



**HUNTINGTON'S DISEASE
YOUTH ORGANIZATION**

Top Tips for Friends Of Young People Impacted by HD

November 24, 2021

HDYO has more information about
HD available for young people,
parents and professionals on our
site:

www.hdyo.org

Does your friend come from a family with HD? Do you want to learn how to be supportive and understanding for your friend with regards to HD? Don't worry, we've got you covered! Check out these top tips for friends of young people impacted by HD.

Tip #1: Understanding how brave your friend is

First, you are probably here because your friend has recently told you that their family has HD. Without knowing much (or anything about HD) it's easy to underestimate just how brave it is of your friend to share this information with you. HD is a serious condition and if your friend has taken the decision to tell you about it, well, that is a really brave thing to do and they must trust you a lot.

Tip #2: There's a lot to learn...

Ultimately, as a friend, you likely want to be there to support your friend when needed. In order to support your friend you need to understand their situation. There's no getting away from the fact that if you want to gain insight into what it is like for your friend in a HD family then you have to be willing to learn. Your friend may have told you the basics of HD, but HD is fairly complex and there are many aspects to learn about, even for those who think they know what HD is. Here's what we recommend, for a basic understanding of HD and how HD impacts on your friend go to our [What is HD?](#) section and check out the [living in a family with HD](#) section. Those will give you a really good start. But if you want to learn more than the basics, try understanding the genetics behind HD in our [being at risk](#) and [genetic testing](#) sections. If you really want to understand the challenges your friend may encounter then (I wish I had a friend like you!), try reading all the sections about how HD impacts young people in many different ways. You don't necessarily have to read them all, but it can be good to understand those aspects which impact on your friend. For example, is your friend thinking about getting tested? Take a look at the [genetic testing](#) section. Are they caring for their family member? Visit the [being a young carer](#) section. Reading these sections and their videos will give you a great insight into HD and also allow you to really have a strong understanding of what is going on for your friend.

Tip #3: Let's talk!



How best to show you know your stuff? Tell your friend! Talking (communicating) about HD is so important and beneficial for your friend and for you in terms of your friendship. HD can be a stigmatised condition, meaning people often struggle to talk openly about it. But talking openly is actually really helpful in coping with what's going on. The fact your friend has told you about HD is a good start which means they probably want to talk about this with you sometimes. Ask them how they are doing? How is their family member with HD? Is anything on their mind with regards to HD? Do they want to talk about it? Let them know you are available to chat anytime... This type of communication should make your friend feel supported and know that they can count on you to be there for them. Ask questions, offer advice, but be careful not to be judgemental with that advice. Sometimes that is an easy mistake to make, especially with topics like testing and having children, in these situations be supportive of your friend's right to make their own decisions. But in general, be open about HD, let your friend know you're always there to chat about HD if that's what they need.

Tip #4: Meeting the Family

At some point, if you're good friends, you will likely meet each other's families. Maybe you have done this already and you're spending lots of time round each other's houses with their family present. With HD in your friend's family things may not be so normal or things may change. What we mean by that is people with HD get progressively worse, they will gradually lose one ability after another, so the family dynamics can change hugely during this time. You may notice these changes in your friend's family member and it can be difficult to witness or know how to react. The same can be said for those friends who are visiting for the first time and have never seen someone with HD

symptoms before. Being prepared for this visit will help you cope with seeing someone with HD and also help you know how to react. Our biggest tip: do your homework. No, thankfully we're not suggesting you do your school homework, but rather get an understanding of what symptoms of HD can look like and how they impact on your friend's family member. We recommend reading the [How does HD affect people?](#) section. If you've done your research about HD you will know that it affects people in three main ways: movements, mind and behaviour. But each person with HD will have different symptoms. Some may struggle with movements, whilst others more with behaviour. Speak to your friend in advance! Ask what to expect when meeting their family member. What symptoms does the person with HD experience? How capable is the person with HD? Can the person with HD still communicate well? Ask your friend if it is okay to try and talk to the person with HD on your own or is it best to have your friend there to help 'translate' if speech is difficult? This information will help you hugely in knowing what to expect. We also recommend watching some videos of symptoms of HD but please keep in mind this may not be accurate of your friend's family member's symptoms and could also be distressing to see. However, if videos make you feel upset then it may give a good indication of how you would handle seeing someone with HD. So in that sense it may be very helpful to test yourself on some videos first and [speak to us](#) if you want to share any concerns you have.

"I used to have my friend come over all the time to play on the computer. Then one time, my dad, who has HD, just got angry and told us to stop and told my friend to get out. I was shocked because my dad wasn't normally like this and it was so embarrassing! I didn't know what to say to my friend." -

Shane



Another issue to think about when potentially visiting their family, especially for the first time, is that your friend may be quite embarrassed to even have someone visit. Just like it was a brave step for them to tell you about HD, it can be an even braver step to let you into their home in the current circumstances. If you feel your friend is being hesitant

about having you at their home, then it may be embarrassment causing this. Perhaps bring this up with your friend and see if talking will help them feel more comfortable with the situation.

It's also important that you keep yourself safe. Not all, but a few people with HD become angry or aggressive. If that is the case then be aware of that possibility before entering the home. Even speak with your parents, your friend and their family before visiting to check everything is ok. It's important to stress that behavioural issues as serious as this are not common, but they do happen so speak to your friend and be sure.

Tip #5: Use your knowledge to be understanding

Now that you've learned about HD you will be in a much better position to be understanding to your friend's situation. HD can impact on everyone in the family quite heavily, even if they don't have HD themselves. Your friend may be impacted in ways such as maybe being too tired to do all their school work or perhaps their attendance has started to drop because they have to care more and more for their family member. They might be getting stressed out due to thinking about their risk status, testing, care duties, or the progression on their family member? Maybe they can't come out as often as they used to because they feel needed at home more because the family is struggling to care for their loved one? These are all ways HD can impact your friend. With your knowledge of HD and their specific situation, you will be in a really great place to understand what's going on for your friend or perhaps notice something about them that they haven't yet such as getting annoyed or frustrated really easily because they are stressing out about home life.

Tip #6: "I'll be there for you if you're there for me too"



No, don't start singing the Friends TV show theme tune! What we're saying here is be supportive for each other, as good friends should be anyway. Does your friend need to be back by 10pm to help care for their family member? Ok, then change plans and go for the 7pm movie rather than the 8pm so your friend is back in time to help out at home. Adapt to accommodate your friend if you need to. Having a positive approach to HD can be a really great way for your friend to cope with the impact of HD, we recommend them getting involved with support groups, fundraising events (organised or their own creation)! These kinds of actions can make a positive difference to your friend's life, but having a friend there with them can be so helpful in making sure they feel comfortable enough to take these significant steps towards better support. So tip six is all about being there for your friend when they need you. You should absolutely expect the same back from your friend too, because that's what being a friend's is all about.

Tip #7: It's really obvious... be a friend!

What do we mean by being a friend? Well, with all these tips we've given you a lot of thinking about how you can help your friend deal with the impact of HD in their life. It can be easy to forget that what your friend wants more than anything is for you to be a

good friend to them. They may want to talk about HD with you at some point, but most of the time they want to go and have fun with their friend. If they are in a HD family then they may really want a break from home life and enjoy spending time with their friend to bring them a little normality. So our last tip is not to forget to be a friend first and a person to confide in second.

Good luck! The fact you're reading this article is a really good sign that you are a caring friend. Be there as much as you can, but know your limits too and always look after yourself first. If you, as a friend, want to chat we are always here to help and it's all confidential.



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<https://www.hdyo.org/a/430-top-tips-for-friends-of-young-people-impacted-by>

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