



A guide to Huntington's disease

What is the Neurosciences Unit?

The Neurosciences Unit (NSU) is part of WA Health. We have health specialists who can help to diagnose and treat Huntington's disease.

If you are 18 years old and over and live in Western Australia, you can get our help for **FREE**.

We can help by talking to you about your family's experience of Huntington's disease. We can talk to you about predictive testing for Huntington's disease, and if you're interested, help you get the predictive testing done. If you or one of your family members has a long Huntingtin gene, we can talk to you about services and support that can help you and your family.

The NSU team can:

1. Talk to you to work out what is happening with your body and brain
2. Work out if it is Huntington's disease
3. Develop a plan to help you live with Huntington's disease
4. Prescribe and review medications
5. Monitor physical and psychiatric health, your mind and body.

The Neurosciences Team

- The NSU social worker is usually the first person you will meet. They are there for you when you or your family need to talk about Huntington's disease and how it will affect you all. They can also talk to you about the services and supports that can help make life easier if you have Huntington's disease.
- You can talk to our neurologist when your body is not working like it should. For example if you are finding it harder to balance, feeling strange movements in your body, or weakness in your muscles.

- You can also talk to a psychiatrist if you don't feel good within yourself. For example, if you worry a lot, feel grumpy, lazy, sad or angry more than normal, or if you are not sleeping well, or thinking straight.
- NSU speech pathologists can help you if you are finding it more difficult to talk or swallow because of Huntington's disease. They can help you to eat and drink safely. They can also work with you and your family to make it easier to communicate.
- NSU researchers study Huntington's disease as part of a worldwide study, called Enroll-HD. This study will help us to learn more about how Huntington's disease works. Through research it is hoped that one day we can stop Huntington's disease. If you are from a family with Huntington's disease, you can take part in Enroll-HD.

What is Huntington's disease?

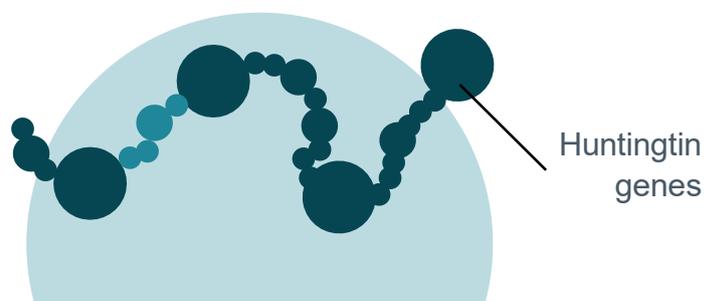
Huntington's makes the brain and body slowly stop working as it is meant to.

What is DNA?

DNA is a special code that everyone has. It is like a recipe book that holds the instructions for making all the proteins in our bodies. Everyone's DNA is different, but some of it is shared with your family.

What is the Huntingtin gene?

Huntingtin genes are two small but important parts of DNA that tell the body how to make a protein called Huntingtin. The Huntingtin gene helps the body and brain work normally.



What causes Huntington's disease?

Huntington's disease happens when one or both 'Huntingtin genes' aren't built properly. If the Huntingtin gene is too long, the Huntingtin protein does not work like it should and causes some damage to the brain.

What happens when someone has Huntington's disease?

Over time Huntington's disease stops your brain and body from working the way they should. It can make it hard to walk and move, can make your brain foggy, make it hard to think, make you happy, sad, grumpy or angry for no reason. Over time it is harder to walk, think and remember, make sense of things, swallow and talk. Eventually people with Huntington's disease need full-time care.

Who can get Huntington's disease?

Like a recipe book, the Huntingtin genes are passed down from your parents - one from your mum and one from your dad. If your mum or dad has Huntington's disease, there is a 50% chance that one of your Huntingtin genes will be too long as well.

It is very important to know your family history to understand if you may be at-risk of having Huntington's disease. It is important to talk with your mother, father, grandmothers, grandfathers, aunties and uncles to learn if anyone in the family has Huntington's disease.

When does Huntington's disease happen?

Huntington's disease can start at any age, but it usually starts between the ages of 30 to 50 years.

Contact Us

Get in touch, we are always happy to have a yarn about Huntington's disease.

Neurosciences Unit
Graylands.Neurosciences@health.wa.gov.au
Corner Mooro Drive and John XXIII Ave
Mount Claremont WA 6010

Is there a cure for Huntington's disease?

There is no cure yet, but treatments can help with how the sickness affects you and what happens to your body.

IMPORTANT:

Predictive testing CAN tell you if you have the long Huntingtin gene.

Predictive testing CANNOT tell you when you will start to get sick.

When should you see a doctor?

1. If you know your family have Huntington's disease or think they might OR
2. If you think your brain and body are not working properly. For example, if you can't control your arms or legs, or make sense of things or start forgetting a lot, talk to a doctor or call the NSU and we can help you to find out if you have Huntington's disease.

How do you find out if you might get Huntington's disease?

Predictive testing is a way to work out if you have a long Huntingtin gene before your brain and body gets sick.

You can get tested for FREE in WA by talking to the team at the NSU. Usually people who need our help come in to see us in Perth. Sometimes we can use the internet or telephone to help, especially if you live far from Perth.

Predictive testing includes:

1. Talking to a doctor
2. Talking to a counsellor about your family history and your experience. This is called genetic and psychosocial counselling
3. A blood test to look at your DNA to see if you have a long Huntingtin gene.



This document can be made available in alternative formats on request.