Scottish Huntington's Association

Specialist support for Huntington's disease families

BRIEFING FOR HEALTH, CARE AND SPORT COMMITTEE
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The essential/ preventative nature of Scottish Huntington's Association services: Testimonials

"The Minister for Public Health and Women's Health was pleased to meet with Scottish Huntington's Association (SHA) earlier this year to discuss the provision of Huntington's Disease services in Scotland. We recognise the valuable support they provide to people with Huntington's and their families. The expertise of their support workers helps to keep people well in the community, prevents crisis admissions to hospital and lessens the risk of suicide, and supports young people through education. The Scottish Government has sought the views of colleagues working in neurology services in NHS Scotland and they have attested to the added value provided by SHA." **Neil Gray MSP (when Cabinet Secretary for Health & Social Care).**

"Huntington's Disease Specialist Support services provide a much needed and highly effective support framework for families impacted by with Huntington's. Huntington's is a highly complex condition that is poorly understood outside specialist clinics and, in Scotland, Scottish Huntington's Association. This is the case even for the vast majority of consultant neurologists, geneticists and psychiatrists, and hospital and community-based health and social care professionals generally, who typically have extremely limited experience and therefore understanding of the condition and its requirements. Without an HD Specialist service, a wide range of interactions with Huntington's patients will be significantly less effective, leading to a rise in GP contacts, presentations to A&E and complex hospital admissions. Furthermore, the existing genetic, neurology, psychiatry and community services absolutely do not have the bandwidth to pick up additional work that would inevitably follow if specialist services were ended. The current support framework provides unbelievable value for money and so it would be a huge mistake to demolish such preventative spending. This will not only lead to poorer care for patients and their families, but also to significantly increased costs to statutory health and social care services in the form of many more crisis situations." **Prof. Ann Rosser, Professor of Clinical Neuroscience University of Cardiff, Chair of the European Huntington's Disease Network 2018 – 2024**

"Huntington's disease (HD) is a particularly devastating and complex genetic condition that has catastrophic consequences on the mental and physical health of people affected and severe consequences for their families. SHA's HD Specialist support cannot be replicated in mainstream services. This is a specialist clinical role and has many facets that allow people affected by this disease to have better outcomes, quality of life, reduced hospital admissions

and increased time at home before care is needed. This condition requires people that are dedicated to focus on Huntington's disease.

“As an HD Lead, I would not be able to provide a meaningful and effective service without the input of my HD Specialist colleagues and the Scottish Huntington's Association team, and this is not a service that can be subsumed into mainstream services. The workload in the HD service is extremely high, and without the specialist skills, knowledge and dedication of the HD team, my role would not be feasible and the high quality of care that is provided to this extremely vulnerable group of people with extremely high level of needs would not be possible.” **Dr Roger Cable, Consultant Psychiatrist and HD Clinical Lead, NHS Lanarkshire.**

Huntington’s disease is a devastating condition for sufferers and their families, not just because of the progressive deterioration that they have to endure but also because of the psychological impact that the anticipation of inevitable deterioration and the 50/50 potential for inheritance has. The deterioration often involves challenging behavioural patterns which is a particularly unsettling prospect for patients and wider families to anticipate.

This is a patient group whose needs are already under recognised and inadequately met by the NHS, in particular in the final months and years of their lives, when they end up being admitted to hospital wards that are unable to manage their behavioural and mental health needs. The only escape from this is a transfer to residential care facilities which are often some distance from family homes and support networks.

The Scottish Huntington’s Association HD Specialists who provide vital clinical and advocacy support for this patient group and their families are an essential lynchpin in an environment which most other clinicians and health and social care workers instinctively avoid due to a sense of helplessness in terms of trying to address the challenges of this hugely complex and widely misunderstood condition. This was exactly why HD Specialists were established in the first instance. If this vital resource for patients with HD and their families is withdrawn, it will be an abandonment on a scale that in my view cannot be justified.” **Dr Alasdair FitzGerald - Consultant in Neurological Rehabilitation, Rehabilitation Specialty Adviser to The Chief Medical Officer for Scotland**

“In both my clinical work with Huntington’s disease and in my role as Clinical Director, I see first-hand the essential role played by Scottish Huntington’s Association’s HD Specialist team. Their involvement consistently stabilises highly complex situations, prevents avoidable harm, and protects capacity across our acute, mental health and social care systems. Without their contribution, outcomes for patients and families would be markedly poorer, and the system would face significantly greater pressure.

“One of the most powerful examples from our service is that of a young woman with severe Huntington’s symptoms who was living alone, drinking heavily, being exploited by a neighbour and expressing suicidal thoughts. She was extremely difficult to engage, and her risk escalated rapidly. It was the relentless perseverance and strong leadership of the SHA Huntington’s Disease Specialist — coordinating multiple agencies, maintaining contact when others could not, and holding the risk in the community — that enabled a safe transition to

residential care. She is now abstinent, safe, and thriving in a supportive environment. This outcome simply would not have been possible through medical input alone; the HD Specialist role was the decisive factor.

“More broadly, HD Specialists are often the only professionals able to stabilise challenging behaviours in the community, reduce carer stress and prevent breakdown, and guide families through complex systems that would otherwise overwhelm them. Their proactive involvement averts crises, avoids unnecessary hospital and mental health admissions, and prevents the prolonged, complicated stays that occur when HD is not expertly managed. Although I am keeping this general rather than numerical, the system-wide savings from preventing such deterioration and hospital dependency are substantial — and well recognised by colleagues across Scotland.

“It is clear to me that removing HD Specialist support would be unsafe, unsustainable, and a serious risk to patients, families and to the wider health and social care system. These roles are not an optional enhancement but a core, safety-critical component of care for an exceptionally vulnerable and complex group. I fully endorse the continued funding and protection of SHA’s HD Specialist services.” **Dr. Pritha Dasgupta, Clinical Director (Mental Health, Complex and Critical care), Consultant Psychiatrist & Huntington’s Disease Clinical Lead, NHS Fife**

“I work regularly with Huntington’s Disease Specialists who are employed by Scottish Huntington’s Association (SHA). They have considerable expertise in Huntington’s disease and its management and provide assertive outreach support for people with Huntington’s, their families and carers, in the community. Their regular proactive input, focused on the needs of patients and families, has an invaluable role in diverting work from primary care and other services. Because of the complex nature of Huntington’s disease, their work helps to avoid complex and potentially lengthy unplanned hospital admissions. They also have a substantial role in streamlining complex discharge planning, thus reducing the length of hospital admission when admissions do occur. They regularly train other staff such as care providers and nursing home staff, thus building capacity across social and health care teams.

“Huntington’s patients have a complex range of issues ranging across physical health, mental health and social care. The integrated and proactive support provided by SHA's Huntington’s Disease Specialists significantly streamlines their care. This delivers tangible benefits to patients and family/carers, but also primary and secondary care colleagues.” **Dr Pete Foley, Consultant Neurologist and Huntington’s Disease Clinical Lead, NHS Lothian**

“Huntington’s disease is a progressive neurodegenerative condition that devastates families. It impacts affected individuals through relentlessly progressive cognitive decline, behavioural issues, and a range of mental health phenotypes as well as physical manifestations of swallowing and mobility difficulties, falls and eventually complete dependency on nursing care. In contrast to other severe neurological disorders the course of the disease is very long, with 15-25 years of symptoms in many. Children of affected individuals have a 50-50 chance of inheriting the condition and grow up often overshadowed by personal risk as well as the burden of caring for a parent who is losing - or has lost - the ability to empathise and needs support in all aspects of living.

“There is more Huntington's diagnosed in Scotland than in most places worldwide. SHA HD Specialist and care support teams address medical and social care issues and support families and carers to deal with the multiple challenges of the condition. Their interventions are often sufficient to keep care in the community but they often also support general care homes to care for residents with Huntington's - avoiding costs of the highly specialist residential care facilities that are often the norm elsewhere in the world.

“Without the existing Scottish Huntington's Association support teams more people will require care home, specialist care home and inpatient admissions, families will break up and young people will grow up without hope for the future.” **Prof. Zosia Miedzybrodzka MB ChB, PhD, FRCP, Honorary Consultant Clinical Geneticist & Service Clinical Director- Genetics, NHS Grampian & HD Clinical Lead for North of Scotland (Grampian, Highland, Western Isles, Orkney & Shetland).**

“Since starting with the Lothian Huntington’s Disease service, I have worked closely with Scottish Huntington’s Association’s HD Specialists. They deal with a complex patient group with complex problems and complex dynamics in a compassionate and responsive manner.

“I have little doubt that their sterling work reduces community risk, crisis admissions, shortens hospital stays and empowers those working with these patients by the regular training they provide.

“I fear that without this service, these key indicators would worsen and the significant costs they save, and more importantly the care they provide, would become even more apparent.” **Dr Douglas Murdie, Consultant Psychiatrist, Huntington's Disease Service, NHS Lothian**

“Huntington’s disease is the most common genetic neurological condition in Scotland, and causes devastating progressive dementia, and movement problems, where patients die within 10-20 years of its onset. It is inherited in an autosomal dominant manner meaning patients often have several other family members also affected by the condition.

“Patients with the condition face numerous hurdles to effective care. There is often significant mood involvement, which can affect relationships with friends and family, and apathy and lack of recognition of the effects of the condition. The condition affects adults of working age resulting not just in a loss of income for them but potentially other affected members of the family. There are far fewer community resources available for young adults with dementia, with most services and accommodation geared towards older adults. Patients with Huntington’s are more likely to be admitted to hospital with complications from, for example, reduced swallow function causing aspiration pneumonia, if this is not well managed in the community. The hospital admissions which follow are more likely to be prolonged due to greater discharge planning requirements.

“I recognise the essential role Scottish Huntington’s Association provides for patients throughout Scotland, which is not replicated by NHS services. This includes education, financial support, family support including specialist youth advisors for children who are at

risk of developing the condition, signposting to research studies, and acting as a point of contact for family members of those affected. I cannot imagine how patients and families from health boards without dedicated specialists would manage" **Dr Tim Soane, Consultant Neurologist & HD Clinical Lead, NHS Forth Valley**

"HD can be a devastating condition, most commonly affecting working-age individuals. The unique clinical course that includes a gradual deterioration in cognition and motor function and is associated with a range of serious psychiatric symptoms is among the most challenging conditions for clinicians to manage. The added impact of the hereditary nature of the condition can be particularly hard for patients and families to deal with.

"Scottish Huntington's Association HD Specialists form a key part of patient care by providing monitoring and support that facilitates their clinical care and overcomes the challenges they would otherwise face in accessing and participating in their care due to the combination of progressive mental and physical disability that occurs. They are uniquely placed to interface with the variety of disciplines who can help people with HD including hospital consultants, allied health professionals, community care services and social workers. HD specialists can ensure that patients with HD get the support they need when they need it and thereby minimise avoidable harms and help people to live as well as possible on their own terms." **Dr James Herron, Consultant Psychiatrist and Joint HD Clinical Lead, NHS Greater Glasgow & Clyde**

"I am writing as a Consultant Clinical Geneticist that has worked with patients and families with Huntington's disease since 1992. Over this time, I have been fortunate to be co-located with Scottish Huntington's Association HD Specialists and have seen the value of their work at first hand. I understand the need to ensure that scarce Health and Social Care Resources have to be used efficiently and want to share my opinion on the value of the Scottish Huntington's Association HD Specialist posts and the need to continue to fund them.

"The recent news about a treatment that potentially slows or even halts the neurological deterioration associated with Huntington's disease has given families hope for the future. However, it also raises concerns and it is important that timely advice and support is available. It could be years before this treatment may be available and until then, Health and Social care need the support of the Scottish Huntington's Association HD Specialists to provide specialised care to HD patients and their families.

"Management of Huntington's disease requires input from a range of medical and social care professionals. Scottish Huntington's Association HD Specialists act as guides to families trying to navigate the system, advocates when difficult decisions are made and support when the diagnosis and its sequelae is leading to fracturing of family bonds.

"Neither Clinical Genetics or Neurology services have the capacity to meet the social challenges that families with HD experience. Decisions about care settings when family members can no longer cope are complex requiring an understanding of likely ongoing care needs and the facilities available. Scottish Huntington's Association HD Specialists play an important part in transition for many families and also provide essential support and training

to health and social care professionals working with the HD community." **Professor Mary Porteous MD, FRCP (Edin), Consultant Clinical Geneticist**

"Huntington's disease is a complex rare illness. Many health and social care professionals will never have supported anyone with the disease, and its combination of profound physical disability, complex mental health problems and cognitive impairment can make it particularly difficult to manage. Having a single point of contact, and someone with knowledge and experience of managing the disease is crucial to the individual affected, their family and other health and social care staff." **Cath Stanley, CEO, Huntington's Disease Association (England & Wales).**

"These services are absolutely essential for people with Huntington's and their families/carers. It's the absolute worst of all of the absolutely horrible neurological conditions. It doesn't present until adulthood in the main but does also occur in a very few children. It robs people of all their cognitive and physical functions including speech. It is rare, can take a long time to diagnose, and there is no cure. There are so few such services, more are needed, not fewer. These services are the only recourse for families affected by this genetic disease." **Elizabeth Porterfield MBE, Chair Genetic Alliance UK.**

"Huntington's disease (HD) is a devastating and complex brain disorder, characterised by progressive dementia, a movement disorder and significant neuropsychiatric symptoms. The care of families living with Huntington's disease requires a multidisciplinary approach involving HD Specialists from the relevant national Huntington's Association, who play a pivotal role. Their specialist knowledge and expertise is essential for both the Huntington's community and other health and social care staff seeking to provide support." **Prof Sarah Tabrizi MD PhD FMedSci FRS, Director of Huntington's Disease Centre & Joint Head of Department of Neurodegenerative Disease, University College London**

About Huntington's disease

Huntington's disease is caused by an inherited faulty gene that damages the brain over time. People with the disease will eventually lose the ability to walk, talk, eat, drink and care for themselves, requiring specialist support from those who understand the condition.

The disease is genetic, meaning it is passed down from one generation to the next. It therefore impacts entire families over generations rather than individuals alone. Each child of a person who has Huntington's has a 50/50 risk of inheriting the condition from them.

Huntington's disease has three groups of symptoms. These symptoms include:

- Physical symptoms: These include repetitive involuntary movements; declining balance, coordination and mobility; incontinence; deterioration and loss of speech and swallowing.
- Cognitive symptoms: A form of dementia that changes behaviour, thinking, personality and judgement, severely disabling the person's ability to make rational decisions, stay safe, and care for themselves.

- Mental health symptoms: These include depression, suicidal ideation, anxiety, obsessive and repetitive thoughts and actions, irritability, aggression, apathy and psychosis.

Generally speaking, symptoms begin to develop between the ages of 30 and 50 and can take between 10 and 25 years from starting until the end of life. However, each case of Huntington's is unique and can vary dramatically both in terms of age of onset, progression, and range of symptoms.

In around 5-10% of cases Huntington's symptoms develop before the age of 21. This is known as Juvenile onset Huntington's disease (JoHD).

Although worldwide research is taking place there is, at present, no way to slow or stop the progression of Huntington's. However many of its symptoms can be managed with a combination of medication and appropriate support from specialist services provided by Scottish Huntington's Association and its health, social care and third sector partners.

Scottish Huntington's Association has published a Scottish Government backed National Care Framework for Huntington's Disease which outlines the care and support families should be entitled to receive throughout the country. It can be viewed at care.hdscotland.org

About Scottish Huntington's Association

1. People impacted by Huntington's disease need specialist services to cope with a severe and complex disease, the impact on families and a lack of awareness amongst health and social care providers and the wider public.
2. Scottish Huntington's Association is the only charity in the country dedicated exclusively to providing specialist support for those impacted by Huntington's disease.
3. Our specialist services improve quality of life, keep people at home for longer, reduce unnecessary hospital admissions, supports carers and other family members, lowers household poverty and alleviate wellbeing risks to children and young people.
4. We are commissioned by NHS Boards and Health and Social Care Partnerships throughout the country to provide specialist clinical and care management services, share our expertise with frontline staff, and raise standards of care for every family impacted by this devastating disease.
5. Scottish Huntington's Association plays a full and active role in attracting the global research community to Scotland to work in partnership with us to improve the lives of families impacted by Huntington's disease.

About Scottish Huntington's Association Specialist Services

HD Specialist Service

Our HD Specialists provide vital physical health, mental health, wellbeing support and care co-ordination for Huntington's families, whether they are symptomatic, asymptomatic, at risk or carers. HD Specialist support includes specialist assessment, symptom management, emotional support, help to plan for future care needs and enabling carers to build skills and

resilience. Our expertise is invaluable to health and social care professionals who access training and advice from our HD Specialist teams. Most health and social care staff have no experience of Huntington's disease so depend upon our input to help provide appropriate care.

Youth Service

Our Specialist Youth Advisors provide personalised support through 1-2-1 sessions, age-appropriate information and resources, and opportunities to build friendships and enjoy respite experiences that would otherwise be impossible. They also provide specialist education, support and guidance to other professionals who work with children and young people who are impacted by Huntington's disease.

Young people growing up in Huntington's families see the disease changing their affected family member, often while knowing they have a 50% chance of developing the same condition. Many become young carers for siblings or their parents, while others are unable to live with their mum or dad. Huntington's disease impacts their home lives, education and social opportunities.

Financial Wellbeing Service

Huntington's disease cuts working lives short, leaving many households we support living below the poverty line.

Our Financial Wellbeing Officers help families to reduce debt and maximise income through access to benefits and financial products. The service's work includes support with household budgeting and planning for the future by organising power of attorney. The service has secured more than £7million in financial gain for families across Scotland.

HD Clinical Leads

HD Clinical Leads are senior NHS employed doctors (such as psychiatrists, neurologists or geneticists) designated to providing specialist medical advice, care and treatment to people with Huntington's. They work with Scottish Huntington's Association staff and other health and social care colleagues to coordinate care across their local NHS Board area. They run specialist clinics supported and facilitated by our HD Specialist staff, provide home visits to those unable to attend clinic and provide access to HD research programmes. In light of our expertise Scottish Huntington's Association coordinates and chairs the national network of HD Clinical Leads.

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Client survey 2025



For further information visit: hdscotland.org

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