



# Being Young in a HD Family

Sometimes being young can be tough. Being a young person in family with Huntington's disease (HD) can be even tougher. HD is a complex issue and sometimes it takes time for the adults in your life to come to terms with the disease. There is not one right way to deal with HD and each family will approach it in their own way.

## Trust your instincts

If you have noticed changes in a family member or just get the feeling that something isn't right, trust your instincts. If your family has not had a conversation with you about HD, try to keep in mind that they are most likely trying to protect you and are doing the best that they can. However, you have a right to ask questions and talk to your family about the way you're feeling. Even though you're young, that doesn't mean that what you're noticing or feeling isn't real.

## What you're feeling is normal

Regardless of what age you find out about HD, the changes in your family will not be any easier or harder to cope with. There is no right or wrong way to react after finding out that someone you love has HD and you may feel a lot of different emotions from sadness to anger to embarrassment. Keep in mind that feeling this way is completely normal and many other young people in your situation have felt the same way.

### It is important to remember:

- You're not to blame and have a right to feel safe. Because HD affects the brain, it can cause strange behaviours. These behaviours are not a result of anything you've done or said and it is not your fault that your family member is acting in a strange way. If your family member acts aggressive or violent towards you, it is important to tell someone you trust that you are feeling unsafe.
- The more you understand, the more things will make sense. Sometimes what you imagine is actually worse than reality. Learning more about HD will help you understand and cope with the changes that are occurring in your family.
- It's okay to take a timeout and have a normal life. Having HD in the family does not mean you have to give up doing the things that you normally enjoy doing.
- Don't be afraid to ask for help. It's okay to talk to someone that you trust outside your family about how you're feeling (e.g. the school counsellor or family friend).
- You can tell your friends about HD. Letting others know about HD will help them understand you better and you will have the support of others. If you're unsure how to tell your friends, ask an adult or your school counsellor for help.

Check out HDYO for further information on living in a family with HD: <http://en.hdyo.org/tee/articles/62>

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