LIVING WITH HUNTINGTON'S DISEASE

A guide for young people aged 8–12

Scottish Huntington's Association

Specialist support for Huntington's disease families

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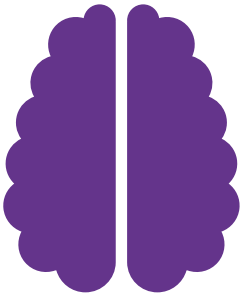
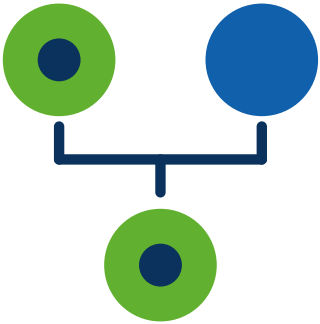
Scan here for more

Scottish Huntington's Association

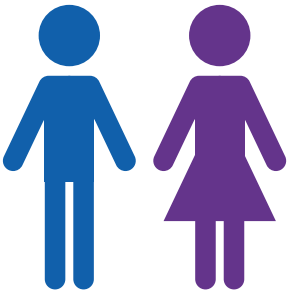


Huntington's disease affects someone's brain

50/50 risk of child inheriting Huntington's disease from parent



Huntington's disease does not skip generations



Huntington's disease affects both men and women

Huntington's disease changes a person's movement, mind and mood

Huntington's disease usually develops in adulthood, between the ages of 30–50

Huntington's disease is a genetic condition

Scientists across the world are involved in the search for a treatment

Around 800 people in Scotland are living with symptoms of Huntington's disease right now

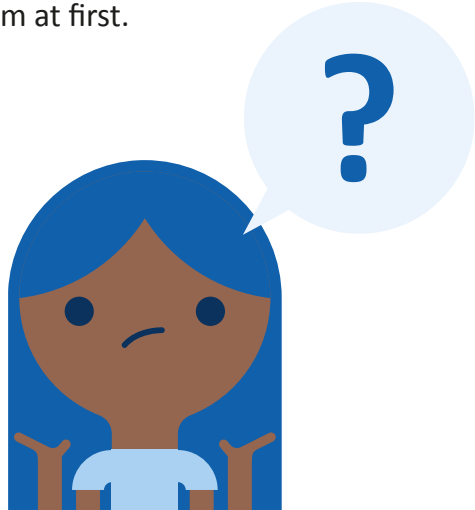
A further 3,200 are at risk of developing the disease and thousands more are impacted (e.g. carers and family members)

WHAT IS HUNTINGTON'S DISEASE?

MOVEMENT MIND MOOD

Huntington's disease (often shortened to HD) is an illness that affects someone's brain and stops it from working as well as it used to. When it doesn't work so well, the brain stops sending the messages that help us move, talk or remember to do things. These changes are called the symptoms of HD. The symptoms can be grouped together as **Movement**, **Mind** and **Mood**. Most people start to show symptoms of HD when they are an adult – usually between 30–50 years old.

When someone has HD, they may change the way they move, behave and think. Sometimes, they are not able to walk and talk as well as they could before, or they might be more forgetful. Sometimes they may be more bad-tempered or get cross about things that wouldn't have bothered them before. These changes may take a long time and you might not even notice them at first.



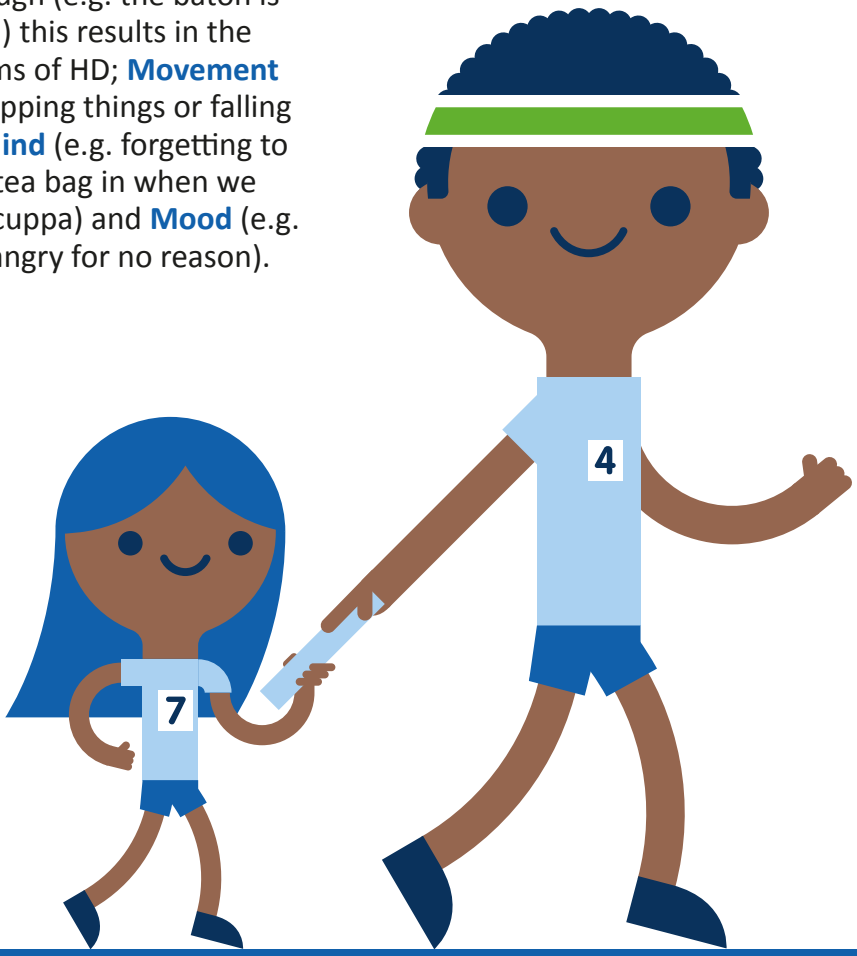
We see these changes because of the way Huntington's disease is affecting their brain.

A human brain is very complex. It helps us to think, walk, talk, play computer games, swim and remember the way to school.

In fact, everything that we do is controlled by the messages sent by the millions of brain cells inside our brains. When someone has HD, some of these brain-cells become sick and begin to die. When enough of these brain cells die, this stops some of these important messages in our brain get to where they are meant to and this causes the symptoms of Huntington's disease.

One way to think about this is with an example. Imagine that you are taking part in a relay race – each member of your team has to pass the baton onto the next runner who then completes their lap. Each person passes the baton onto the next member of the team until they finish the race.

When the message doesn't get through (e.g. the baton is dropped) this results in the symptoms of HD; **Movement** (e.g. dropping things or falling over), **Mind** (e.g. forgetting to put the tea bag in when we make a cuppa) and **Mood** (e.g. getting angry for no reason).



For example, if you wanted to pick up your phone, your eyes send a message to your brain about where the phone is and then the brain sends a message along your arm and hand to move it to the right place. This message gets passed through your brain by your brain cells just like the baton in the relay race.

For someone who has HD, the message gets passed through the brain by the brain cells but sometimes a cell drops the baton. The message then doesn't get through properly and they drop the phone. This is one of the reasons why the person with HD may seem clumsy, drop things or fall over.

People can live with HD for many years. This is because the brain cells die slowly over a long time. They may live at home for a while and manage well, however as time goes on they may need more help with day-to-day life and they might need to be looked after by other people.

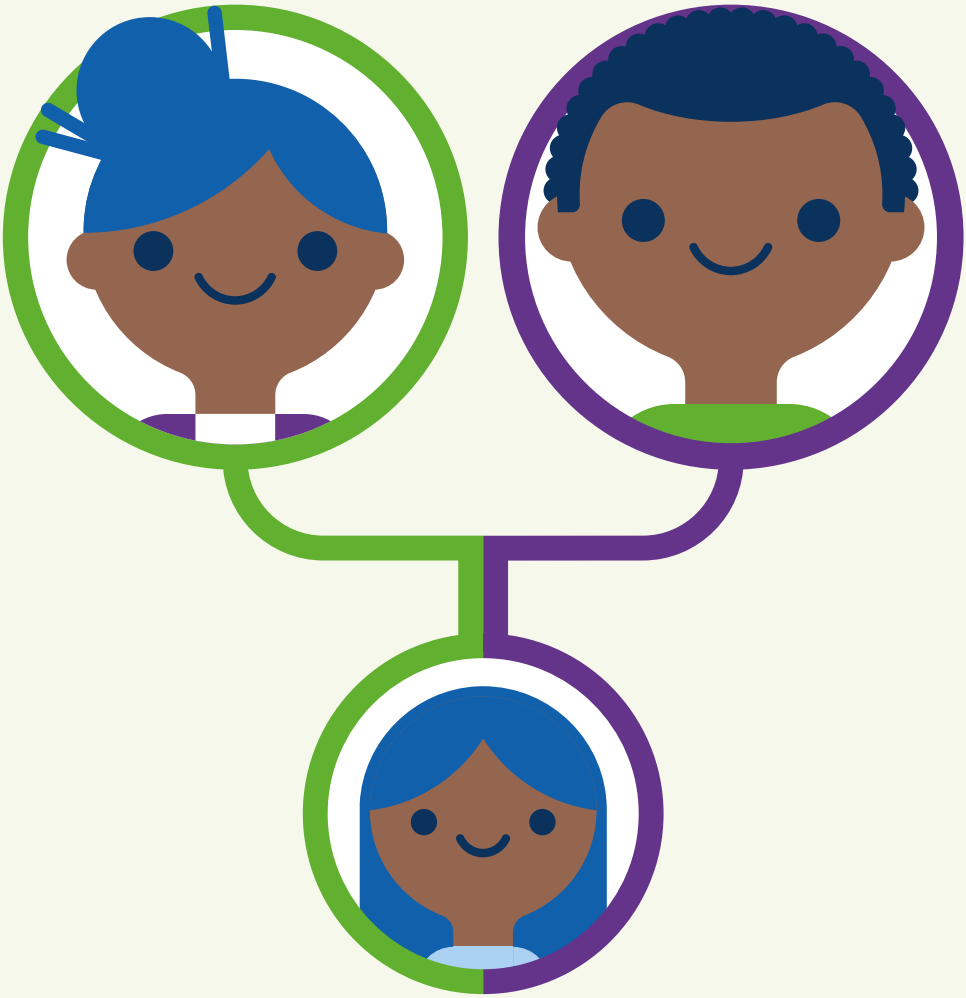
WHAT CAUSES HUNTINGTON'S DISEASE?

You might have more than one person in your family with HD. This is because HD is **hereditary** (say: huh-red-i-ter-ee). If a parent has HD then their children will have a 50/50 chance of having it too.

You might hear people talking about **genes** (say: jeenz). Your body is made up of millions of cells and your genes are contained in each of these cells. Genes contain the instructions for how to make up your body – they decide what colour your hair is, how tall you are and the colour of your eyes. It's a bit like a recipe book where your genes are the instructions that make up you, and everyone has a different recipe. That's why everyone is a different shape and size.

People might say that you look like someone else in your family. This is because of your genes too. Genes are passed from your parents – half from your mum and half from your dad. That's why you might have the same colour of eyes as your mum or a nose like your dad. Everyone has about 30,000 different genes in their body.

Sometimes, genes don't work properly and they can cause people to become unwell. HD is caused by a gene that doesn't work properly. This gene is what makes the brain cells become sick and die. No one is entirely sure why this happens but scientists around the world are working incredibly hard to find more effective treatments and ultimately a cure for HD.



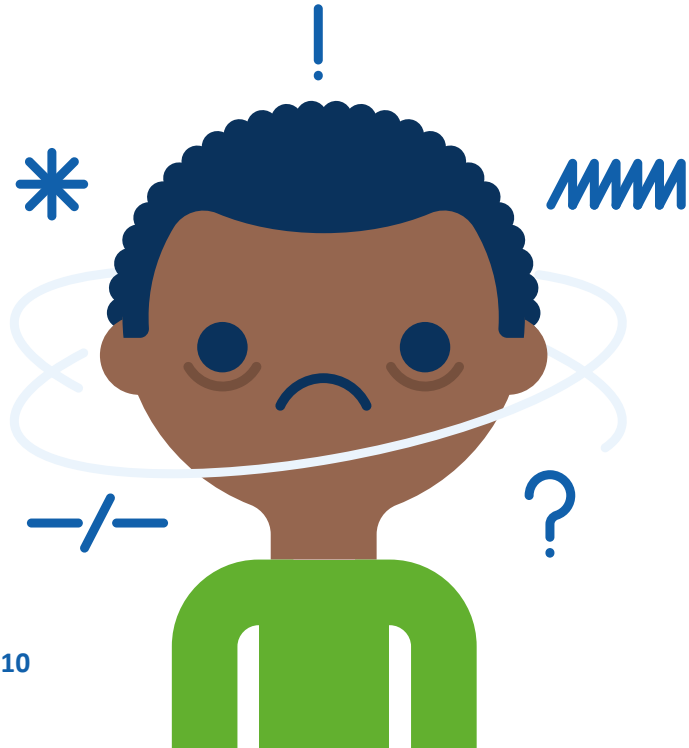
If your parent has HD then there is a 50/50 chance that you might get HD when you are older too but there is the exact same chance that you won't get it at all.

LIVING WITH HUNTINGTON'S DISEASE

It can be difficult when someone you love has HD. There can be lots of changes to cope with – they might not be able to do some of the things that they used to. They might not be able to walk or talk as well, they might get angry or be rude to you, or they might forget to do things. These changes are because of the cells that are dying in their brain. **It is not your fault** – or theirs. They still love you but just might not be able to show it as well as they used to do.

Other people might not understand that these changes are because of HD. If you wanted to, you could show them this booklet to help explain the illness.

Talking about Huntington's disease can make things easier. Finding out all of this information can be a lot to take in and confusing. If you have questions you can write them down on page 11 of this booklet and then ask someone. This may be someone in your family or a Scottish Huntington's Association Specialist Youth Adviser.

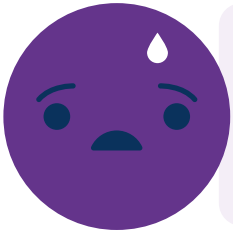


Write down any questions you may have here:

It’s okay to ask these questions more than once!

FEELINGS ABOUT HUNTINGTON'S DISEASE

Sometimes it can feel unfair or difficult that you have to deal with HD when your friends don't. Some people might feel:

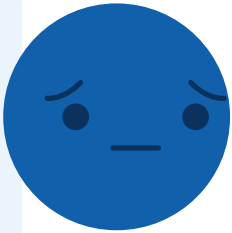


Worried: You may feel worried about the person with HD and your family. It is normal to feel like this. Remembering to have fun and sharing your worries with someone you trust can help you feel better.

Sad: Thinking about the changes that HD may have on your family can be upsetting. If you are feeling sad – talk to someone about it. Sometimes a hug and a cry can help you feel better. If there is no-one to talk to try talking with your pet or a teddy bear – they make good listeners and huggers too!

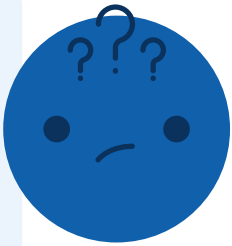
Embarrassed: People with HD can behave differently from other people. They can sometimes walk in a strange way or slur their words. Other people might not understand why they do this or realise that they can't help it. Remembering that not everyone knows about Huntington's disease, and can often mistake the symptoms for something else, might help you to cope better with their reactions. If you feel like it, you could try to help them understand a bit more about the disease.

Guilty: Sometimes you might feel guilty that your parent can't do some of the things they used to. Perhaps they aren't able to go out with you or can't play games with you anymore. It's important to remember that none of this is your fault. Find someone that you can talk to about it.



Angry: It's okay to feel angry, or get angry about things to do with Huntington's disease. When we are angry it is important not to hurt ourselves, someone else or things. Why not try doing as many star jumps as you can or see how high you can bounce a ball?

Confused: There is a lot of information about HD which can be confusing when you first find out about it. If you have any questions about what you have read or heard it is best to ask someone you trust. This might be someone in your family or your Specialist Youth Advisor from Scottish Huntington's Association.



What you are feeling is normal. Everyone deals with things differently and there is no right or wrong way to feel about HD. Telling your school about HD can also help.

WHAT'S NEXT?

It can be really tricky to keep calm when you are unsure what the future will hold. You may be thinking – what will happen to me? Will my brother or sister get HD? Will I still laugh and enjoy myself?

No one knows what the future will hold but here are some hints and tips that you can try to help you cope with HD.

Look after yourself

Enjoy each day and take good care of yourself. Make time to do things you enjoy – like seeing your friends, going swimming or cycling, or playing your computer. Have some fun!

Be informed

Make sure that you get the information you need. Ask questions if you are not sure what something means.

Talk about HD

Talking about HD can help others understand what you and your family are going through. Keep talking about HD!

Remember that you are still growing and learning as a person

You are still young, how you feel now might change as you get older.

Be yourself!

Don't let others tell you how you should feel. Allow yourself to cope at your own pace and in your own way.

Accept people's help

Right now you may feel more confused and lonelier than you have ever felt before in your life. Try to remember that you are not alone. Family, friends, Scottish Huntington's Association, neighbours and teachers are all there to lend a hand, listen to you and be there for you. Taking help is not a sign of weakness – it's a sign of strength and you could really benefit from their support.

Live each day to the full

You can still enjoy quality time with the person who has HD. You may have to adjust the activity to help them continue to take part with you. This can help you all to make lasting memories.

WHAT DOES YOUR SCOTTISH HUNTINGTON'S ASSOCIATION YOUTH SERVICE OFFER?

Our Specialist Youth Advisors work across Scotland

Support for young people, parents and professionals

Support

Group sessions

Activity days

Residential breaks

5-day summer camp

Scottish Huntington's Association

Specialist support for Huntington's disease families

NATIONAL LOTTERY FUNDED