huntington's victoria
Hope Dignity Awareness

Genetic Counselling - Guide to the Community

This fact sheet is designed to give you clear and accurate information about genetic counselling, especially if you or your family are at risk of a genetic illness like Huntington's disease. It's natural to be worried or uncertain, but a genetic counsellor can provide support and guidance. This factsheet, designed in collaboration with Sachini Poogoda, an Associate Genetic Counselor at Monash Health, ensures accuracy and expertise in the information provided

It is essential to note that for any individual showing symptoms of Huntington's disease, the individual will be triaged to consult a neurologist, before predictive or diagnostic testing can be done for the individual. Additionally, the wait times are different for someone going through predictive testing as opposed to diagnostic testing.

Who are Genetic Counsellors and how can they help you?

Genetic counsellors are specialised healthcare professionals who help individuals and families understand genetic conditions. They provide support, education, and guidance so you can make informed decisions about your genetic health. They will help you understand what genetic testing involves and what the results might mean for you and your family.

What to expect after a referral?

Any person going through genetic counselling will usually receive a call from the Genetic Counsellor (GC) assigned to their case, when they receive their referral. During this initial intake call, the GC explains the process of pre-symptomatic testing/diagnostic testing and also ask for specific documents like proof that Huntington's Disease runs in your family and any genetic testing reports from family members.

What types of documents should I have ready before a GC session?

Usually, they require:

- Documentation to prove that the condition running in the family is Huntington's disease and not another neurological condition.
- Copies of genetic testing reports for family members who have tested positive for Huntington's disease (But, it does not always matter the outcome of the result).

If you do not have these, the Genetics Services will try and gain some more information around who was diagnosed in the family (name and DOB); and if there is any way we can get records (by having a POA/NOK signing a consent form to access records).

huntington's victoria®
Hope Dignity Awareness

Genetic Counselling - Guide to the Community

What happens if you do not have any of this information on the affected member in my family?

If you ca not provide records for affected family members, genetic counsellors can work with medical records and other resources to fill in the gaps.

Is there anything else you should know about my family history?

It is helpful to know which family members are affected, their names, dates of birth, and where they received medical care. If you do not have all this information, you can still proceed with testing.

Do they need to see a neurologist or be referred to any other specialists before coming in for a genetic appointment?

If you suspect symptoms or have a family history, start by seeing your GP, who can refer you to a neurologist. If you're over 18 and have a family history, you can contact genetic services directly for predictive testing.

Additionally, if you are someone looking to get Prenatal Screening or Preimplantation Screening, please note that you need to contact your primary Gynecologist and schedule for tests during your pregnancy at the earliest possible.

What should they expect going into a genetic counselling consultation?

During your session, you'll discuss the logistics, benefits, and limitations of genetic testing. The genetic counsellor will explain what the test results could mean for you and your family. It's helpful to bring a family member or loved one for support.

You are encouraged to bring along a family member or a loved one – whether it's a partner, parent, friend or relative. As a genetic test result can have a significant impact on your loved ones, it important to have these conversations with them. Therefore, enabling you and your loved ones to absorb information and asking questions that might help you understand the implications of undergoing genetic testing.

How long do the sessions last?

On average, genetic counselling sessions are scheduled for an hour, but remember, you very much lead the session. If you're not showing symptoms, a minimum of 2 consultations before ordering the genetic test. How quickly these appointments occur is up to you and you can choose to meet your Genetic counsellor for more than 2 sessions if you feel like you or your loved ones have more question before making a decision. The goal is to be informed and empowered in making a decision to get genetic testing done.

huntington's victoria®
Hope Dignity Awareness

Genetic Counselling - Guide to the Community

Will I be expected to get testing done? Will genetic testing be the main focus of these sessions?

You won't be pressured to undergo testing. The sessions focus on how the information might affect your life and help you make the best decision for yourself.

What other topics are discussed in a genetic counselling session?

Sessions also cover how genetic results could affect your family, pregnancy planning, insurance, and when it's best to test. You'll also get advice on how to discuss genetic results with your family.

Remember, genetic counselling is about empowering you with knowledge and support, so you can make informed decisions about your genetic health.

For more information or to book an appointment, contact your GP or genetic services.