



**HUNTINGTON'S DISEASE
YOUTH ORGANIZATION**

Visiting a Care Home

November 23, 2021

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

www.hdyo.org

As Huntington's disease (HD) progresses, people tend to need more care and this can be an incredibly difficult task for someone to undertake. The kind of care needed can become an exhausting “24 hours a day, 7 days a week” job. This is why many people with Huntington's disease eventually live in a care home, a place where they can receive care around the clock and have their needs met by professionals. This section highlights some of the emotional difficulties experienced by young people who have a parent with Huntington's disease in a care home, and some tips on how to make the situation as positive as possible.

Making the decision that a care home is necessary

Coming to the realization that the person with Huntington's disease may need to move into a care home, in order to get the support they need, can be one of the most heart-wrenching moments for a family to experience.

'My mom went into a care home when she was 46 years old. I remember this being one of the hardest decisions our family had to make. I wanted to look after my mom, as I really felt a nursing home was not the right place for her, but eventually I had to agree to her going into the nursing home. My family all struggled a lot with this decision and I remember there being a lot of hurt, worry and fear around this huge step.' Milly

It's important to remember that not every person with HD goes into a care home, but due to the complexity of the illness, people may eventually need more care than can be provided at home. The decision on whether and when this transition becomes necessary may be made by the family, alone, or may be based on the recommendations of the affected person's medical team. For those that do decide a care home is necessary, there can initially be a sense of guilt and an urge to want to keep the person at home with their family. This makes the decision incredibly difficult and emotional for everybody involved, including the young person. However, care homes are there to support, provide care, and ensure the safety of the affected family member.

'Emotionally, it was difficult. Although we visited her at least once a week, it was hard seeing my mum there, as from my point of view this was not her actual home. The care home was not her living with us and I saw it as if she was alone, without her family. However after a few months, it became easier. I realised that she needed this full-time care, so this was the best place for Mum.' Lucy

Care homes can also take a huge amount of stress off the family. Caring for someone with Huntington's disease takes an awful lot of time and effort. Families may have previously been providing the care for their loved one at a cost to their own careers,

social lives and well-being.

Finding a suitable care home



Once it is determined that a care home is necessary, the next step is to find one suitable for the person with HD and the family. This is not always easy. Ideally, it would be best to be able to select a care home that specializes in HD. However, not many HD-focused care homes exist, and those that are available may not be near other family members, which can make visiting difficult.

To facilitate this transition, it may help to arrange a meeting with the nursing home manager and talk to them about HD. Your [National Huntington's Disease Association](#) may be able to provide information or even training on HD to better prepare the staff for the needs of your loved one.

The financial costs of the care home need to be taken into account also. Care can be quite expensive in many regions of the world, with financial support varying depending on your situation. Sometimes, this can have an impact on what care home you are able to choose. A detailed search may be required to find the most suitable care home for each family's/person's situation. Your [National Huntington's Disease Association](#) may be able to help you find the right care home in your area.

'Finding a care home suitable is the first, but one of the most important steps. It took us 8 months to find the right care home, but after we had selected it, we knew it was the right choice. We built connections with a few

of the key nurses that would be caring for Mum, so we had that trust that was much needed in them.' Lucy

Making it like home

Once a care home has been selected and the move is done, it can be a great idea to make the person's new surroundings feel like home.

'The first few visits I helped in making her new room feel like home, pasting the walls in photos of my brother, myself, my father and my mom.' Ryan

Making their bedroom feel like home with nice bedding, photos and items from home can make the transition a lot easier.

Visiting a care home

Visiting a loved one in a care home can sometimes be challenging, both practically and emotionally, for a young person in a family with HD. It can provide many issues such as these below.

Having to travel long distances

As was mentioned before, the care home that is most suitable for the person with HD may not be located near some family members which can make regular visits challenging.

'Mum's care home was a round trip of 3 hours - an hour and a half to get there and the same back. Which was difficult as it was hard knowing that she wasn't local, so I knew that I couldn't see her if I wanted to on a whim, and up until a year ago I could not drive, so could never go as and when I wanted, which was hard in itself.' Jess

A long trip to the care home can be very tiring for a young person and as a consequence, it can be hard to find the energy to enjoy quality time with their affected family member. Plus, as young people grow up, their schedules may become more packed, which can make regular visits difficult.

'As I reached 16, I got a Saturday job and had college in the week; it was a bigger struggle visiting my Mum as she was so far away. We contemplated moving her to a home more local, but she was settled in her care home.' Jess

Sometimes it can be useful to plan ahead and make the visit a day trip. This can ensure that the time being spent with the person at the care home is quality time.

'We would visit for whole days, staying in the care home until lunch, watching morning TV then taking her out in the afternoon, before bringing her back to the care home. We would stay for dinner, and then it would be

time to say goodbye to mum, give her a kiss and tell her that we would see her next week.' Trish

Communication

As people progress with Huntington's disease, talking and communicating in general can become very difficult. A person's speech may gradually fade away until they are unable to communicate at all. For young people, this lack of communication during visits can be difficult, especially if you are unable to visit as often as you'd like.

'It's extremely hard not being able to communicate with my mum. We knew my mum could hear us, but could not communicate back, so we would simply talk to her. I hoped that she would understand what we were saying, remember who we were and have all the good memories still in her mind, but we could never tell as she could not communicate back.' Rob

However, just because the person with HD can't speak, it does not mean they can't hear or understand you. You can keep talking to your family member and sharing what is going on in your life. You might say something that generates a smile!

Making difficult decisions

Making the decision to transition a family member to a care home can be challenging, but other difficult decisions may be required as the person's HD progresses. For example, making decisions around feeding tubes and next steps if the affected person has an infection may be incredibly emotional and can be quite distressing. It can be helpful to discuss late stage plans with the person who has HD before they are unable to make decisions for themselves. If this can't be done, you might feel like you're making the wrong decisions. However, just imagine how much harder things would be for your loved one if you weren't there to help. If you find yourself in this situation, [HDYO](#) may be able to provide some advice, support and peer contacts. You can also find professional support with these decisions from your [National Huntington's Disease Association](#).

Witnessing the deterioration

One of the hardest parts of growing up with a loved one diagnosed with HD is witnessing the disease progression.

'My mum is an incredibly strong person, and seeing Huntington's disease take over her body has affected me deeply over my teenage years. Without the support of my father and my brother, I don't know where we would be as a family unit. My mum is a fighter, and I love the bones off her.' Lucy

Seeing someone in a care home infrequently can make the impact of disease progression even larger. Some people may also want to avoid visits because they don't want to see their loved one deteriorate. It may help to remember that your loved one is

still there, in that body, and they'd probably love to see you and hear about what you have been doing.

'As I got older, visiting actually got harder for me personally. I grew up without my mother, and really craved the mother daughter relationship that my friends would talk about. I struggled seeing my mum being taken over by Huntington's disease, but knew that for her sake and mine too, I would keep visiting her.' Lucy

However, some young people make the decision to visit their family member with HD infrequently or not at all. You do not need to feel guilty about making this decision. It is important to take care of yourself and your emotional wellbeing.



Talking about this issue can really help, so don't hesitate to go to [HDYO](#) for support from other young people in the same situation.

Enjoying quality time together and having fun

Although visiting a family member with HD can present many challenges, it is still possible to enjoy quality time together!

'It's been hard to watch mom deteriorate in the home, but I try to make our visits fun. She loves my visits and always demands her ice cream! My kids

jump on her bed, put makeup on her and make her laugh. We listen to music, dance around, and hang things on her walls or from the ceiling. We have a good laugh.' Teresa

Planning some activities or day trips can really make a visit special. It may require extra work and organization, but the results can be so rewarding for everyone.

'The activities at the nursing home are more like bowling, line dancing, bingo... all things my mom hates! But as a family we take my mom out regularly so she could still attend some of the fun things she loves doing. My brothers play in a band and we take her to their gigs, my kids played soccer on Saturdays and we would pick her up and take her to games, birthday parties etc. So eventually I came to accept that the nursing home provides the 'care' but we provided the fun, recreation and love.' Teresa

How you approach a trip to the care home can have a huge impact on the mood of the visit. Having a positive plan for the trip may result in a more enjoyable visit, leaving everybody with smiles on their faces. Nothing is certain of course, and you can only try your best. Here are a few ideas and tips to help.

Things to do with someone in a care home



- Show them some photos or videos, perhaps of a recent trip or to highlight an achievement etc.
- Bring gifts to them.
- Take them for a walk in the care home grounds and gardens, so they can enjoy time in nature and a new setting.

- Bring in something that you are really proud of or would like to show them.
- Take them out to a social event with family and friends or bring everyone (family and friends) to them instead!
- Hold their hand.
- Watch a favorite TV show or movie with them.
- Make sure they are comfortable by moving their sheets, fluffing their pillow, etc.
- Sing songs together (or for them).
- Bring up old memories, funny stories and remember good times.
- Share a smile or a hug, even your family member can't smile or hug back
- Listen to their favorite radio station or CD
- Give your loved one a foot rub or hand rub

Perhaps you have other ideas of fun things to do when visiting a loved one at a care home? If you do, let us know and we will add them to the list!

Having a loved one with Huntington's disease in a care home can be very difficult to cope with at times and presents many challenges. However, you can still enjoy each other's company. If you would like to talk, HDYO is here. You may also be interested in some of our programs for young people to share with other young people.



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<https://www.hdyo.org/a/44-visiting-a-care-home>

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