



Telling others about Huntington's disease

There are occasions when you have to tell others about Huntington's disease (HD), such as informing the DVLA if you are experiencing symptoms or your employer if your ability to carry out your work safely is impaired. Telling family, friends or other people in your day-to-day life, however, is a very personal decision and there are no right or wrong answers.

[Your Scottish Huntington's Association HD Specialist or Specialist Youth Advisor can support you to have these conversations when you feel ready.](#)

Having the conversation

- You are in control of who you tell and choosing a time that is right for you.
- Have accurate up-to-date information and be as open and honest as you can.
- Practise what you might say and be prepared for questions.
- Don't worry if you don't know an answer - you can find out from someone who does.
- Choose a place where you will be comfortable without being rushed or interrupted.
- You don't have to give all the information at once; you can keep communication open for future discussions.
- For some people simple facts will be enough, for example: "I've found out I have a genetic/neurological disorder, I'm okay right now but it's a disease that progresses." You may, however, want to share more with those closer to you.
- Keep discussions at an age appropriate level. For example, younger children will only require basic information that can be built on over time.
- Give written information if it's too difficult to talk about initially, then follow up with a conversation. Your HD Specialist or Specialist Youth Advisor can help or your genetic clinic can provide a letter to explain your result to family members.

What difference might it make?

- Telling others about Huntington's disease can open up new support and help you to plan for the future.
- You may feel relieved that you are not facing this on your own any more.
- You can help others to understand. and adapt. For example, if you are struggling at work, your employer can look at making reasonable adjustments to help.
- Close family members, particularly children, may sense that something is wrong. Knowing the facts might make them feel relieved and more informed.



You are not alone

We're here to help you and your loved ones with these conversations. Speak to your HD Specialist or Specialist Youth Advisor for more advice or support. You can also call us on 0141 848 0308.

Scottish Huntington's Association is the only charity in the country exclusively dedicated to providing expert and personalised support for those impacted by Huntington's disease.

Our HD Specialists provide vital physical health, mental health, wellbeing support and care co-ordination for all adults within a Huntington's family – whether they be symptomatic, asymptomatic, at risk or carers.

Our Specialist Youth Advisors provide personalised support, age-appropriate information and resources, and opportunities to build friendships and enjoy respite experiences that would otherwise be impossible.

Visit our website at hdscotland.org

