

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

