

Staff

Senior HD Specialist

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HD Specialist

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Specialist Youth Advisor

Peter Carruthers

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Financial Wellbeing Officer

Joanne Baldock

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Admin / Resource Worker

Shona Cumming

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Office

Scottish Huntington's Association

Clinical Genetics Department

David Brock Building

Western General Hospital

Crewe Road South

Edinburgh

EH4 2XU

Contact

If you wish further information about
the Service please contact
Scottish Huntington's Association

Lothian Office- 0131 537 1058

Further information is also available from
our website www.hdscotland.org

National Office
Scottish Huntington's Association
Business First
Linwood Point
PAISLEY
PA1 2FB

Phone: 0141 848 0308

Email: sha-admin@hdscotland.org

Recognised by the Inland Revenue as a
Scottish Charity – No. SC010985



scottish
huntington's
association



Part of the HDA
Family Worldwide

Lothian
Service

Empowering ordinary people to
meet extraordinary challenges

What is Huntington's Disease?

- A genetic, hereditary, neurological, disorder of the central nervous system
- It is an autosomal dominant gene so if you have the faulty gene you will develop the illness at some point in your life
- It affects males and females equally
- Every child born to a parent with the faulty gene has a 50% chance of inheriting the gene
- Average age of onset of the illness is between 30-50 but this can vary widely
- It causes physical, emotional and cognitive impairment in varying degrees for each individual
- There is no known cure for this illness

Who are Scottish Huntington's Association?

- A registered charity
- Community based Huntington's Disease service provision since 1989
- Has community based services throughout Scotland
- Promotes needs led services and has a user led focus
- Commissioned in partnership with NHS Lothian and local authorities

What service do we offer?

The Lothian Service has two HD Specialists and aims to significantly improve the quality of lives of those living with Huntington's Disease (HD) and their families through timely specialist assessment, condition management, information, advice, advocacy and emotional support. The Lothian Service also provides practical help for those with HD, carers and family members with benefit maximisation, adaptations, equipment, and access to services. The service works cohesively with the multi disciplinary teams in Health and Social Care across the whole of Lothian that support our families by providing specialist information, educational sessions, and case management support.

Youth Service

The Specialist Youth Advisor, Peter Carruthers, works with children and young people aged 8-25, living in families with HD, and provides one-to-one support, group work, advocacy and befriending. This service ensures accurate age appropriate information is given. The one-to-one support is essential to manage the daily challenges of living in a family with HD.

Family Branch Group

This group was formed by family members to provide an opportunity to meet informally with others whose lives are affected by Huntington's Disease.
Last Wednesday of each month at 7.30pm in URC Church Hall
Duke Street
Leith
Edinburgh
EH6 8HL

Financial Wellbeing

The Financial Wellbeing Officer, Jo Baldock, provides specialist welfare rights advice including benefit checks, assistance with applications, disputes and appeals, money (debt) advice, and financial guidance on money matters such as planning for the future, power of attorney, pensions and life insurance. As well as responding to specific enquires, the aim is that all the clients of SHA will be offered a 'Financial Health Check'.

Where do we see people?

Wherever the person is most comfortable, either at the individual's home, at or at another suitable venue.

Who can refer to the Lothian Service?

The service has an open referral system. Direct referrals can be made from those affected, a family member or other third party referrals with consent. Please get in touch by phoning, writing or emailing the Lothian Team.

Contact - Branch / Support Group Officer

Isobel Darroch
Tel: 0141 848 0308

Further information about the Lothian Family Branch Support Group is available from the Lothian office.