



**HUNTINGTON'S DISEASE
YOUTH ORGANIZATION**

Loss & Bereavement

November 24, 2021

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

www.hdyo.org

'Loss' is when you lose someone or something that means a lot to you. 'Bereavement' is the period of grief after losing someone or something close to you. Loss and bereavement are something that many young people impacted by Huntington's disease experience at some point in their lives. HD is a progressive condition that currently has no cure, meaning the disease will eventually take the affected person's life. Everyone passes away at some point. However, the difference for people from HD families is that they might have to deal with the loss and bereavement at an earlier age than most people.

Loss

The slow progression of HD in someone you love or care for can be very difficult to witness. As the condition progresses and the person loses more and more abilities, it can impact your life in different ways. Young people may experience many different kinds of loss due to the impact of HD. This loss could be:

- financial due to the person with HD not working anymore
- lack of emotional support
- educational or career impacts
- loss of the family home
- family estrangement

"Sometimes when I look at pictures of my friends with their parents I feel sad because I think about my father and his progression with Huntingtons. And how he is not able to do as much as he did before and now we have to worry about financial issues and do a lot more to help around the home." - Maria

These different types of loss can be very difficult to cope with and talking about them is important. For more about these kinds of losses and the impact HD can have on a young person try the ['Living in a family with HD'](#) section and if you would like to talk to someone about your experiences of loss [HDYO](#) is always here to listen.

"Losing a loved one twice to HD"

Perhaps the main aspect of loss young people experience with regards to HD is the gradual loss of a family member as they progress with HD. Many young people mention feeling like their family member who has HD 'is not there anymore', even though the person is still very much alive. In this sense, as a young person witnessing the progression of HD, you may already be dealing with emotions of loss even before that person has passed away.

'My mom passed away in 2007 after having HD for over 20 years and it was weird because I really do feel like I actually lost my mom twice. Once to HD many years before her actual death when she had lost her ability to speak,

walk and pretty much do anything, and then a second time in 2007 when she finally passed away.' - Kirsten

If you feel like you have lost someone to HD, despite them still being alive, then talking about how you feel is a really good way to make sense of your emotions. Who you talk to is up to you but it could be a family member, trusted adult, teacher, or counsellor. HDYO is always here to listen and support you should you want to share your feelings.

Bereavement

The death of someone you care for can be very distressing. It's natural to have strong feelings when someone you love or are close to dies. It takes time to process the death of someone you love, and it can be different for everyone. It may feel overwhelming at first. You might feel scared, numb, or that you have lost control. You may worry that you will never feel okay again. Young people often say they sometimes feel bad or guilty because they feel a certain amount of relief that the person with HD isn't suffering anymore. It is important to understand that these are all very common feelings to have and time and support can help you deal with them.

Final days and moments



The final days and moments of a person's life are different for everyone but can often be very distressing and emotional times. Sometimes people may have advance notice that

someone they love is near death. This may happen particularly when the person is in the late stages of HD. This could mean that you get to spend time with someone, knowing that they don't have much time left. People react to situations differently. For some, it can be a comfort to spend as much time as possible with their loved ones during their final days. For others, this can be an extremely difficult time.

'We were told by the doctor that my dad had only weeks to live. He was at the very end stages of his progression with Huntington's. Me and my family spent pretty much all our time in the care home where my dad was, just being with him. He was not responding to anything, but it felt good to spend that time with him while we could. We were all there when my dad eventually passed away. It was incredibly hard to witness but I was glad I was there' -

Grace

Witnessing the death of the person you love can be very distressing. There can be good and bad elements to witnessing the moment someone you love passes away. Some young people like Grace mention that they are glad they were there when their loved one passed away, but Grace also mentions how 'incredibly hard' it was to see the person she loved pass away. Witnessing death can be a traumatic experience to have to cope with. It may not be something that you want or are able to do and that is also fine, you should not feel guilty about that it is better for you to be honest to yourself.

Some people may not have advance notice that someone is near death and may not be there when the person they love passes away. It can feel very sudden and a real shock when someone you love passes away unexpectedly. Some young people mention that they feel guilty about not being there when their loved one passed away. They wish they would have been able to have said something they wanted to say or spend more time with the person they loved before they passed away. These feelings of guilt are common but it is important to know that you have nothing to feel guilty about. It is not your fault that someone you loved passed away and it is often difficult to know when someone is near the end of their life. Many people feel the desire to have one last moment with the person they loved.

It is important to recognise that each individual's experience is different and there really is no right or wrong way to get through the experience of losing a loved one. Talking about your experience of losing a loved one can be very difficult to do, but it can really help you to feel better. You could talk with a family member, trusted adult, teacher, counsellor or HDYO - we are here to listen and support you.

'If you share your emotions people will know you are feeling bad and will come and help you feel better...' - Joe

Losing someone through suicide

If someone close to you has taken their own life, it can be especially difficult for those left behind. Don't be surprised if you feel completely shocked and numb or even angry at them. It's OK to feel this way, and other people who knew them may experience the same emotions. Many friends and relatives feel guilty or haunted by the thought that they could have done something to prevent it. These feelings are normal and part of the grieving process. Talking about your feelings and experiences may help you to feel better about the situation. We are here to listen and can point you in the direction of professional support.

The grieving process

After someone close to you dies, you go through a process of mourning. Grief is the visible sign of mourning and there are a wide range of physical and emotional symptoms that you may experience after a loss. It is really helpful to let your feelings out during this time as not sharing your emotions may lead to problems in the future. Some young people struggle to talk about how they feel, or don't feel like they can talk about their grief for whatever reason. If you don't feel you can talk about your loss and your feelings, perhaps you would prefer to send HDYO a private message and we will listen.

It is said when a person is grieving they pass through seven stages. They may occur in any order, and some stages may occur simultaneously. The seven stages of grief are:

1. **Shock** - an attempt to avoid pain by denying the loss
2. **Pain** - a period of devastating pain and feelings of guilt
3. **Anger** - which may include emotional outbursts
4. **Depression** - usually a time when someone looks back at what has happened and realises the full impact of the loss
5. **Moving** forwards - when the person begins to adjust to the loss
6. **Reconstruction** - building of life without the loved one
7. **Acceptance** - Acceptance may not mean happiness. But usually, the grieving person can now reminisce about the loved one with sadness, but without intense emotional pain.

The grieving process takes time and should not be hurried. How long it will take depends on you and your situation. We all go through the process in different ways and often experience conflicting or even overwhelming feelings. Sometimes feelings of grief may happen at unexpected places and times. It's also common to feel especially vulnerable on certain days, such as their birthday, the anniversary of their death, and during holidays. You may not feel any of these things but rather feel a sense of relief. Do not feel guilty as this may be because you entered the grieving process before the person with HD passed away.

Funeral/memorial services

Usually, quite soon after someone passes away a service is held to remember the person who has died. There are many kinds of funerals but usually it is a religious ceremony for friends and family to celebrate the life of their loved one and say a final goodbye. Each

religion has slightly different ways of holding this ceremony. Funeral services can be a very emotional experience, but they are also opportunities to remember the person who has passed away. Sometimes the funeral can be a positive experience as a chance to remember the person before HD, and share those memories with family and friends. There are lots of things you may be able to do at a service such as:



- Give a speech about the person you've lost and share what that person meant to you - if you don't feel able to deliver the speech maybe you could ask someone to read it out for you.
 - Choose music that was special to your loved one to play at the funeral
 - Write a poem that could be read out at the service
 - Bring an item that was special to the person you loved which you may be able to leave on the coffin or have cremated depending on the type of service
 - If it is a cremation the ashes are either buried or scattered in a place which the person loved. You could help decide where the ashes should go and maybe help scatter the ashes.
 - If it is a burial you could bring something to put on the top of the grave to show this person was special for you - many people bring flowers to put on top of the grave
- All these things can bring some comfort at a time which is often very difficult. Doing something special to remember the person you've lost can often make you feel better. If you want to talk about any worries you have about going to a funeral or memorial, or

have any questions HDYO is here for you.

'At my dad's funeral I asked if I could give a speech about me and my dad's relationship. I talked about how much he meant to me and no matter how much HD impacted on his life he was always my dad. It was really emotional for me to do but I just felt the need to do it, to tell people what kind of person he was for me.' - Harley

Remembering those you've lost



As time goes on you can continue to remember those you have lost in positive ways.

Things other young people do to remember loved ones include:

- Creating a photo album
- Looking at old videos or making a remembrance video to help remember
- Writing poems
- Keeping a diary of how you are feeling so you can look back at it and see the progress you are making with regards to accepting loss
- Creating a memory box with which to put all the things that help you remember your loved one in
- Visiting the grave or place ashes were scattered when you feel you want to, perhaps on anniversaries or other significant dates
- Wear an item of jewellery that they used to have
- Visit a favourite place you and the person you lost may have had - this can help you remember good memories
- Write down those good memories you remember, make a book containing all these good memories you have of you and the person you've lost
- Reminisce with others about your loved one/share memories
- Developing a section in your garden of their favourite plants, as a living memory

There are lots of positive things you could do to remember the one you have lost.

Maybe you have thought of or do something which is not on the list, if it works for you we would be interested to hear about it.

Losing a loved one or someone you care for can be very distressing. It's natural to have strong feelings when someone you love dies, and the grieving process may take a long time. You do not have to go through this on your own. Talking about how you are feeling and what you are experiencing may help you feel better. You could talk with a family member, a trusted adult or friend, or teacher. You can also speak with a doctor about how you are feeling, as they may be able to help you or suggest a bereavement counselor who will listen and support you.

Contact us

Finally, your local HD Association may be able to help and HDYO is always here to listen and support you should you wish you talk to someone about how you are feeling and discuss possible options for support.

Thank you to www.thesite.org and www.childline.org.uk for their support with this section.



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This document was downloaded from the HDYO website at
<https://www.hdyo.org/a/209-loss-bereavement>

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