

Huntington's Disease Association Factsheet

Huntington's disease is caused by a faulty gene in your DNA. It affects your nervous system which co-ordinates your body's activities including your:

movement – unexpected movements may happen, and actions become difficult

cognition – memory lapses and difficulties with planning / thinking

behaviour – mood swings, depression and changes in personality

Living with Huntington's disease can be very difficult – the person affected deteriorates and family members often become carers. It is common for those affected to feel scared, frustrated, angry and lonely.

Quick facts:

- Around 8,000 people in the UK are currently living with the disease.
- Around 32,000 are at risk of developing Huntington's.
- It is genetic – every child conceived naturally to a parent who has the faulty gene has 50:50 odds of inheriting it.
- Symptoms develop between 30 and 50 years old.
- Sometimes symptoms can develop before the age of 20, this is known as Juvenile Huntington's disease.
- Symptoms gradually worsen over 20 years.
- It is a terminal disease. There is no cure.
- People can find out if they carry the faulty gene by taking a blood test, but they need to be 18 years old to take the test – not everyone chooses to get tested.

Huntington's Disease Association – how we help

The Huntington's Disease Association is the only organisation in England and Wales offering support to people affected by Huntington's disease.

We offer practical advice and support to anyone affected by the disease including training for health and social care professionals.

- £11.98 helps pay for five booklets for children to learn more about Huntington's disease.

- £27.85 helps pay for one hour of telephone support from our helpline.
- £67.69 helps provide care and support for families and individuals via our webinar series.
- £350 will help provide a welfare grant to improve people's lives by making adjustments to their homes, buying equipment or replacing appliances.

Huntington's Disease Association

Vision – together we will build a better life for anyone affected by Huntington's disease.

Mission – to enable everyone affected by Huntington's disease to live life to their full potential by:

- improving care and support
- educating families and the professionals who work with them
- championing the needs of the Huntington's community by working together
- influencing decision makers to tackle discrimination and secure equity of access to services

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