

## Who can refer to the Lothian Service?

The service has an open referral system, which means direct referrals can be made by those impacted, a family member or a third party with consent. Please email [sha-admin@hdscotland.org](mailto:sha-admin@hdscotland.org) or get in touch on one of the numbers below:



### Services for Lothian

Senior Huntington's Disease Specialist:  
07957 374 417

Huntington's Disease Specialist  
07474 859 304

Financial Wellbeing Service  
07710 391 622

Youth Service  
07538 951 425

## Lothian office

David Brock Building  
Clinical Genetics  
Western General Hospital  
Crewe Road South  
Edinburgh  
EH4 2XU

## National office

Scottish Huntington's Association  
Business First  
Burnbrae Road  
Paisley  
PA1 2FB  
Telephone: 0141 848 0308  
Email: [sha-admin@hdscotland.org](mailto:sha-admin@hdscotland.org)

Further information can also be found on our website at [hdscotland.org](http://hdscotland.org)



[hdscotland.org](http://hdscotland.org)

Scottish Charity No: SC010985  
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## Lothian Service



## Huntington's disease: How we can support you and your family



## What is Huntington's disease?

Huntington's disease is caused by an inherited faulty gene that damages the brain over time.

**People with the disease can 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. Anyone with a parent who has Huntington's has a 50% risk of inheriting the condition from them.

As Huntington's progresses it can affect:

**Movement:** People can experience repetitive involuntary movements resulting in a decline in mobility, balance and coordination as well as difficulties with speech and swallowing.

**Thinking processes:** As the disease advances, people can lose their ability to process information, make decisions, solve problems, plan, organise and care for themselves.

**Mental health:** People can also experience a decline in mental health. Depression, anxiety, irritability, obsessive pre-occupations and apathy are amongst the most common mental health problems experienced. Psychosis may also occur.

## About Scottish Huntington's Association

Scottish Huntington's Association is the only charity in the country exclusively dedicated to providing expert and personalised support for those impacted by Huntington's disease.

Our personalised support reduces unnecessary hospital admissions, supports carers and other family members; lowers household poverty; and alleviates wellbeing risks to children and young people living in Huntington's families.

We are commissioned by NHS Boards and Health and Social Care Partnerships throughout the country to share our expertise with front line staff and build support for improved services and higher standards of care for every family impacted by this devastating disease.

## What services do we offer?

### HD Specialists

Our HD Specialists provide vital physical health, mental health and wellbeing support, and care co-ordination for all adults within a Huntington's family – whether they be symptomatic, asymptomatic, at risk or carers. They liaise with, amongst others, occupational therapists, speech therapists, physiotherapists, care homes, dieticians and community mental health teams. Additional 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 at all, and so depend upon the support of our specialist teams.

### Youth Service

Our Specialist Youth Advisors provide personalised support, age-appropriate information and resources, 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 parent, with many knowing they have a 50% chance of inheriting the same condition. Many become young carers for siblings or their parents, while others are unable to live with their mum or dad. Some are grieving for loved ones, others are struggling with genetic testing. Huntington's disease impacts their home lives, education and social lives.

### Financial Wellbeing Service

Our Financial Wellbeing advisors help families to reduce debt and maximise income through access to benefits and financial products. The service's work includes support with household budgeting, planning for the future by organising power of attorney, and providing specialist energy advice to help cut domestic fuel costs. Since 2015, the service has secured more than £6 million in financial gain for families across Scotland. Huntington's disease cuts working lives short, leaving many households we support living below the poverty line.

### Where do we see people?

Wherever is most comfortable, whether that be at home or in another suitable venue.

## 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 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.

### HD Management Clinics

Clinics are held three times a month at the Anne Rowling Regenerative Neurology Clinic (Royal Infirmary of Edinburgh campus) and occasionally the Western General Hospital. Please contact the Lothian service for more details.

### National Care Framework for Huntington's Disease

We have 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 <http://care.hdscotland.org>

