

## What help is available?

Help is available from the **Scottish Huntington's Association (SHA)**.



## What is the SHA?

The SHA is a Scottish voluntary organisation which was formed to provide a Scottish support network and specialist advice for individuals and families living with Huntington's disease. We aim to raise awareness through information and education.

## What is an HD Specialist?

We provide specialist information, confidential advice, help and emotional support. We work in close liaison with health authorities, social services and other statutory and voluntary agencies. Further information about other services such as our Youth Specialist Service are available from our website

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

The Specialist Services also offer advice, education and information to care providers. Management Clinics are available in some areas as are Support Groups for Carers and those living with HD. Contact your local Specialist Service for more information about these services. Most areas in Scotland are covered by a Specialist Service and details are on our website.

If you have concerns about any issues on HD contact your local HD Specialist or local Genetics Centre.

## Who are the Family Support Group?

There are several Family Support Groups who meet on a regular basis. Details are available from the National office of the SHA.

## HD Specialist Service Details

### Scotland

Angus	T: 01241 437 247
Ayrshire	T: 01294 276 430
Fife	T: 01592 647 993
Glasgow	T: 0141 556 4100
Grampian	T: 01224 550062
Tayside	T: 01382 425549
SHA Head Office	T: 0141 848 0308
Highland	T: 01463 729 958
Lanarkshire	T: 01698 239 600
Lothian	T: 0131 537 1058

### Youth Services

Youth (South West)	T: 0141 556 2136
Youth(North East)	T: 01224 550063



### Text your donation

Text **HDSCOTLAND6** to **70003** to make an instant **£3** donation to **Scottish Huntington's Association**

Texts cost £3 plus network charge. Scottish Huntington's Association receives at least £2.67 Please obtain bill payers permission.

Customer care 08448479800. Charity No SC010985

**Follow Scottish Huntington's Association on Facebook and Twitter @ScottishHD**



Scottish Huntington's Association  
Suite 135 St James Business Centre  
Linwood Rd Paisley PA3 3AT

**T: 0141 848 0308**

**E: [sha-admin@hdscotland.org](mailto:sha-admin@hdscotland.org)**

**W: [www.hdscotland.org](http://www.hdscotland.org)**

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## scottish huntington's association



## What is Huntington's Disease?

Empowering ordinary people to  
meet extraordinary challenges!

## What is Huntington's disease?

Huntington's disease (HD) is a hereditary illness that causes damage to certain areas of the brain. This stops the brain and body from working as well as they used to, and affects a person's movement, thoughts, behaviour and emotion. Symptoms can occur at almost any age but most commonly appear between the ages of 35 and 44.

## What causes Huntington's disease?

Huntington's disease (HD) is a genetic disease. Each child has a 50% chance of inheriting the gene that causes Huntington's disease. People with the genetic change will most likely develop the disease, unless they die of other causes prior to developing signs and symptoms. People who do not inherit the genetic change will not develop the disease, neither will their children or their children's children. The faulty gene can affect both males and females.

## How many people are affected?

No one is exactly sure of the numbers of people affected. It is generally stated that 1:10,000 people has HD, but research in Scotland shows that this varies enormously from area to area and in some parts of Scotland can be 1:6000. A good estimate is that there are about 850 people in Scotland who currently have HD. In addition there are between 4000 and 6000 people living with the risk of inheriting Huntington's disease.



## How do you know that you have the genetic change that causes HD?

Now that scientists have discovered exactly what the genetic change is that leads to HD, it is possible to be tested to see if you have that genetic change. Usually you have to be 18 to have a test and it involves giving a blood sample. The process takes about 3 months and involves the chance to talk about any concerns with a genetic counsellor. Tests are carried out at Regional Genetics Centres which are based in Aberdeen, Dundee, Edinburgh and Glasgow (see our leaflet on genetic testing).

## How does HD affect people?

There are different ways in which people are affected by HD e.g. **movements, thoughts, emotions and behaviour**. Everyone will be affected in different ways, some people have more problems with changes in their behaviour; others have more problems with their movements.

HD usually progresses slowly over a period of 15-25 years resulting in gradual physical, psychological and emotional changes and most commonly a combination of these. Often in the early stages of the disease the problems are associated with changes in the ability to co-ordinate information efficiently, so the messages being passed through the brain don't always get to the right place, or get lost along the way.

As the disease progresses it can be hard to cope with all the changes HD can bring. Feelings of anger, sadness, depression, worry, confusion, guilt and embarrassment are often experienced by those who have HD as well as their friends and family.

## What treatments are available?

It is possible to manage some of the symptoms with a range of therapies, there are no treatments that will halt or reverse the disease process at present. Through ongoing research there is now greater hope than ever before that a way forward will be found to fight this disease.

## How can I help myself?

A healthy diet, regular exercise, and avoiding stress are important to those with Huntington's disease. This will enable the person to maintain a good quality of life and cope with the symptoms of the disease. Help and support can be sought from your local SHA Huntington's disease Specialist or G.P. services.

Complementary therapies such as massage, reflexology and aromatherapy can also be beneficial. Information and help to access these can be provided by a local HD Specialist.

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