her knowledge of HD.”*

Demand for the HDA Regional Care Advisory Service in England and Wales is growing and the service has now reached full capacity, resulting in a pressing need to create yet more full-time posts. However, before we can even consider the creation of new posts, **existing regional posts must be fully funded so that support to current service users is not compromised.**