



## About Scottish Huntington's Association

**Scottish Huntington's Association (SHA) was founded in 1989 by families for families whose lives are impacted by Huntington's disease (HD). What began as a network of support groups has grown to provide a range of personalised specialist services for individuals and families across Scotland.**

As the only charity in the Scotland dedicated exclusively to supporting the Huntington's disease community, Scottish Huntington's Association delivers its lifeline support through a network of HD Specialists, Youth Advisors and Financial Wellbeing Officers. These services make the difference between families coping and not coping.

### 1. Specialist support and advice

Scottish Huntington's Association delivers nine [HD Specialist Services](#) in Scotland (Highland, Grampian, Tayside, Fife, Lothian, Lanarkshire, Greater Glasgow & Clyde, Ayrshire & Arran, and Dumfries & Galloway). If you live outwith these areas, please contact our National Office (0141 848 0308) for advice about how to access support.

You, a family member, or anyone who knows you can contact our HD Specialist services directly. You can also be referred by your GP, social worker, genetics service or any professional involved in your care. HD Specialists will support you with information about Huntington's disease and advice on symptom management. They will visit your home or meet you in a mutual place to carry out specialist assessments. Any assistance that you require, e.g. a swallow assessment, will be followed up and the necessary steps taken.

Our HD Specialists also deliver training and advice for staff working in health and social care settings.

## **2. Supporting young people**

Our [Youth Service](#) works with children and young people between the ages of eight and 25. Age appropriate one-to-one work is carried out at home, school or in a mutually agreed place. Our four Youth Advisors also offer opportunities for young people to meet up, learn about Huntington's disease and talk about their own experiences through group work, activities and an annual summer camp.

## **3. Reducing financial hardship**

Our [Financial Wellbeing Service](#) offers a 'financial health check' to individuals and families facing household hardship as a result of Huntington's disease. You can also receive advice about benefits, debt management, planning for the future, pensions, life insurance and energy savings. One of our four Financial Wellbeing Officers will visit you at home or in a preferred location.

## **4. Raising the standard of care**

[The National Care Framework for Huntington's Disease](#) - the first of its kind in the world - was developed by a multi-disciplinary expert group led by Scottish Huntington's Association with funding and support provided by the Scottish Government.

The online resource seeks to help ensure families impacted by Huntington's disease are able to access the best possible care, information and support, regardless of where in Scotland they live. The Framework has been endorsed by NHS Boards, health and social care partnerships, family members, academics and national and international third sector partners.

## **4. Empowering families**

We facilitate a network of Family Branches across Scotland, which are run by family members. These enable people to meet informally with others

from the Huntington's disease community to socialise, share information and generate ideas for fundraising at local level. Your HD Specialist will provide information about these groups, including when and where they meet and how you can make contact.

### **Useful links**

[Contact a Scottish Huntington's Association HD Specialist](#)

[Scottish Huntington's Association Financial Wellbeing Service](#)

[National and Regional Care Frameworks for Huntington's Disease](#)

[Scottish Huntington's Association Youth Service](#)

[Sign up for regular updates from Scottish Huntington's Association](#)

You can also email us [sha-admin@hdscotland.org](mailto:sha-admin@hdscotland.org) or call 0141 848 0308.

Updated January 2022