
Living at Risk of Huntington Disease

Introduction

Being at risk of Huntington Disease (HD) can present a number of difficulties, but perhaps the basic one is learning to live with the knowledge realistically. If you have a parent with HD then you have a 50% chance of inheriting the disease as well. Some people experience a kind of seesaw effect; on some days they feel sure that they will get HD, and on others they are sure they will not. Either extreme distorts reality. If you are too pessimistic, you live in continual dread and are unable to plan a career or rewarding relationship, or cultivate interests. You may also be constantly looking for symptoms and the smallest accidents take on a different meaning. Being too optimistic, on the other hand, may lead to denial and irresponsibility, such as not telling your partner and having children without making the decision rationally, and considering the many aspects of this decision. This can lead to mixed emotions later in life. The more knowledge you have about the disease, then the more you are able to view your situation realistically and plan your life accordingly. Being prepared for both getting it, and not getting it, can mean that you can enjoy a satisfying life, which is not destroyed if you are unfortunate enough to get HD. Moving on in your life can be easier said than done, that keeping it to yourself makes it worse, and that even after the onset of the disease life can have meaning and happiness. All is not lost there is a great deal of research ongoing adding new and exciting advances to what is known about HD.

Learning that you are at Risk

However you learn that you are at risk of HD, you are going to worry about the possible consequences, but the manner in which you are told will to some extent affect

your outlook. If your parent developed HD early on, you may have grown up with its constant presence but never actually told about HD – though the knowledge is around. You may have been subjected to the stresses of living with HD from an early age and though this may have had a profound effect on you, knowledge of the disease does not come as a shock. If you are little older when your parent is diagnosed, then again the knowledge of its effects comes gradually. No matter how you come to learn about your risk for HD-your response will be unique to you.

You may experience great sorrow at a loved parent changing physically and mentally until perhaps roles are reversed and the child begins to care for the parent. It needs to be remembered that not all people living with HD are affected in the same way. If there is one aspect of the disease that you find particularly distressing in your parent it does not mean that you would suffer in a similar way.

Seeing a dependant parent may also make you fearful for your own future and possible loss of independence, a thought that is difficult to live with. Where there is no evidence of HD in the family, perhaps because a parent is 'at risk' but has not shown any symptoms, it can be a great shock for a teenager suddenly told the facts of the disease. It may seem at first to disrupt completely all your plans for a career, marriage and the way you want to live your life. However you learned about HD, you will have a number of anxieties about the future. Perhaps you may even be worried about your present health – whether in fact you could already be showing symptoms.

You may be concerned that you look like or have a similar personality to your parent

with HD and irrationally fear that you are therefore more ‘at risk’. These are common and very understandable anxieties that can be dealt with if brought out into the open and discussed, but can be overwhelming if kept to yourself. Knowledge of the real facts of the disease, rather than the belief in some of the myths that surround it, leads to realistic assessment of your situation. For instance, having a parent who is ‘at risk’ puts you in a different position from those whose parent is already affected and this may influence your outlook.

There are many options now available to those who have now come to know that they are living “at risk” of HD.

1. **Become informed:** There are many resources available, including a representative of the Huntington Society of Canada in your community or province and www.huntingtonsociety.ca
2. **Speak to a Genetics Counsellor:** Each province has a genetics program to help people learn about the risk factors and help identify if this is the time for them to receive genetics testing.
3. **Speak to a Social Work or other counsellor:** If you are having trouble dealing with the information that you may be “at risk” and this is impacting on your home or work environments.
4. **Mutual Support:** Speak with others at risk, or a HSC Chapter.

Taken from the Australian Huntington Disease Association