

WHAT IS Huntington's Disease?

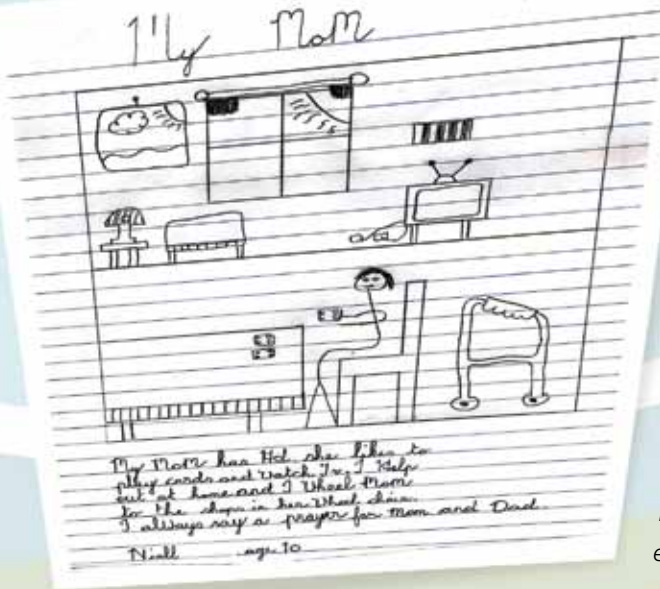
**A Guide for
Young People**

produced by



**Huntington's
Disease**
Association of Ireland

by Niall, 10 years old



If you are reading this you probably have a Mother or Father or someone in your family who has Huntington's Disease

(from now on I will call Huntington's Disease HD, except for the headings).

IF SO THIS BOOKLET IS FOR YOU.

In this booklet I will try to answer some of your questions, such as: **What is HD? What will HD do? How do you get HD?** Together with how you can look after your self during any difficult times.

What is Huntington's Disease?

HD is named after the American doctor George Huntington who was the first person to describe and write about HD in 1872.



HD is an illness that affects the brain; (the brain is just like the computer of our bodies). HD causes the brain to mix up messages and signals it sends to the body.

This causes thoughts, feelings and movement to become jumbled and confused.

HD usually starts to develop in people from age 30 to 50, sometimes it can develop in younger people but that is very rare; we call that Juvenile Huntington's.

Sometimes it can start in elderly people over the age of 60 or older.



What will Huntington's Do?

The changes that happen in people with HD are usually very slow to occur, they take a long time and can often be very well managed with the correct medication and changes in lifestyle.

Some of the symptoms which are most common are:



by Rory Glynn, 9 years old

- *A change in mood or behaviour.*
- *The person may get more frustrated and confused.*
- *They may become clumsy.*
- *You may notice funny twitchy and jerky movements.*
- *People with HD may find it difficult to speak and swallow their food.*

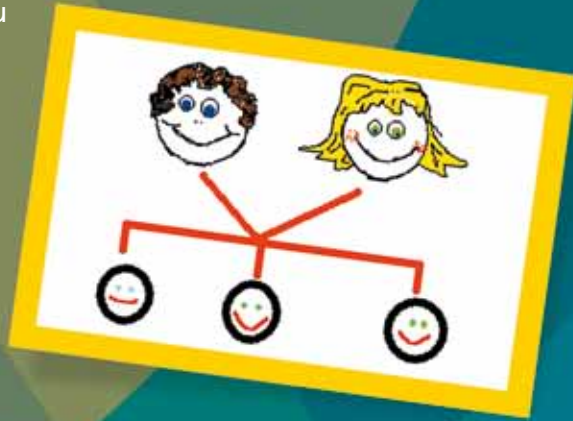
Remember everyone is unique and different so this may not be the same for every person with HD.

How do you get Huntington's?

You cannot catch HD like you would catch a cold. It is a family disease and you inherit the disease from your Mother or Father.

Now this is the complicated bit. All of our bodies are made up of cells, and in each of these cells there is what we call genes. Your genes have all the instructions or ingredients for who you are; they have all the information for your eye colour, your height and your hair colour.

We get our genes from our Mother and Father. We all have 2 copies of each gene, one we receive from our Mother and one from our Father. In some cases we get sick and unhealthy genes from our parents, and it's this faulty gene that causes HD.



If your Mother or Father has HD you have a 50:50 chance of developing HD but you also have a 50:50 chance of not getting HD. Just like the toss of a coin.

If you don't get the HD gene your children will not be able to get HD. If you do inherit the HD gene it does not mean your children will have HD. Remember they too have a 50:50 chance of not getting HD.

Looking after me?

HD can be scary; it can cause you grief because it is filled with so many unknowns and uncertainties. There is no cure for it yet and you don't know who else in your family may have it.

This may cause you to feel:

Angry Afraid Worried SAD

All these feelings are normal for you to have; they can be confusing at times as you can experience more than one feeling at once. Feelings are different just like us, some may swamp you like being hit by a wave, some may be quiet and still and some may take you by surprise. The most important thing here is to teach yourself skills that can help you identify how you feel and cope with these feelings safely.

There are three parts of you, your mind your body and your spirit, learning to cope is how you can best look after yourself; it's a skill that you can learn. You will need to look after all three parts.

by Rory Glynn, 9 years old



Express your feelings - when you are sad let someone know, a hug can make you feel better, cry if you need to, crying reaches beyond words and touches your soul.



It's ok to be angry, let your anger out in a safe way scream out loud or punch a pillow. If you are worried talk to someone you trust tell him or her what you are thinking about, all your worries will feel better out of your head.

If you are confused, ask questions until you understand the information, this may take time.

Make time for the things that you enjoy most:



Get fit, keep a diary, write, make music, take baths, laugh, surround your self with your friends, remain positive, and share your problems. You may be able to see that **TALKING** to others is the biggest thing you can do for yourself. Don't keep things to yourself that's my biggest tip!!

The Future of Huntington's Disease

Scientists all over the world are working on HD. There is no cure for HD just yet, however every day brings progress and with that hope.

NO ONE IS GIVING UP!

You are not alone

There are other family's living in Ireland with HD. If you want to get in touch or need more support contact the Huntington's Disease Association of Ireland's office for more information.

Huntington's Disease Association of Ireland
Carmichael House, North Brunswick Street,
Dublin 7, Ireland.

Telephone: 01 872 1303. Fax: 01 872 9931.

E-mail: hdai@indigo.ie

Website: www.huntingtons.ie

FreeFone 1800 393939



Huntington's Disease Association of Ireland

Other useful numbers

Child line: 1800 66 66 66.

Samaritans: 1850 60 90 90.