

Huntington's disease (HD) is a genetic disease therefore involving everyone in the family. It is a natural instinct to want to protect your children against the tough realities of life and illness. However, young people are far more perceptive than you may realise.

## Why?

It is inevitable that HD will have a psychological and social impact on the family unit as a whole. As such, a young person within that family will notice changes in his/her parents' behaviours or established routines. Without explanation, these changes are likely to confuse or cause them worry that it's their fault.

On the other hand, explaining the situation simply and honestly will **foster trust and a sense of security** for a young person. Providing a context through open communication allows the young person to feel included, less isolated and better able to ask questions and discuss issues in a safe environment.



## Who?

The first step is to identify a person who already has an established trusting relationship with the young person(s) to initiate the conversation. This might be the parent with the disease, an older sibling, relative, close family friends or even a pre-existing relationship with a professional such as a school counsellor or teacher.

Once you have an identified person who is comfortable to speak, please direct that person to relevant resources in relation to HD and how to speak to children. If you have any questions or concerns or are unable to identify a person who is comfortable to speak with the young person(s), please feel free to contact Huntington's Victoria, who have experience speaking with young people about HD. Huntington's Victoria is happy to work in collaboration with you to ensure that this process is as constructive as possible for the young person(s).

## When?

A young person **at any age has the capacity to engage** with the conversation about Huntington's Disease, depending on how information is presented. This means that primary school aged children will respond to more basic information whereas teenagers might require more factual information. Studies have shown that the younger the child is, the easier it is for them to cope with the impact of HD on their family as the introduction of this information earlier in life **normalises their experience of HD**.

# Talking to Young People about HD

## How?

The level of discussion you choose to have with your children will depend on their age, temperament and emotional maturity. In planning the initial conversation with the young person, choose an environment in which both parties feel comfortable and safe. It is normal to feel anxious or concerned about the young person's reaction, however, it is often the case that the discussion ends up being far less stressful than the anticipation leading up to it.



- Start by **discussing how the young person is feeling**, what their worries are and what they know. In the initial discussion, it can be quite normal for some young people to have trouble contextualising and articulating their feelings and worries to you. If you come across this situation, you can have the conversation by asking yes or no rather than open ended questions  
**Example:** Rather than asking "How have you been feeling?", you might ask "Are you worried about Mum?"
- **Provide an explanation** of the disease by **linking it directly** with the changes the young person has noticed in their parent. Make sure to use examples and language that the young person will understand.  
**Example:** "Have you noticed that Mum is hard to understand when she talks?" or "You know how Mum has had a couple of accidents lately?" You can utilise these examples that the young person relates to and link directly to the impact of HD on the brain.

Please be reassured that you cannot cover everything there is to know in one conversation alone. It is important to work within the young person's capacity to engage with the information and not to overwhelm them. Discussions in relation to HD should be ongoing. As the young person gets older, they may ask different kinds of questions. For instance, it is not unusual for teenagers to ask at what age they can be tested for the gene. Do not panic if things don't go to plan. Your children will not be devastated by one discussion that doesn't go smoothly, they will more than likely be appreciative that the discussion took place.

## Additional resources

[HDYO - Talking to Kids about HD](#)

[HOPES - Talking to Children about Huntington's disease](#)

[Headspace - Information for Parents and Carers](#)