

# Telling others about HD: What to Consider

To tell or not to tell is a question faced by everyone who is impacted by Huntington's disease (HD). Most people who have an illness are reluctant to admit it to themselves let alone to friends for fear of being different, misunderstood, and thought of as a burden or an object of pity. It is important to keep in mind that there is no right or wrong time or way to make known your situation to others.

Your relationship to HD will be one of varied emotions at any given point in time and it is okay to be uncomfortable and confused. In saying this, it might be helpful to discuss with someone you trust, how, what or if you want to disclose to your broader social network. When you are considering communicating your situation to others, we also suggest that you are as informed as possible to be prepared for potential impacts, some of which are listed below.

## Relationships

Relationships can be challenging at the best of times. Introducing a complex chronic illness such as HD into the mix adds another dimension. It is up to you whether you disclose or not and when. However, due to the genetic nature of the disease, the impact of disclosing a diagnosis to family members is different than a non-genetic disease. You will need to consider not only your own but your family members' potential future health needs.

Be prepared that when you disclose to your close family, friends or significant others, their emotional response will not be a reflection of the stability of your relationship. To prevent any undue confusion, be sure to provide who you chose to disclose to with clear and concise information.

You may need to tailor the information you give to accommodate the person you are speaking to, whether it is your child, your neighbour, or your oldest friend. It helps to remember that it may take time for the person you tell to absorb all of the information presented to him/her.

As it is unlikely that the initial discussion will cover everything, further communication with that person will be required as time passes. Don't hesitate to seek advice from your HD association for further assistance or advice



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## Genetic Discrimination

Genetic discrimination may occur when a person is denied access or treated unfairly due to being at-risk, gene positive or diagnosed with HD. Due to a lack of understanding about HD in the community, discrimination may occur based on false perceptions of potential long-term health problems. Disclosing that you come from a Huntington's family may therefore have implications for current and future employment as well as your ability to access insurance.



### In the workplace

Different work places will require different health checks and health information about their employees. Even in the most supportive work environments, a lack of understanding about the impact HD or a family history of HD may lead to discrimination. When considering informing your current or future employer(s) about the impact of HD on your life, your local HD association can help you to best prepare for this.

**Please be aware that any discrimination you face based on your genetic history is unlawful. If you feel that you have been discriminated against in your workplace, don't hesitate to get in touch with the Fair Work Ombudsman <https://www.fairwork.gov.au/>**

## Insurance

When you are applying for life and health insurance, it is common to be asked to disclose any information in relation to your medical and family history that might be relevant to your coverage. Insurers use the information you provide to determine your eligibility and level of insurance premium and period of coverage. Depending on the information you provide, possible outcomes could be higher insurance premiums, reduced period of coverage or denial of insurance coverage altogether.

Prior to engaging with an insurance company, seek advice from your local HD association who can link you to a financial/insurance advisor.

### For further Information:

Life Insurance Products and Genetic Testing in Australia: <https://www.genetics.edu.au/publications-and-resources/facts-sheets/fact-sheet-20-life-insurance-products-and-genetic-testing-in-australia>

These information sheets have been compiled in collaboration with the HD community, volunteers and health professionals.