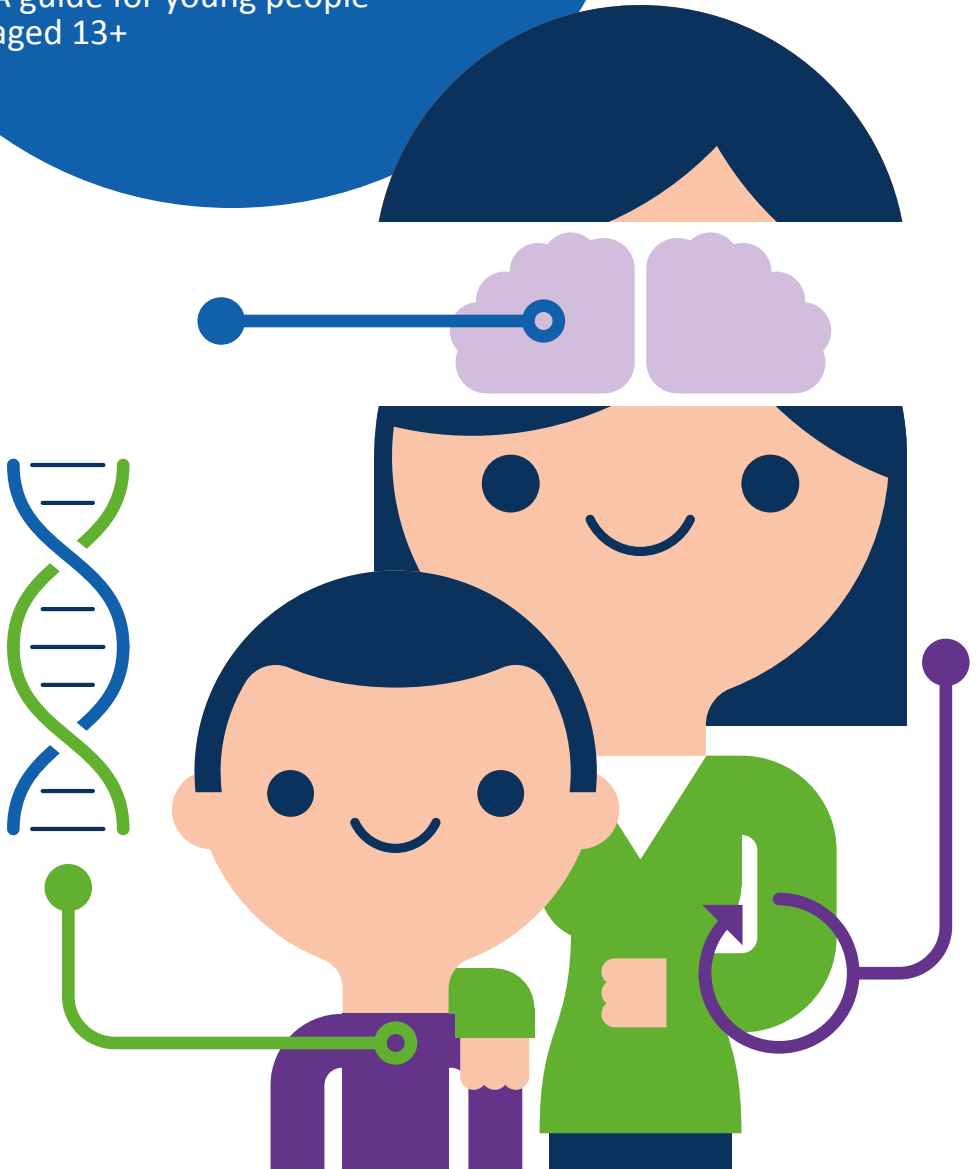


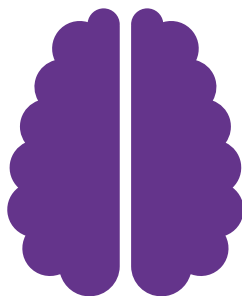
# LIVING WITH HUNTINGTON'S DISEASE

A guide for young people  
aged 13+



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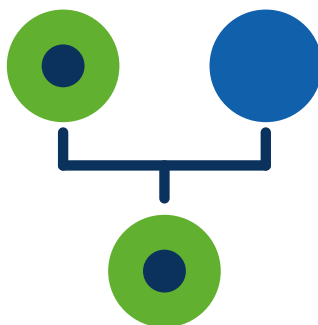
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**Huntington's disease affects someone's brain**

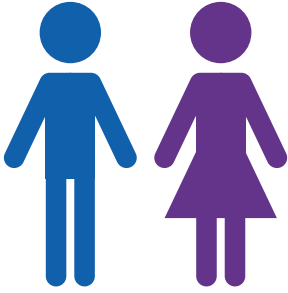


**50/50 risk of child inheriting Huntington's disease from parent**



**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**

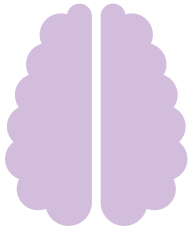


A further 3,200 are at risk of developing the disease and thousands more are impacted (e.g. carers and family members)

# FACTS ABOUT HUNTINGTON'S DISEASE

Huntington's disease (HD) is a complicated condition. Before we discuss it in more detail, here are four key facts you should know:

1



Huntington's disease affects a person's brain. This causes a change in the way they control their movement, mind and mood.

Huntington's disease is a medical condition where brain cells in a specific area of the brain, called the **basal ganglia** (say: bay-sul gang-lee-ah) slowly die. When these brain cells die, this part of the brain doesn't work as well as it should which can cause people with Huntington's disease to have jerky movements that make them appear fidgety, experience poor mental health and have difficulty controlling their mood and behaviours.

2



Huntington's disease affects everyone differently.

There are three main types of symptoms that Huntington's disease causes. These are called **Movement**, **Mind** and **Mood**. Some people will struggle more with controlling their movements, while others will have more difficulty with their mind (like remembering things or making decisions) or controlling their moods.



3



There is a test, which someone can take to find out if they have Huntington's disease.

In 1993, scientists identified the gene that causes Huntington's disease. This has allowed those at risk of inheriting the disease to undergo a **test** to see if they carry the HD gene. In Scotland this test is available to those who are 18 or older. This has allowed diagnosing Huntington's to become a more straightforward process.

4



Huntington's disease can be treated.

Although at the moment there is no cure for Huntington's disease, doctors are able to use a range of **medications** to help manage its symptoms. There is also a range of other treatments that may help, including; **physiotherapy** (physical treatments to help people improve their movements), **occupational therapy** (to help find other ways to carry out everyday tasks and activities) and **speech and language therapy**.



# WHAT IS HUNTINGTON'S DISEASE?

One of the first questions you might have is  
*"What is Huntington's disease?"*



MOVEMENT



MIND



MOOD

Huntington's disease (often shortened to 'HD') is an illness that causes damage to someone's brain. This damage means that their brain doesn't work as well as it used to, and results in changes to the way they control their **movements**, **mind** and **mood**.

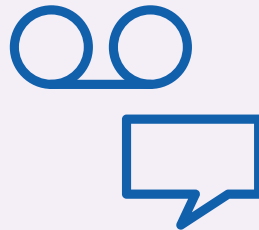
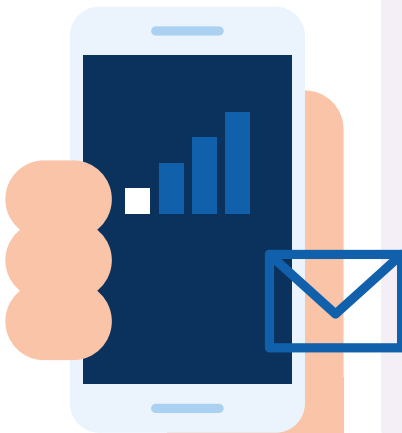
Huntington's disease is a hereditary illness – this means that it runs in families and can be passed on through generations (from grandparent, to parent, to child). It is also **neurodegenerative**, which means that it causes damage to the brain cells and gets worse over time. People with Huntington's disease normally start to develop symptoms when they are an adult (aged between 30–50) and it affects both men and women.

Scientists are undertaking a lot of research to establish what causes Huntington's disease and why people don't show symptoms until they are older. They are fairly confident that the damage to the brain is caused by the build-up of a protein called **huntingtin**. Everyone creates this protein, however most people create just the right amount. When someone has Huntington's disease, they create too much huntingtin. This starts to build up in the brain (a bit like a traffic jam) which it can't cope with. The brain cells become sick from the extra huntingtin and start to die. When enough of the brain cells die we see the symptoms and changes caused by Huntington's disease.

The part of the brain which is most affected by Huntington's disease is the **basal ganglia** (*say: bay-sul gang-lee-ah*). This part of the brain is very important because it acts as a message sorting area and co-ordinates all of the different messages sent by the brain. It handles a lot of information and makes sure that these messages get to where they are supposed to go. HD causes the brain cells in the basal ganglia to deteriorate and die. When this happens, the brain struggles to co-ordinate these messages whizzing around as well as it used to. Some of the messages get lost or don't always get to where they are meant to be which causes the symptoms of Huntington's disease.

**One way to think about this is to compare it with the signal on your mobile phone.**

Sometimes you can have a really good signal, but move and the signal gets poorer and you are unable to call, text, or get the internet. Sometimes your phone has limited signal that lets you start a call – but you get cut off half way through. With Huntington's disease, the brain can be a bit like that. Sometimes when the brain sends a message it manages to get to where it is supposed to or sometimes only half of the message gets through. At other times none of the message will be sent. When the brain cells become damaged and die, it's a bit like having a limited signal on your phone – the mix-up of the messages sent by the brain results in the symptoms Huntington's disease causes. The symptoms of Huntington's disease cause significant change in someone's ability to control their movement, mind and mood.



# SYMPTOMS

Another question you might have is *“What happens when someone has Huntington’s disease?”*

Huntington’s disease affects people in three main ways. The **symptom triad**; **movement**, **mind** and **mood** are the broad categories for lots of different symptoms someone with Huntington’s disease may be affected by. It is important to remember that everyone is unique and HD affects everyone differently. The person you know with Huntington’s disease might have some of these symptoms, and these may change over time.

Most people experience symptoms from each of the Movement, Mind and Mood categories. However, some people with Huntington’s disease may struggle more with their movements (like walking or keeping their balance) while others have more difficulty remembering things or controlling their anger. Just like the person with Huntington’s disease, you may find some of their symptoms more difficult to live with than others. Some young people may be embarrassed by the jerky movements caused by Huntington’s disease while others may get frustrated by their parent’s frequently changing mood.

## Movement



Huntington’s disease can affect the way someone controls their movements and muscles. The muscles

in our body control all of the different movements and activities we do everyday – like walking, running, chewing, swallowing, breathing, talking and driving. Some of our muscles help us stand up, keep our balance, and go to the toilet. HD can affect all of the muscles in our body, and these changes to someone’s movements are often the most obvious symptom to see.





### Voluntary movements

Huntington's disease can make it difficult for someone to move their body **in ways that they want to**. This can make performing certain activities more complicated and tricky. Sometimes it is the co-ordination of many different movements together that makes it difficult for the person to complete the action.

Their walking may become slower, their balance may become less steady, their speech may become less clear and things like writing or making a cup of tea take more effort and are less precise.

### Involuntary movements

Huntington's disease also causes involuntary movements. These are **movements that the person cannot control and are not choosing to do**. Involuntary movements can affect their whole body and cause the person to jerk and shake. These movements can make carrying out everyday tasks, like making a sandwich, more complicated. Keeping still can become almost impossible for someone with Huntington's disease over time, even when they are sleeping.



### Some other symptoms associated with movement difficulties:

- Jerky movements
- Shaking
- Walking in an unusual way
- Falling over more
- Moving slowly
- Difficulty speaking
- Finding it hard to swallow food
- Making strange faces
- Dropping things
- Difficulty breathing easily
- Becoming stiff and rigid
- Slowing down of movement
- Changes in weight

## Mind



Huntington's disease can change how someone thinks and they may find it harder to carry out tasks

that require them to think and concentrate. Our brain is complex. It allows us to organise our thoughts and get things done. Huntington's disease causes the person to have difficulty making decisions, keeping things organised, concentrating for a long time, remembering things and maintaining their focus.

When the brain is affected by Huntington's disease, it struggles to keep all of the messages whizzing around in order. Sometimes these messages can get mixed up and cause the person to become confused and muddled. A person with Huntington's disease may do things in a different order, or forget to do a specific step in a task, like forgetting to add the tea bag when they make a cup of tea. They may take longer to complete the task, or give up altogether.

### Tips

- Give them time to answer
- Talk slowly and precisely
- Give limited options (e.g tea or coffee)

Sometimes tasks, like remembering different words or answers, might take them a bit longer. You can help by giving them time and space to answer, or only giving them two options to choose from (e.g. would you like tea or coffee?).

While people with Huntington's disease struggle with certain thinking tasks it doesn't mean that they are not aware of what is going on around them. They will remember who you are – and that they love you. They are still interested in your day, will want to hear how it has been and what you have been up to.





## Mood



Huntington's disease can cause changes to the way someone controls their emotions and behaviour –

perhaps you have noticed that they have become more irritable, angry or sadder than before. Sometimes, they might say things that they wouldn't have before, or behave differently from others. They also might not be aware of how their behaviour or actions can affect others.

These changes happen slowly over a long time and can make it harder for the person to do some of the things they used to do with you (like watching TV programmes or going for days out). They might become angry more often, be rude to you, or appear uninterested in things. There are different medications that can help these symptoms and help people control their mood.

Try to remember that it is the illness that is causing all of these changes within your parent, or family member. It is not your fault or theirs. They still love you but sometimes may not be able to show it because of the changes caused by the illness. Young people often identify the changes to their parent's personality and mood as being one of the hardest to live with.

### Tips

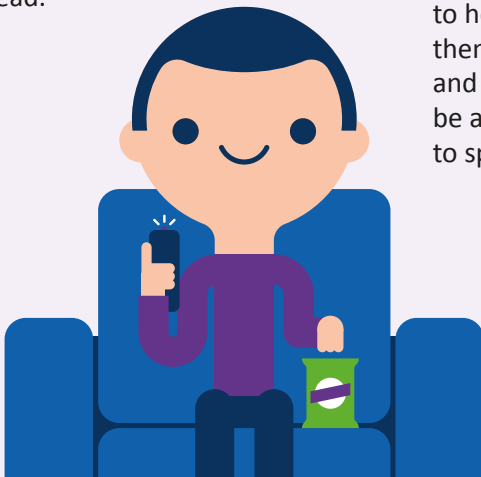
- Try to keep calm yourself and keep a nice relaxed atmosphere
- Try to avoid confrontations or from making it worse
- Try to get them to focus on something else
- Try to keep routine, and structure in their day

# LIVING WITH SOMEONE WHO HAS HUNTINGTON'S DISEASE

It can be tough when someone you love has Huntington's disease. There are a lot of changes and difficulties to deal with. Over time, symptoms of Huntington's disease become more obvious than they used to be. Most of the time people with Huntington's disease continue to live at home but might need some extra help and looking after. Some young people help by tidying up, cooking and cleaning, or looking after younger siblings. It can be a good thing to help out and make sure your parent is okay. However, sometimes this can lead to a lot of pressure for young people and it might get too much. It is normal to worry about your parent when you are not with them, and feel that you want to help as much as you can. It is also important to take some time out and look after yourself. Try to fit in time to do things you enjoy – you could join a club, a sports team, watch TV, or read.

Usually people will give up work when their symptoms become too much. Giving up work may have a big impact on everyone – there may not be as much money as before, or you might need to help out around the house more often. Sometimes the person with Huntington's disease, or those looking after them, might need a break. It is possible for them to go somewhere for a short time to give everyone some time-out and rest. This is called **respite**. Sometimes, it can be very difficult, and draining to look after someone all of the time. Respite breaks are also available for those caring for the person with Huntington's disease too. Respite can help everyone feel better and continue to live together.

Sometimes, it may become too much to look after someone with Huntington's disease at home and they may have to live in a care home. In a care home there will be people to help look after them, cook for them, give them their medication and take them for day trips. You will be able to visit them, and continue to spend time with them.



# GENETICS

You may also have thought about *“What causes someone to have Huntington’s disease?”*

There might be more than one person in your family with Huntington’s disease. This is because it is **hereditary** and can run in families. Hereditary means that it can be passed from parents to their children through genes. Sometimes, people might say that children look like their parents – perhaps you have the same nose, hair colour or freckles. Children look like their parents because their genes decide these characteristics and their genes are passed on from their parents when they are born.

**Deoxyribonucleic Acid (DNA)** is the genetic instructions for building our body. Our DNA contains genes that are the specific instructions to make all of the different parts of our body – they decide everything from our eye colour, the shape of our nose, and our height. These instructions help our body make lots of different proteins. In 1993, scientists discovered that Huntington’s disease is caused by one of these instructions being repeated too many times. This instruction is known as a ‘C-A-G’ repeat and is the genetic code for the huntingtin protein. Everyone has instructions to make the huntingtin protein. Usually the body makes just the right amount that it needs. However, when someone has Huntington’s disease this instruction is repeated too many times and their brain makes more protein than it can use. This extra huntingtin protein gets stuck in the brain (a bit like a traffic jam) and becomes toxic. The toxic huntingtin protein causes the brain cells to become sick and die. When enough brain cells die, we see the symptoms caused by Huntington’s disease.

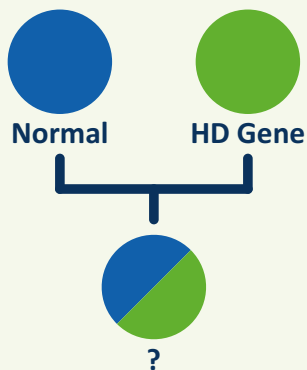


# BEING AT RISK

You may also be wondering “Do I have HD?”

**Genetic risk**, or being ‘at risk’, is the phrase used to describe the chance that someone has of inheriting Huntington’s disease. Huntington’s disease is a genetic condition; it is hereditary so can be passed down from parent to child through genes in our DNA. This means that anyone who has a parent with Huntington’s disease has a 50/50 risk of inheriting it themselves.

Children inherit their genes from their parents, half from their mum and half from their dad. If a child inherits the Huntington’s disease gene, that means they will develop Huntington’s disease at some point in their life. Most people who are at risk of Huntington’s disease have a 50% chance of inheriting the Huntington’s disease gene because their affected parent has one copy of the Huntington’s disease gene and one normal copy of the gene. This can be written as 50/50 or a ‘1 in 2 chance’.



Being at risk might make you worry about whether you have inherited the Huntington’s disease gene. You may start to look out for symptoms in your own behaviour and actions. This is called **symptom watching**. Usually this happens when you feel that you have been clumsier than normal, or a bit more forgetful.

Everyone has ‘off-days’ or goes through times like this. It doesn’t mean that you have inherited the Huntington’s disease gene. Sometimes it can be easy to jump to thinking that you have Huntington’s disease when it is a part of your family; maybe because you have seen your parent be clumsy or trip up. Other young people can be clumsy and forgetful but have never even heard of Huntington’s disease.

If this is on your mind it can be really helpful to talk with someone. Get in touch with one of the Specialist Youth Advisors from Scottish Huntington’s Association.

***It is important to remember that there is the same chance of NOT inheriting HD as there is of inheriting it.***

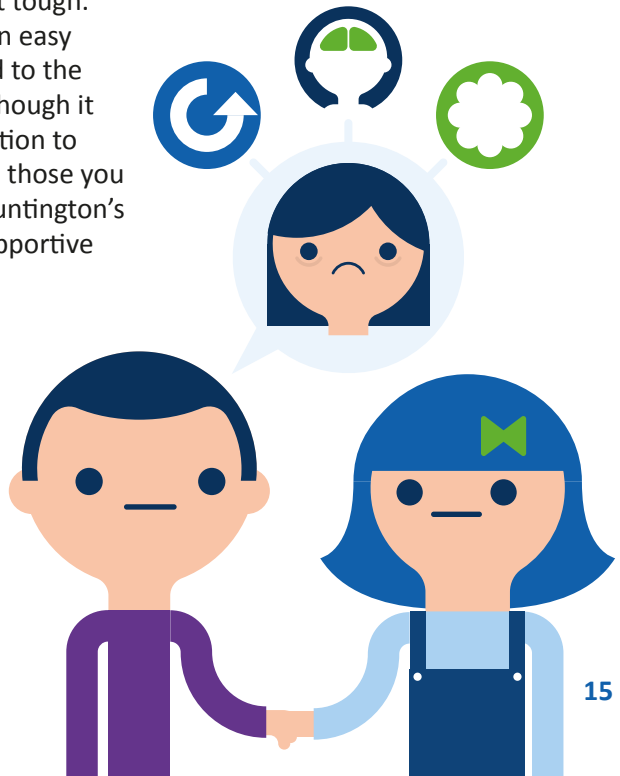
# RELATIONSHIPS

Life can be more complicated when your parent or grandparent has Huntington's disease. You might have to consider more things than other people your age have to. You will still be able to go to university, have a career, go travelling, get married and have a family – you can do whatever you would like to do.

Choosing to share your risk status or your family history of Huntington's disease can be difficult – especially if you are in a serious relationship. It is often better in relationships to be **open and honest** with people about Huntington's disease. These are the people who are important to you and those who will be there to support you if times get tough. Keeping secrets is never an easy thing to do and it may add to the stress of the situation. Although it can be a difficult conversation to have, it is beneficial to tell those you love and care for about Huntington's disease. People can be supportive and understanding.

If you decide to tell them, it is best not to go in expecting a 'big chat'. It can make the conversation much easier if you are relaxed and allow them time and space to think about it and come back to you with any questions they may have. Why not show them this booklet to help them find out a bit more about the disease, and then you can chat it through with them.

***Remember – it is up to you who you tell and when you tell them. Trust your judgment; if it feels right then go for it.***



# GENETIC TESTING

You may now be thinking “How do I know if I have Huntington’s disease or not?”

Since 1993, when scientists discovered where the gene that causes Huntington’s disease is in our DNA, there has been a genetic test that someone can take to find out if they have inherited the repeated instruction that causes Huntington’s disease or not.

## Predictive testing

Those who are at risk of Huntington’s disease but are not currently showing symptoms are able to take a predictive test to find out if they have inherited the disease or not. This test involves examining someone’s DNA in a lab and counting how many times their instructions for the huntingtin protein is repeated (known as their C-A-G repeat). A positive predictive test will tell them that they carry the Huntington’s disease gene. It will not be able to tell them when symptoms will start. A negative result means that they do not carry the gene and they will not develop Huntington’s disease. Any children they have will not be at risk.

## Diagnostic test

Someone who is showing symptoms of Huntington’s disease but who does not currently have a diagnosis will take a diagnostic test. This will confirm if it is Huntington’s disease that is causing the changes in their life.

In Scotland, genetic testing is available to those who are 18 years or older. Your local genetics department will provide counselling and carry out the test. Some young people choose to go for the test as they feel it will relieve some of the uncertainty about their future. It may also help them make an informed decision about getting married, having children or deciding on a career choice. Other young people choose not to go for the test and feel that the result will not change how they choose to live their life.





## IS THERE A CURE?

At the moment there is no cure for Huntington's disease, however there are medications that can help manage the symptoms caused by the illness. Scientists around the world are working incredibly hard to find more effective treatments and eventually a cure for the condition. Important steps are being taken every day and there is a lot of hope in the research currently being undertaken.

More information about the current research being conducted into Huntington's disease can be accessed online at [hdbuzz.net](http://hdbuzz.net).



# THINKING ABOUT HAVING A FAMILY

Having children is a very personal decision that everyone has to make for themselves. If you have Huntington's disease and choose to have a child then they will be at 50% risk of inheriting Huntington's disease. If you are at 50% risk and do not want to find out if you carry the Huntington's disease gene then any child that you have will be at

25% risk. Many people consider this before having a family. Some people choose to have a baby naturally. For others they may choose not to have children or to use an alternative method. Here are two examples which reduce the risk of passing on Huntington's disease.



### **Pre-Natal Genetic Testing**

This is a technique which allows a couple to test their foetus to see if it has inherited Huntington's disease or not. This test would be carried out at a Genetics Centre and a specialist would be able to discuss any concerns and the different outcomes.

### **Pre-Implantation Genetic Diagnosis**

Pre-Implantation Genetic Diagnosis (PGD) uses In-Vitro Fertilisation (IVF) techniques to fertilise the woman's eggs in a lab. These are then tested to see if they have the Huntington's disease gene or not. Only embryos that do not have the Huntington's disease gene are implanted into the woman in the hope that she becomes pregnant. This technique ensures that the baby will not have the Huntington's disease gene. In Scotland, PGD is available through the NHS, however there is a list of criteria you have to meet before you can be considered.

## **THE INTERNET**

The internet can be a really useful place to find out lots of good information. However, remember that it also has lots of poor, inaccurate information that can be scary or offer false promises.

The best websites to use for information about Huntington's disease are:

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

**[hdyo.org](http://hdyo.org)**

**[hdbuzz.net](http://hdbuzz.net)**

These websites are written by professionals involved with Huntington's disease and contain accurate, up-to-date information about Huntington's disease.



# EMOTIONS

When you find out that someone in your family has Huntington's disease you might feel all sorts of different things. It can feel unfair that you have to deal with all of this when you just want to be like your friends. Some people want to talk about it, others don't. It is important to remember that everyone will react differently.

## Tips on managing emotions:



**Worried:** You may feel scared for the person with Huntington's disease or about what the future might hold for you and your family. It is normal to worry about the person you love with Huntington's disease or yourself. Remembering to take time out to have fun can help you. Sharing your worries with someone you trust can help you feel better.

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**Sad:** Sometimes when we think about Huntington's disease, it can make us feel sad and want to cry. It can also make us feel lonely, tired, or want to be by ourselves. Feeling this way is normal. Sometimes having a good cry or a hug can help us feel better and let go of some of the sadness. Try to do things that make you smile and laugh – but if the sadness doesn't go away make sure you tell someone you trust.

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**Angry:** It is okay to get angry – everyone gets angry. Sometimes, anger can build up inside us and it can come out in ways that we don't want it to. This can make us feel even worse. We have to be careful about how we express our anger. It is never acceptable to take our anger out on other people – we should never physically, or verbally, hurt other people or ourselves.

Physical activity is an excellent way to release anger. It helps get rid of the tension that can build up when we're angry. Some people find it helpful to go for a jog, punch a pillow, or write down what is causing them to be angry.



**Confused:** 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 23 of this booklet and then ask someone. This may be someone in your family or a Scottish Huntington's Association Youth Adviser.

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**Embarrassed:** Those with Huntington's disease can often act and behave differently from other people. Changes in the way that they walk, talk or behave might cause you to feel embarrassed when others stare, laugh or comment. Remembering that not everyone knows about Huntington's disease, and can often misinterpret the symptoms, 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 Huntington's disease.

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**Guilty:** You may feel guilty when you are having a good time or enjoying yourself when your parent is ill. Remember that this is not your fault and feeling bad about it won't help you or them. They want you to be happy and enjoy yourself. Living with Huntington's disease can be difficult – everyone needs a break from time to time.

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**Resentment and jealousy:** It is normal to think 'Why me?', 'Why my family?' or 'Why do I have this extra responsibility?'. You may feel jealous and resentful of other families who don't have to think about Huntington's disease – it's okay to feel this way. Try to focus on the positives – think about the things in your life that are important and what you are happy with. Remember that everyone has struggles and difficulties that you may be unaware of.

What you are feeling is normal! Everyone deals with things differently and there is no right or wrong way to feel about Huntington's disease. You are not alone – many teenagers are in a similar situation to you and will have felt the same way at some point. Sometimes Huntington's disease can make you look at life differently and some have said that it has brought them closer together.

# 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 get Huntington's disease? Will I still laugh and enjoy myself?

No one knows what the future holds, but here are some things that you can try to help you cope with Huntington's disease:

## **Discover you own needs**

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

## **Remember that you are still growing and learning as a person**

Many teenagers say that having a parent with Huntington's disease has made them more sympathetic, more responsible and a stronger person.

## **Accept people's help**

Right now you may feel confused and lonely. Try to remember that you are not alone. Family, friends, Scottish Huntington's Association Youth Advisers 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 that you could really benefit from their support.

## **Live each day to the full**

You can still enjoy quality time with the person who has Huntington's disease. 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.



No booklet, or person, can tell you exactly how things are going to work out. Living in a family affected by Huntington's disease is tough and you may never be quite the same as before you found out. In the end, you will get through it. You are strong and capable – even if you don't always feel that way.

**Write down  
any questions  
you may have  
here:**



**It's okay to ask these  
questions more than  
once!**



# 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



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