

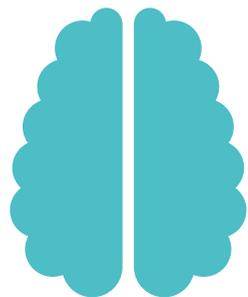
Talking with young people about Huntington's disease

A toolbox guide for parents

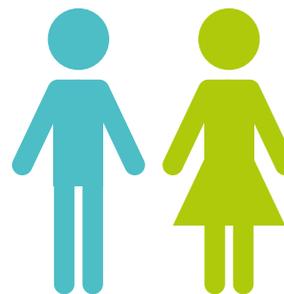


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HD affects someone's brain



HD affects both men and women



HD changes a person's movement, mind and mood

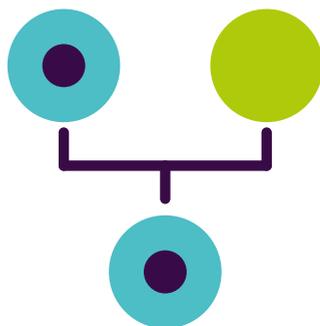


50/50 risk of child inheriting HD from parent

HD usually develops in adulthood, between the ages of 30–50



HD is a genetic condition



HD does not skip generations



£250m spent on HD research annually



1 in 5000 people in Scotland have HD

That's around 1500 people with HD in Scotland and 6000 people affected by HD (e.g. young people/carers etc)

Scottish Huntington's Association Youth Service (SHAYP)

has developed this booklet to support you in discussing Huntington's disease (HD) with your child/ren. Explaining Huntington's disease to young people may feel difficult and overwhelming. This booklet isn't designed to tell you exactly what to say, but will give you a starting point. Talking sensitively and honestly about the disease can help provide young people with reassurance during a time of uncertainty and change.

To help you discuss the subject of HD with young people, this booklet offers evidence-based, practical strategies that can build upon your existing strengths and knowledge. Sometimes it may take a few attempts before you find the best way for your family. Remember that you are the expert on your children, and your understanding of their individual personalities and needs can help guide you.

You may like to use this booklet to ensure your children hear a consistent message about Huntington's disease and how it is affecting your family. You may want to pass it on to grandparents, teachers, family, friends or neighbours – anyone who may talk with them.

Remember that talking about Huntington's disease is an ongoing process, and whilst the initial conversation may be the hardest, the more you discuss HD openly and honestly in the family, the more normalised the conversations will become.



Why talk to young people about Huntington's disease?

When someone is diagnosed with HD, adults are often unsure about discussing the situation with young people. Parents and other adults sometimes feel overwhelmed by their own anxiety, fears or emotions and their first impulse may be to protect young people.

SHAYP's experience and research suggests that giving young people age-appropriate information about HD provides a better outcome and it becomes a part of normal life for them. This could be after a new diagnosis of HD, or once they become aware of a family member's symptoms. Being open and honest can help to relax everyone in the family and alleviate some anxiety about keeping secrets. You can start the conversations about HD regardless of the age of your child.

Secrecy can make things worse

Parents often feel that they are protecting their child by not telling them about HD until they are older. No matter how hard you try to hide HD, most young people will suspect something is wrong. Even if it is not a parent who has HD, but a close relative, this may cause changes that children can pick up on. They may notice a decline in their Mood, Mind or Movement, whispered conversations or a difference in their relationship (e.g. parent may not go out as often). Children of all ages may notice changes.

Young people who are told about HD tend to cope better than those who are kept in the dark. Secrets can be difficult to keep and may

add more stress – you may worry about whether you should tell or feel guilty if you haven't already. Children may notice that a routine has changed without knowing why, which can be confusing for them and tricky for you.

HD is a rare condition and is not often the first illness a child will think of if they suspect something is wrong. A lack of information may increase their distress, and lead them to spend a lot of their coping energy on an imagined situation.



Young people have a right to know

Young people can feel hurt if they suspect or discover they have been excluded from discussions about their family. The United Nations Convention on the Rights of the Child (UNCRC) empowers children with many rights, including Article 24 which states that 'children have the right to the best health possible and to medical care and information.' Therefore if you are unsure whether to tell your child, the UNCRC is stating that they have a right to know. Furthermore sharing information shows you trust and value them, which can reaffirm their place in the family. Sharing this information can help build their resilience and their coping strategies. It may also help them to develop and improve their relationship with their affected family member as it can give an explanation to changes in their Mood, Mind or Movements.

Young people might find out from someone else

Ideally, young people should hear about HD from their parents or another close family member. If you tell friends and relatives about HD in the family, but you don't tell your children, there is a chance they will hear about the disease from someone else or overhear a conversation. Young people may pick up on adult conversations even when it seems like they are not listening. Overhearing information in this way can be detrimental to your child. They may think the topic is too terrible for you to talk about, or that they are not important enough to be included in family discussions. It can also affect their sense of trust that their parents will tell them the truth.

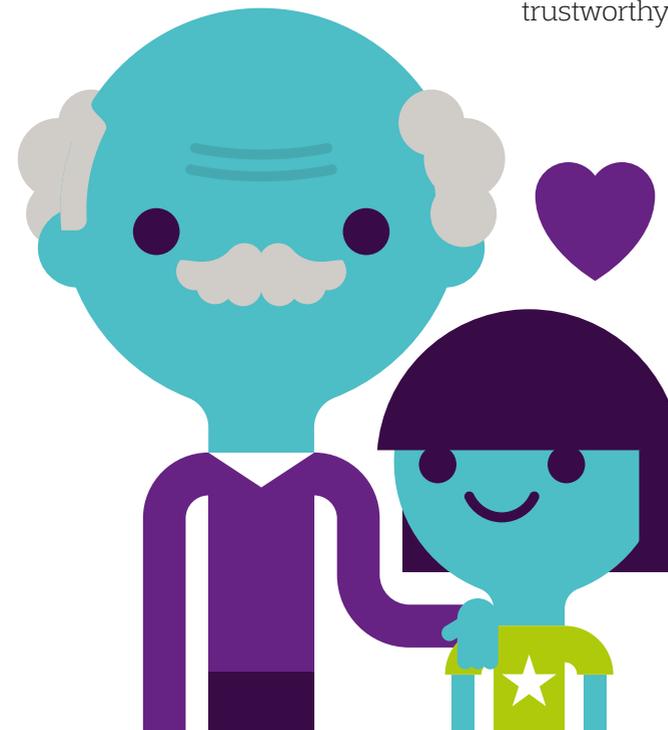


Young people can cope

When children are in a family affected by HD, it can be a challenging time for them. You may wonder how they will get through it; but with good support most children cope well. A key factor in children getting through difficult times is a close relationship with an adult who values and supports them and accepts them for who they are. That adult can be a parent, a grandparent, a favourite aunt or uncle, or a family friend. Whatever the connection, a trusted adult who provides support can help a child through tough times.

Young people need a chance to talk

Talking to your children about HD gives them the chance to tell you how they feel and lets them know it's okay to ask questions. Don't be afraid to express your own feelings or cry. As long as your emotions are not out of control, it can be helpful for young people to know that feelings such as anger and sadness are normal reactions and that adults feel them too. Sometimes children will open up to adults who are not their parents. They may feel guilty about burdening their parent so may confide in someone else like a teacher. As a parent, it is important to encourage your children to talk about their thoughts and feelings with you or someone else who is trustworthy.



How should I prepare for the conversation?

Parents often doubt their ability to talk with their children about HD. By taking time to consider how to approach the conversation you will be able to find the right words and answers to their questions. This section will help you reflect the different options to include in the conversation.

Try to role-play the conversation with someone. Doing this means that you've spoken the words aloud and perhaps dealt with some of the anxiety attached to them before chatting with your child. Taking time to practice can help set the words in your mind. Try not to worry about getting the conversation perfect, you have many conversations ahead of you about HD. It's unlikely that your child will be affected by one conversation if it doesn't go exactly to plan.

Consider beforehand how you would like to bring the conversation to a close. You may want to plan an activity to help your child settle again. Allow them some time after the conversation to think about things, and let them know it's okay to come back to you to chat more, or with questions.

Be prepared to answer questions, even if you think you know how your child will react to the conversation. You may not have all the answers (there's some practice Q&As on P16–19), but you can find them out together or speak with SHAYP.



At what age should I tell?

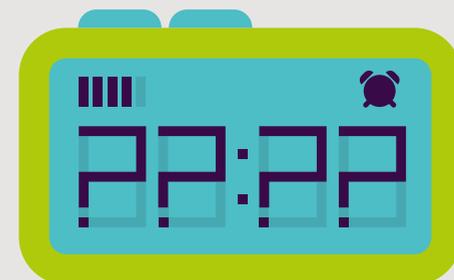
Sometimes parents can be unsure about the best time to tell their children about Huntington's disease. You may wonder if you should tell them as soon as possible, or wait until you feel that you know more about the disease. It can be difficult to decide how much information to give, and what information is suitable for different age groups. As previously mentioned, keeping secrets can be stressful and your children may probably sense that something is wrong.

SHAYP advises that you tell young people as soon as you feel able to do so. Research and experience indicates that the younger a child finds out, or as soon as possible after diagnosis of Huntington's disease, the better a child copes with this information. This is because children assimilate information (take the information in, process and normalise it) especially when the information is given in a calm and relaxed manner. Many children speak of 'always knowing about HD in their family and it not being a big deal' as it has been openly discussed with them from their early years.

When should I tell?

You might be unsure of the best time to tell your children and often there is no 'right' time. When considering when to tell your children about HD, it can be beneficial to tell them at a time which will allow them time to come back to you with any questions. Therefore, it is recommended that you have the conversation earlier in the day and avoid having it immediately before bedtime. This allows young people to process what you have told them, and you can check in with them to make sure they are supported. You can also monitor any subtle changes to their mood or behaviour.

It can be helpful to approach the conversation as an ongoing process and not a one-off chat. Imagine opening the door to conversation and questions, rather than having all the answers. This lets children and young people know that they can come back to you at any point if they have questions or worries. This may help normalise discussing HD within the family.



Where should I tell my children?

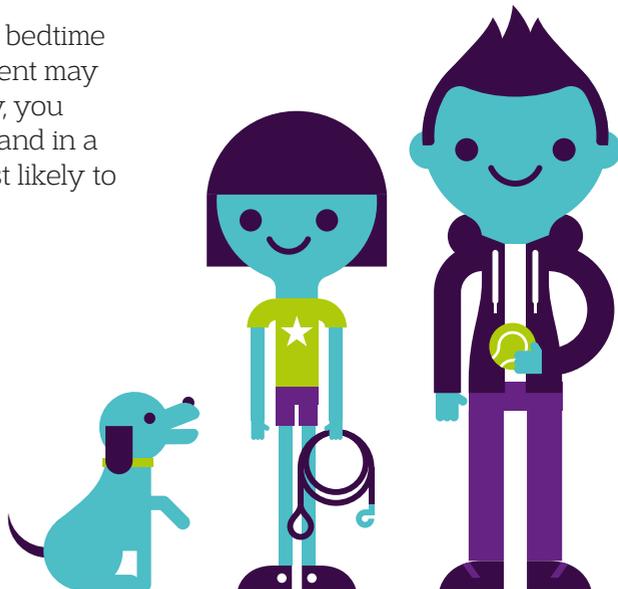
You will know the best place and time for your children to hear important family news. Try to find a time and a place where you won't be interrupted or have to rush off without answering questions.

Children can often find it intimidating if they are sat down for a formal discussion and many catastrophize the information they are given in this situation. Many people find that bringing up the subject casually while doing something else – like walking the dog or washing dishes – can help reduce the tension and this allows the child to be relaxed when they are receiving the information. Choosing an environment where your child feels comfortable, safe and protected is of paramount importance.

Talking to children before bedtime or before an important event may not be a good idea. Ideally, you should tell them at a time and in a place where they are most likely to listen and take it in.

Should I tell my children together or separately?

Depending on the ages and abilities of your children, you may decide to tell them individually or together. Children within families may need to know different information because of their age or developmental stage. Talking with all your children at the same time and giving basic information about HD can work well as then all the family members have been included in the same discussion and it can promote unity between siblings. You can then have a more detailed conversation with older siblings after the younger siblings are out of ear shot. If you do decide to tell your children separately, try to tell them on the same day. Asking older children to keep the disease a secret from younger siblings can add to their stress.



When you don't feel ready to talk

While some people can be open about HD, others find it hard to discuss the illness, particularly with their own children. Some parents don't want to tell their children at all and try hard to hide the disease. People have their own reasons for not telling children, including cultural, family circumstances or an earlier death of a close relative from HD. Most people find that when the time comes to tell their children they find the strength for the conversation. After the initial conversation, talking about HD becomes easier.

Differing views about telling children

Sometimes there can be conflict between family members about whether it is right to tell children about HD. This may lead to increased stress and division within the family which young people can pick up on. SHAYP would recommend that both parties try to discuss their view points in a calm and relaxed manner to try to reach a consensus on how to proceed.

SHAYP advises being open and honest with children about HD and suggest parents consider telling children as soon as practically possible. Sometimes, giving age-appropriate information might be as simple as telling children the name of the illness.

What should I tell my children?

The following checklist is a guide to the kinds of information you might discuss in your initial conversations about Huntington's disease. You can tailor the information according to the ages and reactions of your children. Remember that you are the expert in your child.

Tell them the basics in words they can understand

You can break the news with a few short sentences explaining what you know so far and what will happen next. Be clear about the name. Sometimes it can be referred to as Huntington's disease, but often it is shortened to HD. Try not to overwhelm children with too much information as little bits of information are easier to understand than lots of complicated information. You can always give them more detailed information later on if they are interested. You may want to give them some real-life examples of how HD affects their parent;

"Huntington's disease changes the way Dad controls his emotions and you might notice that he gets a bit angrier or sad than he used to."

Find out what they already know

Ask your children if they have heard of Huntington's disease, what they know about Huntington's disease and then correct any misinformation or myths (e.g. they might think that you can catch Huntington's disease or that they have caused the disease). Children get information from various sources, such as school, TV programs and the internet, and they may have their own ideas of what having Huntington's disease means.

Don't assume children will have the same fears as you. Ask them what they want to know, and only answer questions that they ask.

Give small bits of information at a time. You may need to keep repeating the information to ensure they understand what you have told them. Accept that they may ask the same question several times.



Be honest and open

When discussing Huntington's disease with your child, be open and honest throughout your discussions. Don't be tempted to lie to protect your child as they may find out the truth and may be angry or resentful that you didn't tell them the truth.

If your child asks a question that you don't know the answer to, be honest that you don't know the answer. Explain that you'll try to find out the answer and you'll let them know as soon as possible. Make sure you follow this through.

Tell them what to expect

Your children may want to know what this will mean for them. Will you still be able to drop them off to school, make them dinner, or take them to after-school activities? Reassure them there will be a plan and you will involve them in the ongoing decision making process.

Ask them if they want to tell anyone

Your children may also want to tell their friends, the teachers, the whole class – or nobody else. Supporting your child to confide in others is important in establishing their support network – which they will need as the disease progresses.

Explain to your child that there will be a few people you may need to tell, such as their teacher, Head Teacher or other key figures in their life, such as a music tutor or sports coach. Discuss with your child what information they would like passed on, whether to adults or children and devise a plan together.

Balance hope with reality

Often children will ask if there's a cure for Huntington's disease. This can be a sensitive topic for parents and it is important to balance a child's sense of hope with the current reality. If appropriate you could discuss that whilst at the moment there is no cure for Huntington's disease, there are medications that can help manage the symptoms caused by the illness. Scientists around the world are working incredibly hard to find more effective treatments and eventually a cure for the condition. Important steps are being taken every day and there is a lot of hope in the research currently being undertaken. More information about the current research into HD can be accessed online at www.hdbuzz.net.

❑ Offer a listening ear

Your children may say very little and not ask questions when you first tell them. Some young people need time to absorb the information, but it doesn't mean they don't understand. Let them know they can come back to you at any time with questions, worries and scary feelings. It is helpful to regularly start conversations with your child to make sure that they are okay and see if they have any questions.

❑ Tackling difficult questions

Sometimes there can be difficult and upsetting conversations which may arise after you have told your child about HD. These may include questions about medication, a cure for HD, if a parent is going to die. SHAYP would recommend being honest and gentle in your responses to these questions, don't lie or make promises that cannot be kept. The aim of the conversation is to educate and inform your child – not scare or panic them.

❑ Show your love and emotion

Tell your children that you love them, and assure them they will always be looked after. Express your love by hugging them, comforting them and making them feel valuable. Try not to overwhelm or frighten children by your reactions, but it's alright to cry; this gives young people the message that it's okay to show feelings. Being honest with each other about fears and feelings can positively affect your relationship with your children and help your children's wellbeing and ability to cope.

❑ You are not alone

It is important to remember that you are not alone throughout your HD journey. SHAYP can help you prepare for your HD conversations and are happy to meet with you to discuss this in further detail. SHAYP can also provide ongoing support to your child through one to one support, group work, residential activities, summer camp and fun activities.



http://www.internet.com

Young people may misunderstand information and think a situation is much worse than it is. They may feel afraid to ask questions. They might worry in silence or spread incorrect information to other children in the family. Many young people will pick up on a few key words and turn to the internet for answers, which can lead them to unreliable websites. Huntington's disease is complex and there is a lot to find out about the disease. The Internet can be a wonderful resource to find out more information, but it can also contain a lot of inaccurate, scary and misinformation. Often parents can be the best way for young people to find truthful, specific and accurate information.

Huntington's disease and other genetic illness are regularly highlighted in the media and there are many websites that provide information about HD. It has also featured on many prime time TV shows. Genetics is also a topic that comes up within the Biology curriculum.

SHAYP recommends the following websites for further information:

- www.hdscotland.org/youth
- www.hdyo.org
- www.hdbuzz.net

Bookmarks

Huntingtons.txt

Biology Notes

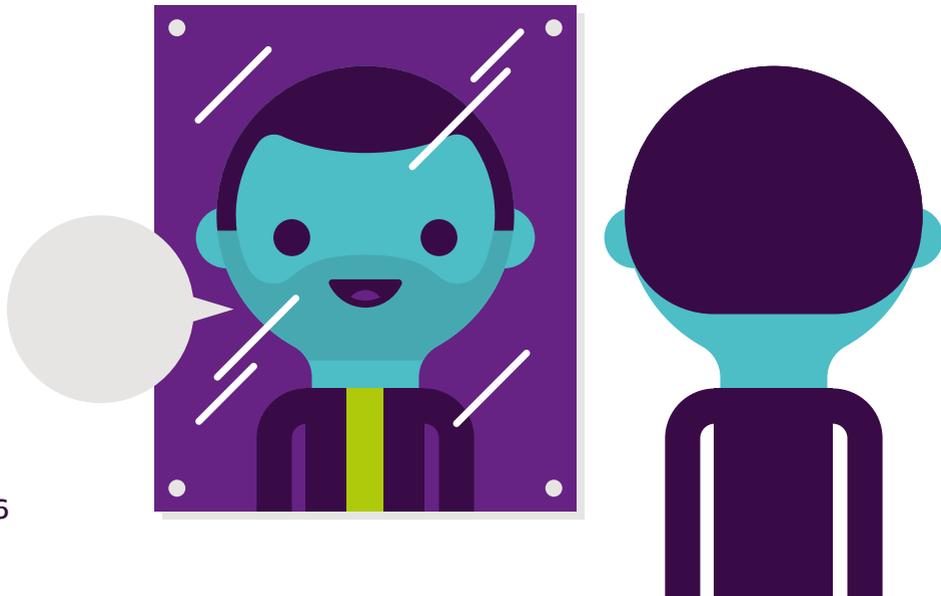
Practice questions and answers

"What is Huntington's disease?"

"Huntington's disease (or HD) is an illness that makes my brain not work as well as it used to."

"It changes the way I control my movements – so sometimes you might notice that I have some jerky twitches, drop things, or am a bit unsteady on my feet."

"HD sometimes makes Mum a bit more forgetful – she might misplace her car keys, or forget about appointments. Sometimes she might not be able to concentrate on more than one thing at a time."



"HD makes it a bit tricky for Dad to do some of the things he really enjoys to do – like cooking, playing football, or driving."

"HD can also change the way I control my emotions – you might notice that I can get angrier than before, or be a bit more upset than I used to do. This isn't your fault, it's because my brain isn't working as well as it used to."

"You may have noticed that Dad has been dropping things recently and can sometimes stumble or fall. This is because Dad has an illness called Huntington's disease."

"Huntington's disease changes the way that I control my movements. HD makes it harder for me to do the things I want to – like cooking, driving or playing games."

Do I/ we have HD?

"I honestly don't know if you have it or not."

"It's normally something that only affects adults, when you are much older so you don't need to worry about that just now."

"When you are 18, there is a test you can take to see if you have HD or not, but normally people don't start to become unwell until they are between 30–50 years old."

How did Dad get HD?/ Why have you got it?

"It's something that Dad was born with but it just didn't make him unwell until he was an adult."

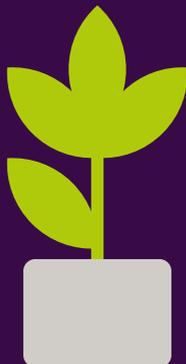
Is Mum going to die?

"Well everyone dies one day, but what is really important that we take good care of Mum; help her to eat well, take any medication and keep her brain active and as busy as possible. That will help her stay as healthy as possible for as long as possible."*

** Perhaps there is an example of a pet / grandparent that has died that you could link back to here)*

"Is this what Grandad had?"

"Yes, Grandad also had HD. That's why some of Dad's movements seem similar to Grandad's."



Can you cure HD?

"At the moment there's no cure for HD, but doctors and scientist across the world are working really hard to try and find one. If Dad wants to, he can see a special doctor (HD Management Clinic) who can give him medication."

What's going to happen to you?

"We are not really sure what's going to happen to Mum. She might stay the same as she is now for a long time, or we might notice some changes to her. She is going to have another driving test soon to see if she is okay to still drive."



"It's really important to remember that he is still your dad, and he really loves you both a lot. He'll still want to hear about your day, and come out with us if he can. You can still talk with him and spend time with him - he'll enjoy that."

In the future I might need to have a special team of people to help me. People like doctors and nurses, social workers and housing. We can all work together to make sure that I'm OK."

Relaxation tips

Count Backward

To focus your mind, try slowly counting to 10 and then back again to calm down.

Breathing

Focus your attention on your breath, your inhale and exhale. You can do this while standing, but ideally sit or even lie in a comfortable position. Try to take ten breaths, with each breath being longer than the one before. Slow, deep breaths can help lower blood pressure and heart rate.

Be more mindful

Notice what you are doing as you are doing it and tune into your senses. For example, when you are eating, notice the colour, texture and taste of the food. Don't feel that you need to fill up all your time with doing things. Take some time to simply be.



Be Alone

Allowing yourself to take five minutes of alone time can help you collect your thoughts and clear your head.

Try Progressive Relaxation

Progressive relaxation involves tensing the muscles in one body part at a time to achieve a state of calm. To use this method, squeeze your muscles, release and repeat. Start with your toes and work up your body.

Close Your Eyes

Take a quick break from a busy office or a chaotic household by lowering your eyelids. It's an easy way to regain calm and focus.

Over to you

Having reached this point in the booklet, you may now have considered several different options and lots of different information to share with your children. SHAYP would now encourage you to complete the following exercises to help you with your final preparations to talk about Huntington's disease.

How do I feel?

What do I think they already know?

What do I want them to know?



Where?

Who?

Afterwards?

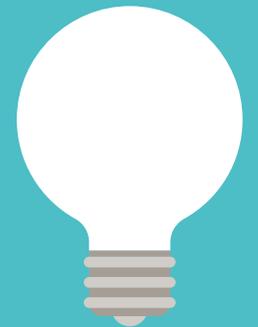
Future chats?

When?



Top Tips

- Keep calm
- Use simple, age-appropriate language
- Don't be afraid to show your emotions
- Tell them the truth
- Contact SHAYP if you need further advice



What does SHAYP offer?

Work
throughout
Scotland



**Supports
young people,
parents &
professionals**



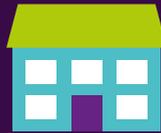
Support



**Group
sessions**



**Activity
days**



**Residential
breaks**



**5-day
summer camp**

scottish
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association



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