

# About Scottish Huntington's Association

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## What is in this fact sheet

- About us
- How we can help
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- How things are changing for people with HD and their families
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## Key points from this fact sheet

- SHA provides a lot of help and information about living with HD
- Things have got better for people with HD over recent years
- There is new research happening on the causes and treatments for HD

## About us

Scottish Huntington's Association (SHA) is a Scottish charity established by families living with Huntington's disease (HD). We began in 1989 when there were very few services for people with HD. We set up family support groups and since then have developed an extensive network of specialist services.

## How we can help

These are the services we have at the end of 2016.

- There are 8 specialist HD services in: Highland, Grampian, Tayside (including Angus), Fife, Lothian, Lanarkshire, Glasgow and Ayrshire. People can contact HD specialists directly. You can also get referred through your GP or Genetics Unit.
- The HD Specialists can also give training and back-up advice for other staff in general health or social care settings who are supporting people who have HD.
- We have 4 Youth Advisors: one covers the North East of Scotland and is based in Aberdeen, one covers the East of Scotland and is based in fife and the others cover the South and West and are based in Glasgow.

- The HD Specialists give advice on managing the symptoms of HD to make life more comfortable for someone who has HD. They visit people in their own homes and carry out specialist assessments. They give ongoing support to people with HD and their families, and provide advice on aspects of living with HD. They pass the assessments on to the appropriate services, to ensure the person with HD and their carers receive the support they need and reduce the need for the person to keep giving the same information to different services. The HD Specialists make sure that each person gets the support they need for each stage as their condition progresses. The aim is to ensure each person with HD always has the best quality of life possible.
- SHA supports a network of family branches. These are run by family members and provide information and peer support. The groups also do fundraising and are able to help people in practical ways by offering welfare grants and providing social activities. There are currently groups in Tayside, Lothian, Forth Valley, Aberdeen, Elgin, Glasgow and Ayrshire. In addition our Peer Support Officer runs support groups in other parts of Scotland.
- Our websites and our publications have information for everyone, in any part of the country. The youth service has a special section on our website ([hdscotland.org](http://hdscotland.org)), with resources for children, teenagers and for young adults. It also has material to help parents and teachers of young people who are affected by HD.
- We can offer advice and support for most people who live in areas that are not covered by the specialist HD services. If you contact the main office they will put you in touch with the right person.
- We often give advice to staff in other services, to help them give good support to people who have HD. We also have publications that are useful for staff in other services.
- We have a Financial Wellbeing Service which provides advice on maximising your income, managing debt and planning for the future.

The website has current contact details for staff and the Family Branches. You can also contact the National Office.

### **Links with other association led by people with HD and their families**

SHA brings together people and families in Scotland who are affected by HD. There are equivalent associations in other parts of the world. We keep in touch, so share ideas and good practice on what helps people with HD and their families.

We also share information about the research that is going on across the world into ways to stop or slow the onset of HD and ways to manage symptoms. For example, there is a big research study going on that involves people across Europe and some of the SHA service are involved in the Euro HD studies.

You can get links to the other organisations through SHA.

### **How things are changing for people with HD and their families**

Many of the people living with HD who contributed to this factsheet say how much more support there is now than there used to be. The other aspect that we are trying to change is public understanding about HD.

Some of the people reading this resource will remember their parents or grandparents being ill and not getting much care, or being in a hospital ward where no-one really understood what the problem was. Over the years families living with HD, working in partnership with SHA, have helped to change things.

We are also benefiting from general laws and policies that are designed to benefit everyone or to give more rights to people who are in any special situation, even though they were not designed specifically for people with HD. An example is the increased rights for anyone with a disability – so better access to buildings for anyone who has difficulty walking or needs clearer information, and protection against discrimination by other people. There is also more emphasis on getting public services to work well for everyone who uses them. So we have included information about general rights and about some of these services that you might find useful.

**SHA's main office is at:**

Business First,

Linwood,

Paisley,

PA1 2FB

Telephone: **0141 848 0308**

Email: **sha-admin@hdscotland.org**

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

HD Buzz is a website that brings together and explains the latest research findings about HD from all over the world. The aim is to help people with HD and their families to be more involved in their care and to plan their lives. It also aims to give people hope for the future.

Website: [www.hdbuzz.net](http://www.hdbuzz.net)

[www.euro-hd.net](http://www.euro-hd.net) has some good information on HD. It also tells you which Genetics Centres are involved in the international research study.

**HD Specialists – at 2016:**

- Angus **01382424196**
- Ayrshire **01294322305**
- Fife **01592647993**
- Glasgow **01415564100**
- Grampian **01224550062**
- Highlands **01463729958**
- Lanarkshire **01355597455**
- Lothian **01315371058**
- Tayside **01382424172**

**Youth service**

- North East **01224550063**
- East **01592647993**
- West **01415562136**

### **Financial Wellbeing Service**

- **01418480308** (option 4)

There is more information about the SHA services in each part of Scotland on the website, [hdscotland.org](http://hdscotland.org).