Huntington’s Disease Charity Reports Sharp Increase in Referrals

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A charity that helps families affected by Huntington's disease reports a sharp increase in the number of referrals it receives from Social Services professionals and GPs.

Referrals to the Huntington's Disease Association (HDA), the only charity in England and Wales that serves the needs of people with Huntington's disease (HD), rose 51% in 2014 on the previous year. Chief Executive Cath Stanley attributes this to more GPs and social workers being aware of the work of the HDA's Specialist HD Advisory Service and find it invaluable in improving the quality of care for people with HD.

"Our specialist advisers have a unique knowledge of Huntington's disease that health and social care professionals find extremely helpful. They also know the families very well and can give a better perspective on the home life of the individuals and their carers, thus improving the quality and delivery of care," she said.

Huntington's disease is an incurable, genetic disorder of the central nervous system that devastates generations of a family. Each child of an affected parent has a 50% risk of inheriting the condition. The age of onset is typically between 30 and 50, though it can be as young as 2, and those affected will usually live another 10-25 years. As the disease progresses, concentration and short-term memory diminish and involuntary movements of the head, trunk and limbs increase. Eventually, the person is unable to walk, speak, swallow or care for him or herself. Although there now is a blood test to determine if an individual has inherited the disorder, there is no cure.

The HDA currently has 23 specialist HD advisers (SHDAs) throughout England and Wales, including one who speaks Welsh, and helps nearly 16,000 people. 4240 adults already display symptoms with another 5,672 adults and children at risk. It also has the only juvenile Huntington's disease adviser in the world.

"We want to help as many people as we can, but to do that we will have to increase the number of our specialist advisers. This little-known but complex disease requires specialist knowledge. Carers in particular need to know they have someone who understands what they're going through and can support them emotionally and signpost them to other organisations," said Stanley.

Prof. Hugh Rickards, consultant in neuropsychiatry at the National Centre for Mental Health in Birmingham, agrees.

"The work of the specialist HD advisers around the UK is unique and invaluable to people with HD and their families. The advisers are an integral part of the care pathway for almost all patients with HD in the UK. They provide emotional and practical support alongside a deep knowledge of the condition. The SHDA team work seamlessly alongside clinical services to provide the breadth of care that is needed," he said. "However, in austere times, people with HD and their families need increasingly strong advocacy to obtain the support that they need. This requires time and resources. We should aim for at least one specialist HD adviser for each 100 people with HD, which is about 60 in the UK. So far we have less than half that number."

Professor Sarah Tabrizi of the National Hospital for Neurology and Neurosurgery concurs: "The HDA SHDAs are pivotal to the care and support of our patients and families with Huntington's disease. They are professional, kind and expert in care. I can unequivocally say that my specialist service for HD depends on the support and help from the HDA SHDAs in the community with our patients. They are simply wonderful! Please support them as they are critical to the care and support of our HD patients and families."

For more information about the HDA and how it helps families with HD, please visit its website, www.hda.org.uk or ring 0151 3315444.

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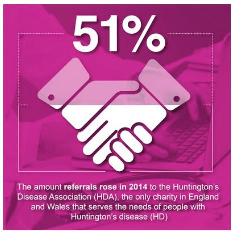

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