



Huntington's  
Disease  
Association

# **Huntington's disease: A Quick Guide for South Asian Families**



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*We'll be there*

## Huntington's disease, what is it?

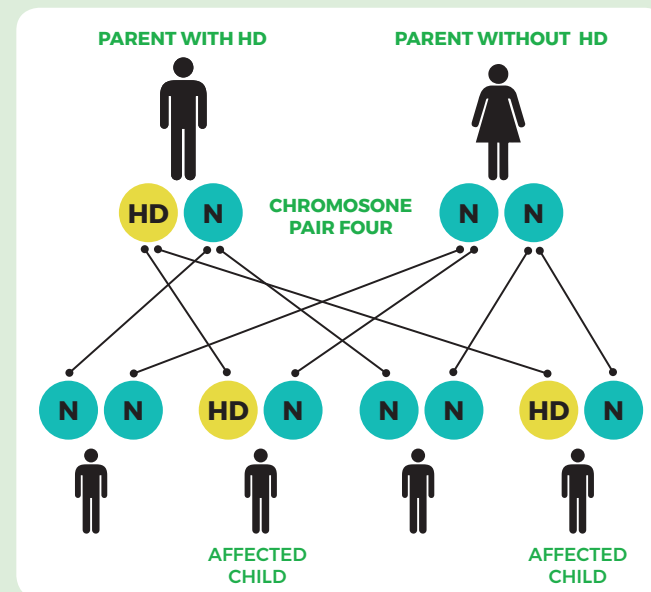
Huntington's disease is a rare illness that affects both men and women and can be passed from a parent to a child. Huntington's usually develops between the ages of 30–50 years old but can sometimes begin earlier or later on in life. Symptoms may include physical, thinking and mood changes. These usually increase over time. You might live with Huntington's for around 20 years or more and will need support from family, health and social care professionals during this time. (Contact the Huntington's Disease Association (HDA) or your GP for further information) Although there is currently no cure, researchers are developing new ways to help with people's symptoms.



## How is HD passed on?

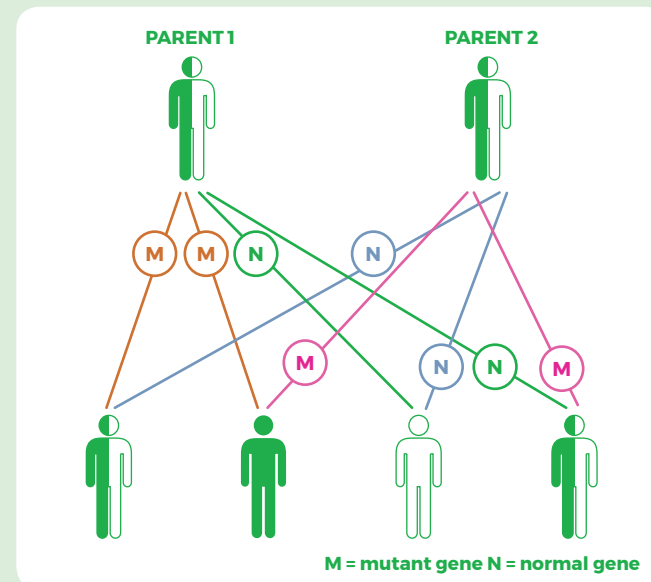
When a parent has the faulty Huntington's gene, each child has a 50% chance of having that gene passed onto them.

If both parents have a faulty Huntington's gene this means that each of their children will have a higher risk of getting Huntington's.



In some rare cases if one parent has two faulty Huntington's genes then all of their children will develop Huntington's.

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## Common symptoms

**People who have Huntington's may show different symptoms. Some of these might be:**



### Physical

- Extra movements (chorea)
- Stumbling and falling over
- Dropping things
- Changes in speech
- Swallowing problems
- Losing weight



### Thinking (Cognition)

- Poor short-term memory
- Trouble thinking ahead
- Hard to do more than one thing at a time
- Being stuck on a thought



### Mood

- Sadness (depressed)
- Anger
- Grumpiness (irritability)
- Loss of interest
- Worry (anxiety)

**Your GP can help treat many of these symptoms.**

## Options - Planning for the future



### Genetic testing

Wondering if you might have the faulty Huntington's gene from your parent with Huntington's can be very worrying. Some people feel better if they can check this early on in life rather than waiting to see what happens. If you are over 18 you can ask your doctor to contact your local genetics service for a predictive test.

### Having children

Sometimes people want to look at ways to stop the faulty Huntington's gene being passed onto their children. Two options some people think about are pre-implantation genetic diagnosis (PGD) and prenatal testing.



**Pre-implantation genetic diagnosis (PGD)** involves a couple undergoing IVF treatment but where embryos are tested for the Huntington's gene. Only the Huntington's free embryos are used to grow and develop. Sometimes people do not want to know whether or not they have the Huntington's gene themselves. A certain type of PGD can often be used in these situations.



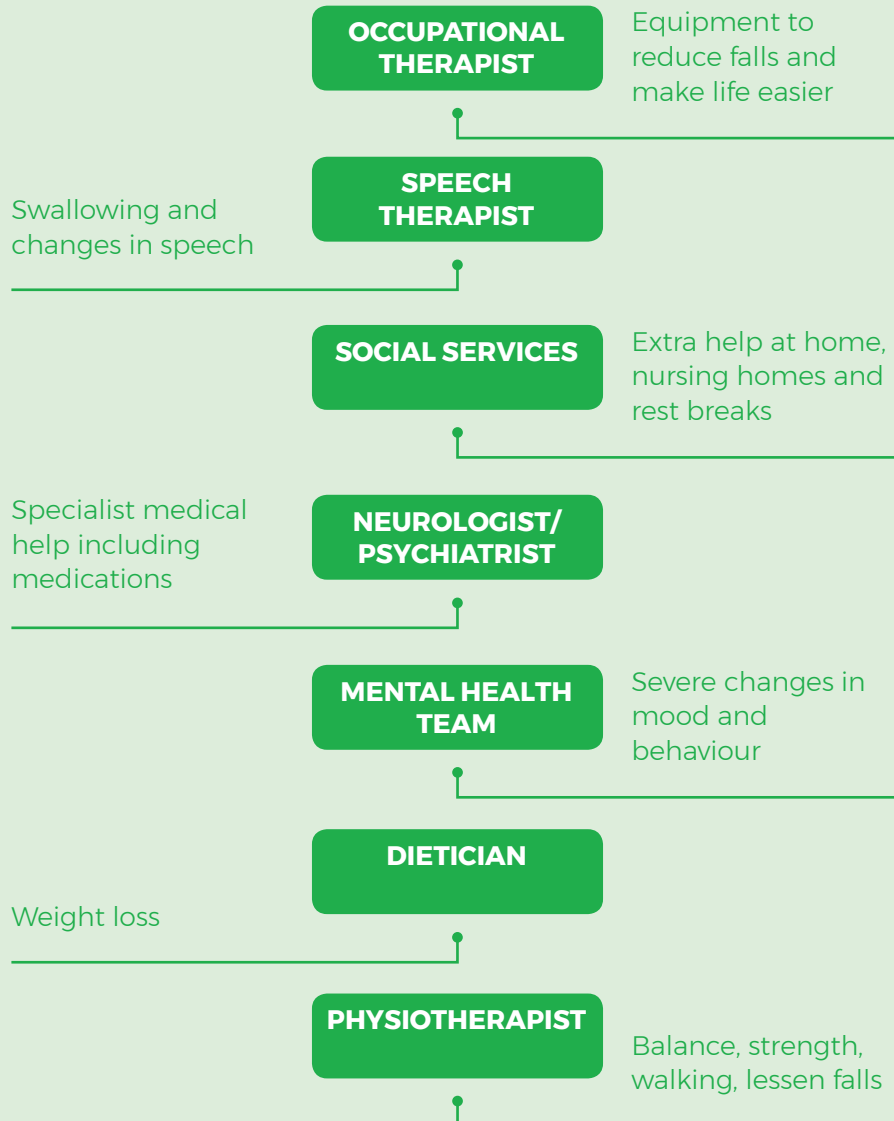
**Prenatal testing.** If you know that you have the faulty Huntington's gene then your unborn child can be tested to see if they also have the gene, using prenatal testing from 11 weeks in to the pregnancy. If the test shows the unborn baby has inherited Huntington's you would be asked to have a termination of pregnancy. For this reason, it is very important that you have talked through all your options with a professional before going ahead with the test.

**For more information on having children please speak to GP about your local Genetics Service.**



## Who can help?

**People with Huntington's may need help when things get harder. Here are some of the people who can help.**



## Research

It is a very exciting time for research and Huntington's. If you would like to know more about this then go to [hdbuzz.net](http://hdbuzz.net), [Enroll-HD](http://Enroll-HD), [www.enroll-hd.org](http://www.enroll-hd.org), European Huntington's Disease Network [www.euro-hd.net](http://www.euro-hd.net).

If you would like to take part in research activities in your area then speak to your Specialist Huntington's Adviser or ring your local Huntington's clinic.



## Huntington's Disease Association (HDA)

The HDA supports people with Huntington's and their friends and families.

We have Specialist Huntington's Advisers who can offer advice and tell you what help you might be able to get in your local area.

Your local Specialist Huntington's Adviser is:



## Advice line

If you need to speak to someone for advice about Huntington's and you cannot speak to your Local Specialist Huntington's Adviser then please ring our advice line.

Tel: 0151 331 5444

Email: [info@hda.org.uk](mailto:info@hda.org.uk)

This is open Monday – Friday 9.00-5.00pm  
(Excluding Bank Holidays)

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## Get in touch

For advice and support or  
to speak to a Specialist  
Huntington's Disease Adviser

email **[info@hda.org.uk](mailto:info@hda.org.uk)**

phone **0151 331 5444**

**[www.hda.org.uk](http://www.hda.org.uk)**

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