



**HUNTINGTON'S DISEASE
YOUTH ORGANIZATION**

Coping

November 23, 2021

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

www.hdyo.org

As a young person in a family with HD, coping is perhaps the most important thing to achieve as it can impact so heavily on your ability to accomplish your personal goals in life. But it's not always easy to cope. This section will explore the challenges to coping with HD as a young person and offer experience on how to cope.

What is coping?

First, what are we talking about? What does coping mean? Well, it means to deal with something in your life. In this case we are talking about the impact of HD in your life and how you handle that. That is coping. Coping is generally thought to suggest that a person is dealing positively with some challenges, but as we will look at later on coping does not always mean dealing well with things.

What makes it hard to cope with regards to HD?

Being impacted by HD as a young person usually means a whole range of challenges that make coping with those issues quite difficult. Issues such as being at risk, being a caregiver as well as financial, social and educational challenges. Trying to accept what is happening to your loved one who has HD or if you have tested positive/negative and the challenges that journey provides. Dealing with loss, not being able to talk about HD, feeling embarrassed about the person with HD and feeling isolated. Watching your family member progress with HD and all the complications that brings to you and the family. These are just some of the challenges a young person can face when trying to cope with HD in their lives. There's a lot of them and it should be no surprise to hear that a recent study suggests young people impacted by HD are over twice as likely to struggle with coping and emotional wellbeing as their counterparts.



If you are a young person and feel you are struggling to cope with HD in your life, this is quite common. You are dealing with so much more than most people that coping becomes a huge challenge. You will have good and bad days but you can get there with

the right support.

Being resilient and coping well

When we see all the challenges young people face with HD it naturally leads on to talking about resiliency. Resiliency is like coping, but resilience refers to the ability to recover after an adverse event (tough time) and the ability to continue to move forward in life despite numerous trauma's and hardships. Young people impacted by HD show a lot of resilience because they usually aren't just dealing with one difficult event, they are dealing with several over time (the progression of a loved one and the challenges that can create). So more than most young people impacted by HD have to continuously be resilient even as things get worse. These are thought to be good signs of both resilience and coping well with HD:

Resilience:

- Feeling ok about approaching new situations and new people
- Seeing good things even when there are some not so good things going on in my life
- Being kind to myself when I start having self-blame thoughts
- When I am able to think of the future with some hope and I can dream of some nice things
- When I see myself as having more than one thing that defines me. I live with HD and I like dancing, reading, horse riding, being with friends, swimming...

To cope well:

- I can see the disease changes as a process and/or a journey
- I don't give up in dreaming and hoping for the future
- I am accepting difficulties and injustices but at the same time I can still see the things that are important or valuable for me and my family

Healthy and unhealthy ways to cope

As was mentioned at the beginning, there are not just healthy ways to cope there are also not so healthy ways too. Here are some ways to cope that will not be helpful in the long run:

- Self-harm (cutting, burning, hair pulling)
- Alcohol abuse
- Drug abuse

People don't really intend to use a unhealthy way to cope with something going on in their life, it can seem like a good option at the time, but unfortunately they can end up causing more harm to themselves as a result. Whilst they are coping and it helps the person move on from the struggle they feel with trying to cope, things like self-harm or alcohol/drug abuse can cause so many other issues for a person that it quickly becomes an unhealthy for the long-term.

These unhealthy ways of coping are often quite addictive as well which can make them really difficult to stop and change for a more positive way of coping. It can take a lot of

effort to make that change and a person may need additional support, such as support groups or health service programs, in order to maintain that change to a more positive way of coping. Others may not have progressed that far with these negative ways of coping and making the switch to a healthy way of coping can be smoother as a result.

Healthy ways of coping

So what are these healthy ways of coping? There's many and each person will have their own unique ways of helping themselves cope. It tends to be things people value, enjoy and brings them happiness such as:



- Listening to music
- Sports
- Reading
- Making music
- Spending time with family and friends
- Treating yourself Treating yourself to something nice (manicure, movie)
- Shopping
- Going for a drive
- Running/going for a walk
- Painting/drawing
- Playing games
- Meditation/yoga
- Cooking/baking
- Journaling/writing poetry

There are so many things you can do to help you cope in a healthy way. Find what works for you and go with it, it doesn't need to be on this list, make your own and see what you enjoy doing. When you are struggling these positive ways of coping can be your ways to let go and feel better.

How can I get to a place where I'm coping?

What if you feel you're not coping well? As we mentioned earlier, HD can throw so many challenges that coping can become difficult. That said, it's very possible for you to go from a place where you don't feel you are coping to one where you do. Here's some important things to remember and think about in order to help you get to a place where you're coping well:

- **What are you struggling with specifically?** It's really important to know what is making it difficult for you to cope as you can't solve a problem unless you know what the cause is. So first, really think about what things you are finding difficult to cope with.
- **Seek support**– This may seem obvious and yes it is very easy to say and harder to do, but it will be easier to overcome your challenges if you develop a feeling of understanding and acceptance of them. This comes from accessing support available to you.
- It's important to **educate yourself** about the parts of HD that you're struggling with. For example, if you're concerned about your risk then becoming more educated about that part of HD should help you feel more empowered to handle it. HDYO has a whole range of information for you to help with this.
- It can be really impactful to **hear other young people's experiences** of dealing with HD in their lives, this will again make you feel empowered to deal with it yourself and know it's possible to do so. Young people tell us repeatedly that meeting/peaking with other young people has such a positive impact on their life. It may also give you some different viewpoints on things you are trying to cope with. Contact HDYO if you want to speak with other young people, we will be able to help you with that.
- Next it could be very helpful for you to **speak with a professional** service like HDYO or your local HD association so you can share your concerns and we will be able to support you with those and offer specific advice for you. If you feel you can, talking with family or friends about your concerns can also be helpful.
- **Finally, find healthy ways to cope.** Avoid the temptations of negative ways to cope and figure out what you enjoy, what helps you feel better, and go do it. When you feel the need go and do that coping method. Potentially even make a list of positive coping methods you enjoy so when you feel like you need some time to go feel better you have a list of options that you know work for you.

Support

It's not easy to cope, don't be disheartened if you're finding it difficult to get through these steps. Keep being positive and try your best. You can get there and HDYO is here for you anytime you need to talk.

Remaining hopeful



Finally, we want to highlight some important points of hope. When you're trying to cope it's really important not to make the obstacle, HD, bigger than it needs to be. HD is a big obstacle, no questioning that, but sometimes we feel it's bigger than it actually is. For example, a lot of people aren't aware how well HD research is progressing and as a result they feel there's no hope to treat HD. But did you know that HD research is really well-funded thanks to an organization called CHDI which puts over \$100 million into HD research each year and has done for over 10 years? Their goal is to cure HD as quickly as possible and they are very well-funded and coordinated. With their funding, research has progressed hugely in the past decade and new treatments are being tested in humans that could slow down HD. We don't have anything that slows HD down yet, but we are closing in on such treatments for the first time. We mention this because it's so important to be realistic and hopeful. In 15 years time HD could have more than one treatment to slow it down, how does that change your view of HD in your life? Does it make it easier to cope with HD knowing that research is actually progressing very well? We think it does.

You may have noticed that life goals and moving forwards were mentioned in both the resilience and coping well lists we did. It's so important to have goals in life and to move towards those goals. Sometimes young people can feel hopeless because of HD and don't bother to plan their life or set goals. But that's not necessary, we would say even without the research progress that you should be hopeful and set yourself life goals to work towards. But with the way research is going there's even more reason to dream to achieve anything you want to do. Think about the things that are really important to you and some of the dreams that you have for the future. They don't need to be grandiose dreams it can be something small but significant for you that it keeps you going.

Finally, you are not alone. Lots of young people impacted by HD struggle to cope and face every day challenges. There's lots of young people out there just like you. You may feel isolated but get in contact with [HDYO](#) and we can let you know what options there

are in your region of the world to meet other young people and get support. We are very serious when we say you are not alone. Do reach out and ask, we are here to help. Suicide hotline is also here if you feel this may be useful.



November 23, 2021

This document was downloaded from the HDYO website at
<https://www.hdyo.org/a/550-coping>

Advice received via the HDYO web site should not be relied upon for personal, medical, legal or financial decisions and you should consult an appropriate professional for specific advice tailored to your situation.

HDYO is licensed under a Creative Commons license.