Young peoples' experiences of finding out about HD

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

www.hdyo.org

It is important that, as well as getting the parents’ experiences of talking to kids about Huntington’s disease, we hear the views and opinions of young people who have been told about the disease by their parent/guardians. This will enable us to hear both sides of this difficult topic and gain a better understanding of different approaches and strategies when it comes to talking to children about Huntington’s disease. If you are a young person who has been told about Huntington’s disease by a parent or guardian, why not fill in the form below, we will add it to the site once it has been checked by HDYO, and parents/guardians will be able to view this section to learn from the various experiences posted below in order to shape their own thoughts on how best to talk to children about the topic.

Send us your experience of HD

feedback@hdyo.org

Felicity

My name is Felicity, and I am eleven years old. In 2008, I found out that my Nan had Huntington’s disease. I had just turned ten, when my Dad told me. I have recently found out more about HD and I am very interested to find out more as I have a 50% of getting it when I am older.

I am so very glad that my Dad told me as I would hate to not know something about my Nan, as I am close to her. Our family has coped with it well, and so have I. There’s only one thing; my cousins do not know about my Nan, because that was my Auntie’s decision not to tell them. I respect her opinion greatly, but I prefer to know. Personally, I feel it is wrong to not know about something that has happened, as they also have 50% chance, the same as me.

My Dad has explained everything to me about HD, so I am quite aware of what happens. He has made many friends over the HD Message Board, who I have also met. Everyone is very friendly, and I have also learnt many things from them.

Some people find it hard telling their children if a member of their family has HD, or may not want to tell them at all. Personally, my opinion (as a child), is to just tell them the truth; children are smarter than you think, and can sense things quite easily. I feel the best way is, like how my Dad told me, just tell them little bits at a time, let it sink in, soon they will start to think about what you have said, they will ask questions and all you need to do is tell them the truth. Do not add any other information, as they will ask you what they want to know. Don’t be frightened of telling your kids, they have a right to know.

Matt

I was told about HD when I was very young, because my dad had been diagnosed with it. I don’t specifically recall being told, but somehow I always remember that I was. At the time I didn’t think much of it because my dad was in the early stages and his symptoms were not very noticeable. Life carried on as normal.

It was when I hit my teenage years that life started to change, my dad’s symptoms were very noticeable by now and he was beginning to need 24 hour care. I felt that, although my parents had told me about HD, they hadn’t explained it to me enough. I lacked an understanding of what the disease was and how it affected people, how it affected my dad. And as a result I couldn’t relate or understand the changes happening to my dad as he progressed with the disease. This caused me to try and ignore this issue in my life and resulted in a lot of problems for me as a teenager. I don’t blame my parents for not telling me more about HD, it is not something anybody wants to discuss, but looking back, I think more education about the disease in my teen years would have been very beneficial for me and I would have coped a lot better as a result.

BJ

When my Mom was officially diagnosed with HD my parents decided it would be best to be up front and honest and tell my sister and I at the ages of 9 and 11 years old. I don’t remember the exact conversation, but I believe our first conversation went something like “Mom is going to get sick, you might notice some changes, and she will always love you and if you have any questions please ask us”. This was the first of many conversations that slowly progressed to talk more and more about the situation we were in, but the key was the conversations always ended with “we love you and please let us know if you have any
questions.” Another thing my parents did that helped me was show us that it was okay to get involved with fundraisers or raising awareness about HD. By my parents choosing to tell me at a young age about HD, HD became part of my life and I learned to accept it. I also learned to teach others to accept it just the way my parents taught me.

**Megan**

The first time my parents told me and my brother about Huntington’s was back in 2007. It was one night, when we were all at the dinner table, that my dad started to show visible symptoms of the disease, when me and brother, being the little children we were, made a joke out of it, as we had noticed it in the past couple of weeks. We were saying how he would twitch every few seconds with his legs, that we thought was really funny, when my dad shouted at us to be quiet and stop joking around. Me and my brother had no idea why he acted like this, he never acted this way before. Later on that night, my mum called me and my brother into the living room, as we had grown to my ‘pacing up-and-down’ dad. I remember thinking to myself that all of this was not right, could it be divorce? No that can’t be it. What could it be? Then my Mum said to us … ‘I think it is time we tell you, your Dad has Huntington’s Disease’ my immediate reaction was ‘Can they cure it?’ which the only answer was ‘no’. After a long night of my Mum and Dad trying to explain to us what Huntington’s Disease was, I went to bed. I had a headache and puffy eyes from where I was crying but now that I look back on it, I am so glad my Mum and Dad told me as they may not have had all the support and fund-raising for the charity as they would have done. Also there are no more secrets and we are closer as a family now as we know we have to support each other in everything we do. Now that I am going to HD meetings, fund-raising and getting involved with HDYO, I feel so much better in myself and I feel like I am making a difference in the world Huntington’s Disease … It is hidden no more!!!!

**Lindsey**

I wasn’t specifically sat down and told about what HD was or what to expect. More or less my mom started behaving differently which sparked her being tested. I would have preferred the family to all sit and discuss what the disease was and what research said about it so everyone was on the same page. Also, so that there was no judgements in the family itself - as HD wasn’t spoken about publically at the time. I think sitting as a group and discussing what it is and what to expect is best because then you have each other to support right there and also making it more “ok” for those who will be diagnosed positive and have them feel it’s an open and safe environment. I more or less did my own research about it which was good but difficult as I was young and didn’t have a ton of resources.

**Keri**

My mum had to pluck up a lot of courage to tell me and Jen as she thought that we might be upset about it and the longer and longer she left it the more and more annoyed she thought we would be that she kept it from us and eventually she did tell us when i was 17 and Jen was 16 (thereabouts). At first we were unsure how to take it as it came as such a shock but eventually we accepted it and from then on have been able to talk about it openly and ask questions whenever we need to. I wish that she had told us sooner so we could be involved with the youth organisation earlier but i do understand her fears in telling us and how hard it must of been. It was then easier for her to tell Chloe because she had the support of me and Jen so Chloe got told at a younger age (11) and understands fully and is loving the youth groups.

**Laura**

My father was very open to my brother and myself about HD, which benefited us as we learnt to understand what HD was about and how it was affecting our mum and our family. My Mum had the disadvantage of not knowing what HD was, as her family never told her that she was at risk until her mother died. Due to this my Dad felt that he had to be open on the subject and help us understand. It was incredibly tough knowing that we were at risk 50%, however I felt this helped me prepare for the testing process and generally understand the effects of HD. I felt that being so open among our family helped, and I am glad that my father took the decision to share all aspects of HD with us at such throughout our lives.

**Amanda**

I remember the day my mother told me, she had Huntington’s disease, as if it was yesterday. The memory of the night will forever be etched into my brain. I was 18 years old, and it was 2 days before my birthday. I was with some friends at my house, and we had been getting ready to go out, and celebrate my birthday. That night I got into a fight with my mom about something stupid and her and I were fighting in front of my friends. I remember feeling embarrassed, but my friends were also used to my mom blowing up over small stuff. As I was walking out the door that night, my mom yelled at me that she had Huntington’s disease and that she had known for a few years. I was at the time a rebellious teenager who was at odds with my mom for years. My mom would always get mad at me over the smallest things and repeatedly yelling that she
hated me. I never knew why she was always saying such hurtful things to me. Later that night I ended up leaving the party emotional and distressed about what my mom had said. It was raining out, and I had been crying while in the car. I also should not have been driving, since I had a few drinks. I ended up hydroplaning into a car that night on the highway. I was lucky that everyone survived, and no one had been hurt. I want to tell my story to parents contemplating when or if they should inform their children. The way my mom told me was not healthy, and I put the lives of myself and my friends in jeopardy that night. I had only heard about Huntington’s disease from my father a few times when I was younger. However, my dad and mom had been divorced, and my mom had told me at the time, that my dad was lying. When my mom starting acting out when I was in high school I started think something was wrong with her, but could not grasp what it was. She was in denial and took her anger out on me, but I could tell that she was suffering from something. My mom should have sat me down when she first started to show symptoms, to educate me on what was going to happen. As soon as I found out that my mom was sick, it was as if I could piece the puzzle of my life together and everything made sense. I have since than built a strong relationship with my mom and forgave her for all the conflict that happened when I was in high school. However, I struggle every day with the fact that if my mom had told me when I was younger we could have had a strong bond when I was in high school. Those had been the last good years of my mom’s life, before she got terribly sick. I feel guilty for taking my anger out on her, because I did not know what was wrong with her. I thought she hated me for the majority of my high school. I think it is extremely beneficial for parents to educate their children on why they are experiencing certain symptoms. It is going to scare the children more to, not know, what is going on, than to be educated on what Huntington’s disease is.

**Wesley**

When I was around 16/17 years old we found out that my aunt was affected by HD. Soon after, we found out that my father and my grandpa also carried the gene. My grandpa was already showing symptoms. He died last year at a respectable age of 83 due to cancer. That means, except for my aunt who died of HD last year at the age of 43, that I am part of a family who has a late age of onset.

When my father found out he was carrying a faulty gene, he didn’t really take time to tell us. But that is just how he is. He keeps things to himself and doesn’t really want to talk about it. Combining this with the fact that most people in my family presumably showed symptoms at a later stage of their lives, made me not care that much. When I was 18/19 years old I did some research and became worried and somewhat scared of what might happen. So, from my experience I would say that, as a parent, you should inform your child (depending on his or her age) about every aspect of HD and what this might mean for each family member. It should become understandable and it should not have to be difficult to discuss such an important topic at home.

**Marina**

When my mother found out she was at risk, she decided that she didn’t want to undergo a predictive test and live her life as if HD was not part of it, and that if symptoms one day would show, she would deal with it then. Therefor she also decided she didn’t want me and my siblings, or anyone else, to know about HD at all. My father did know, and he respected her decision to make HD part of her life when it became accurate, but when the time came and my mother started acting strange she didn’t want to face that fact. She denied it, which later led to my parents separating when I was 9 years old. I didn’t notice my mother’s early symptoms while she was living with my dad, but when her life changed so drastically after the separation, symptoms started to show very clear and very sudden. My siblings and I still didn’t know about HD, since my mom was in denial and my dad still wanted to respect her and let it be her thing to tell when she was ready. We speculated and thought she acted weird because of the separation and everything around it. People started asking. My friends started asking. My mother got into fights with my friends parents. I hated that she embarrassed me, so I was always angry with her and I always insulted her. I always screamed at her to “God dammit mom, stop moving! Stand still! You look like an idiot!” “Stop moving like a drunk, you’re embarrassing me!” I wasn’t easy on the insults. After finding out she was ill I could never forgive myself for how I treated her during that already hard period of her life. No one was nice to her, not me, not my siblings, not people in general.. not even her mother was nice to her. Everyone who knew what it could be was in denial, and the rest of us just didn’t like the was she acted.

When I was 13 years old my father just felt it had gone to far, he saw us unlike our mother for how she acted weird, and he heard people talking about her. He also saw us suffering, in the way that kids do. My sister got really aggressive, I got extremely quiet and shy. He didn’t want to wait anymore, when it was so obvious what this was, and he understood that my mother wasn’t going to tell us either. So he gathers us, my siblings and I, and he told us that our mothers father had Huntington’s disease, and that he committed suicide before we were born because of the depression it caused him. Then he said that every child of a person who has HD has a 50% risk of inheriting the gene, and that our mother with most certainty had inherited HD, and that was why she acted the way she did. He briefly mentioned some well-known symptoms of HD and that there was no cure nor no modifying drug, and that it deteriorates you until it sooner or later leads to death. He said our mother having HD also meant we had a 50% chance of inheriting the gene. He said that science is developing fast and that there might be a modifying drug available quite soon, and even
a cure in a few years, but that we could not know how soon, or even if, a drug could be available for us or our mother. He decided to tell us everything, not to hold back on any information, just let us know everything. He was specific and honest, and I’m truly grateful for that. It would have been harder to hear one part, and when learning to live with that, having something else put on your shoulders. A few days later my dad took us to see a genetic counselor who explained more about the disease itself, since he didn’t feel comfortable with himself giving us fully correct information. He also insured us we could meet up with the genetic counselor anytime we needed to ask or talk about something.

It the point my dad told us I couldn’t really let it all in, I even laughed a little when he started talking, not at what he was saying, but at the seriousness in his voice and the quietness of the room. He didn’t blame me for it. He just continued. For several days the facts didn’t touch me that much, it slowly got to me what he had said. It felt good to understand why my mother was acting strange, and not at my mom for being embarrassing. I got nicer to my mom, and the guilt of how I had treated her before came quite sudden. It was hard understanding that my mother wasn’t going to get better, that it would only get worse, but it still felt good to know the truth about it. It was all hard to deal with when the facts started to get through to me, but those were the facts, and the facts wouldn’t disappear just because no one told me about them. For a long time I blamed everyone who knew and didn’t tell us, because dealing with the guilt of how I treated and felt about my mom before knowing, has been harder than any of the other facts. And I’m always thankful to my dad who finally broke the silence and let us in on the truth, he gave us a chance to deal with what was really happening.

Elli

When I was about 12 my Granddad fell off a ladder, I’m not particularly sure how but the doctors discovered that he had Huntington’s Disease. At first I didn’t really know enough to have a proper reaction, so I thought it wasn’t a bad thing.

But then my mum started telling me the information about the symptoms. She told me that until she knew if she also had it, that I should not worry, but reading the list of symptoms she printed out, I started to feel that I had it. Slowly I convinced myself this was unlikely as my mum might not even have it, then she tested positive. I was about 13 at that point, my theories about myself having the symptoms grew and I was very upset.

I’m 15 now and after talking to a councillor I understand everything. I still get upset, but it’s easier to deal with. So I suggest that letting them talk to a genetic councillor to answer their questions or whatever when telling them would make things a lot easier.

Sophie

I think HD should be brought to the publics attention, there isn’t enough awareness about the disease. I had never heard if HD until my mum was diagnosed. For years I cared for my mum because i knew she was ill but I didn’t know what exactly and for years I spent time arguing with her because I thought she generally hate done at times however I have came to learn about HD and I now know that it’s all part of the condition if I had known I could have done things differently.

Megan

I was told that HD runs in my family at a young age. I don’t exactly remember when I was told, or how, but I do remember I was told. I was taken to visit my grandmother, and at that stage, she had already been admitted to full time care and her symptoms were in full effect. I never had a conversation with her because she couldn’t articulate speech, I never saw her get out of bed, and I think I was only able to visit her two or three times before she passed away.

It feels heartless to admit that I never quite had the proper emotional response to her death. I didn’t cry, and I didn’t feel as if I had lost anyone, because I hadn’t had the opportunity to truly get to know her. What made me cry though, was when my father, a man who seemed to be the epitome of strength and unwavering emotion, called me on the phone, crying, and informed me that she had passed away.

Sadly, my grandmother passed the defective gene to her two sons (my father and uncle). My dad went on to have three kids; a son and two daughters. Each to a different mother.

I am the youngest, and was born in 1995 when prenatal testing was available to the families who had a history of HD. There was an unborn child before me, who ended up testing positive and my parents made the hard decision of terminating the pregnancy. I was born as the result of not inheriting the disease.

My older siblings were not as lucky, and had to wait until they were 18 to decide if they wanted to take the test. My brother gave birth to a son before he got tested, and there was a time where everyone was worried that it hd been passed down again. Luckily, last year my brother finally got the test, and proved negative.
My sister was the only one of the three who inherited the defective gene. She has since given birth to a son of her own, and opted not to have him tested in the womb despite knowing she had the disease. Her justification was that she couldn’t bare to watch him grow up, knowing he would end up like her.

Taking the test is a very personal and stressful decision, but I would recommend that if you are at risk of inheriting the disease, that it is in your best interests to do it.

My uncle had no children, and lives alone. He is already exhibiting chorea. My father had been admitted into full time care, but had convinced himself that he is cured, and begs to be let out. My sister had begun to show subtle signs, but is still in custody of her son. My brother is reluctant to have any association with any of his family besides me.

I educated myself on the facts of Huntington’s Disease, and I believe it has better prepared me for the future. It made me mature earlier in life, and being told at a young age allowed for the knowledge to sink in gradually.

Don’t think that HD has to be kept a secret. Awareness of this disease will help to educate others. And always remember that you’re not alone, and that there are others who are going through similar experiences.

Mackenzie

My mum got diagnosed with HD when I was just 6 months old, we moved to Christchurch when I was 1 to be closer to family so that my grandparents could help look after mum and myself while dad was at work. My mum then got to the stage where we couldn’t look after her any more at home so she went into full time care. I always kind of knew that my mum wasn’t normal like everyone else’s mums but I still loved her to pieces. If I ever had any questions I wanted to know about it I would just ask my dad and luckily for me my dad was very open about and willing to answer my questions. Mum kept getting sicker and sicker and it got to a stage where I found it really hard to go see her with out getting up set and thinking you know that could be me one day. Unfortunately my mum passed away last year with a 14 year fight with HD. I honestly look up to my mum so much how she fought a tough battle ever day. But to be completely honest I reckon the only word that sums up how I feel is scared. I’m scared of what might happen and I always ask myself those what if questions, what if I never get married, what if I pass it on to my children, what if I never have children. But some advice for anyone reading this is don’t let HD get you down until you get tested and know for sure weather your positive or not because what if you don’t have it and you have spent all that time worrying about it.

Molly

The hd is a very sad disease that can hurt very badly i would sujest that adults tell there children about the disease as soon as possible!

Elle

My name is Elle, and I am 16 years old. Last year, at the beginning of year 10, I found out that my Mum has Huntington’s disease.

My great aunty, ever since I can remember had always been a bit off balance and very forgetful but I just never asked why, I didn’t see why I should, she seemed just like everyone else. Then after having a science lesson on genetic diseases, one of which being HD, I suddenly thought of my great aunty and it all seemed to click into place. So after school I came home and told Mum what I had learnt, but what I was not expecting/prepared for was what she was about to say. She told me that my Granddad has it, my 2nd cousin and herself, it never ever once crossed my mind that she could have it. It did put me off tracks for little bit, but I soon just managed to come to terms with things. For a bit I was angry at Mum for not telling me, but I know she was only doing what she thought was best.

My Granddad, 2nd cousin and Mum have all not started showing signs yet, which is a good thing, but I know that the more time that passes, the more the disease will start to take place. But for now we’re taking each day as it comes and making loads of memories.

Olivia

Hi, I am Olivia and my dad was diagnosed with HD two weeks before I was diagnosed with a brain tumour in November 2010. My mum did not tell me about it as it was a lot of stress on me during my chemotherapy, I was just told he was depressed. I was diagnosed in 2010 and I only found out about my dad in 2012. My family were at a 21st birthday and my dad only had one beer however with the medication he is on, he shouldn’t drink at all. I was getting very upset about the fidgeting and was getting annoyed so I asked if we could go home as I felt sick. We told my dad that and on the way home he got a bit annoyed and angry with me, he then eventually blurted out that he had HD when we were home. I was really upset however knowing it was not him behind everything he does, instead the disease, it helped me a lot. My mum told me not to
look on the internet at HD and I didn’t for many months but it got too much and I looked online. I refused to look at wikipedia or anything and I found this website which really helped me understand the disease. The night I was told I also figured out that my auntie had it and that my dad’s mum had it. I was 14 when I was told and I understand why my mum didn’t tell me however I personally would rather have been told straight up as I would have understood why my dad is the way he is.

**Katelyne**

I was told that Huntington’s runs in the family at a very young age and when I was told all I could think of is that my mom wasn’t going to have that much time left, but I was little and didn’t really know anything about the disease other than it can lead to death. As I grew older I made it my obligation to learn all I could about it. Knowing all of this information really freaked me out and worried me. I didn’t want to end up as bad as everyone else and didn’t want to need the help that my mother now needs. My mother had had this for 17 years now, as many people know life expectancy for these patients are about 15 years. I myself have not been tested yet and don’t know whether I’m going to or not but I can say that if anyone chooses not to get tested, it’s not a bad thing. My mom regrets it some days cause she feels if she didn’t know she would have lived her life more fully and wouldn’t have done things differently. All in all everyone who has to deal with this, you’re not alone. We all have own experiences and worries but the important thing is to be there for people and others who have this disease.

**Kelly**

I was in my mom’s room i noticed a large envelope on her bed curiously i went over to see it. It was addressed to my grandparents house I saw it was open, i looked inside it was about Huntington’s i had never heard of it before and was curious i started reading it had a booklet made for children with parents with Huntington’s i figure my parents were going to give it to me.

I started my research i figured out it was genetic i looked at all the symptoms they all reminded me of my grandpa so i always knew he had a problem but i never knew what this was it he has had a heart attack and is very much a perfect example of all the symptoms i thought about it more the booklet must have been for my mom about her dad (my grandpa) being it was addressed to my moms old house!

I thought more why do we have it i thought MY MOM MUST HAVE IT ! She is about 40 and i notice some of the symptoms in her memory loss twitching all that stuff! So the booklet must be for me.

I start doing my research it is genetic i saw all these symptoms i thought no i don’t want it! My grandpa is the oldest of three my mom is the oldest of three and i am the oldest of three!

I started to look at warning signs anxiety which i have ( i have a therapist for it I’m pretty bad) mood swings i have bad coordination i have obsessive habits i have ( i am a a+ student nothing is handed in if its not amazing and above and beyond) i figure I AM DEFIANTLY GOING TO GET IT!

I started crying i cant tell my parents i know because i was snooping i shouldn’t know it was in my moms room i will get in trouble! I texted my friend she said to tell my parents but i can bring myself to do it I’m gonna get in trouble! I am shaking and crying still doing research i should tell them but i cant!

This all happened ten minutes ago!

**HDYO:** Hi Kelly, thank you for sending your message to HDYO. We would very much like to help you with your current situation but the email you left us kept bouncing. If you see this message, please get in touch with chandler@hdyo.org and we will be happy to offer some support for you.

**Ella**

Hi, as you know I’m Ella. I’m 13 and live in the UK. Unfortunately I didn’t find out until my Father was quite advanced in his HD. When I was 10 my Grandmother passed away of Huntingtons, the fact she had HD was no secret to me and my sister Anna. However no one ever told us what it was. We were young and we never thought it would effect us, we were just worried about our grandmother who was rapidly deteriorating. My bond with my Father (her son) was always very strong and we used to have a whale of a time. I’m quite a privileged person and as I was growing up there was never any arguments in the house and we were all very happy. As I got older my Father started developing a temper which didn’t seem abnormal at the time. On 9/5/2011 (kind of a bum day for me. Hence the remembering of the date) My Parents were arguing which was a clear sign something was wrong, my Father came in to my room crying (again a clear sign) and told me the he and my mother had fallen out of love and he was going to leave. I was distraught. Nothing had seemed wrong, there were no signs. Later I found out that my Father had had numerous affairs and my Parents hadn’t just in fact “fallen out of love.” Looking back now I can pick out every single woman my father had been with. So for 3 years I’ve resented my Father for what he did to our family and 6 months ago decided that I no longer wanted anything to do with him and planned on telling him over the summer. Then came Christmas... the agonisingly long trips to see family you don’t like, with people you don’t like!! My
Father, my sister and I went up to Cheltenham to visit an aunt who every time we see her makes rude remarks about our mother and my weight (I'm not even overweight she just likes to live in the past), we coming towards the end of our visit, when my aunt and my father (who is unemployed) were talking about my father getting a job when he said, “I can’t work for medical reasons.” she then replied with, “Is it the thing your mum had” to which he said, “shhh! The Girls don’t know.” Then it clicked for me. I went home and asked my mother about it and she confirmed my father did have HD. I then was reading about it online and realized it was hereditary. When things like this are kept a secret, they do come out and I’m still not sure whether I prefer knowing or not, however I do and I’ve got to carry on with my life. In the last week or so I’ve come to realise that what my father did was in the past and I watched my grandmother die from HD, I want to spend the time I’ve got left with my father liking him. Going well so far... here’s to making the most of the future... where ever it may take us.

Joslynn

My experience with Huntington is that my grandma had the disease and she was put in a home after a while and I never got to see her for 5 years then she passed away. Then about 6 months ago my mom went and got tested for this disease and it was along process then she was finally called to come in and find out her results. I had school that day so it was very very nerve racking. My parents were all ready debating weather they wanted to tell us four kids and I was really hoping they would. So once we all got out of school they sat us down and my dad told us that the test was positive. A part of me was relieved and a part was scared. I was relieved because we knew whether she had it or not so that was good to know so we can help in anyway we could as kids but, I was also scared because if the gene passes me and my brothers and sister have a 50/50 chance of getting this disease. I am trying to help in anyway i can but my mom tells me “i want you to act like i never got the disease and live life normal” She did make a bucket list of things that we are going to do before she starts showing signs. This is nothing to be scared about it is going to happen. All we all can do is just help each other and be supportive don’t be afraid to share your thoughts and feelings with other people:

Rosie

My name is Rosie, I am 14 years old and I only recently found out that my mum has Huntington’s Disease. I hadn’t really noticed that she had the symptoms of it until I knew what it was, my auntie died a few years ago with the disease, but back then I didn’t know what was wrong with her or that I had a chance of developing the disease by a 50/50 chance. When I heard that my mum had it, it came as a shock but as she also has depression and anxiety I had to be strong for her, which probably made me get through it easier as I was distracted. I am glad I know as now I am fundraising and donating to help raise money to raise awareness!

Havanna

Six months before my aunt, Becky, had passed away from HD, my mom decided that it was time to explain to me what was happening to her. I was nine years old when this happened. I guess you could say I was a curious kid because I constantly wanted to know what was going on. So one night, I was watching some Disney show after dinner when my mom, Melinda, came up to me and told me that she wanted to talk to me. She sat me on her bed, and started talking in a soft, nice tone, so she wouldn’t overwhelm me. Then she just abruptly came out with it, my aunt Becky was dying from Huntington’s Disease. She explained that HD makes you walk, talk, and move weirdly, and that it changed her mood a lot. She also explained that my grandfather had passed away from the same disease when I was only two years old. I had a total of four aunts at the time. Becky was in a nursing home, and two of the other aunts, Tina and Jess, had symptoms. My last aunt, Tab, was tested negatively. I took in all of this information and kind of sat there, processing it all. One of the last things my mom said was that she was tested gene positive and that she didn’t have any symptoms. Of course, being so young, I cried because I didn’t want my mom to pass away. After she reassured me that she won’t get sick for a long time, the conversation pretty much ended.

As time went on after that, my mom slowly explained in depth what HD was. My mom was also getting more involved with the HD community and started going to HDSA Conventions and even attended the World Congress in Vancouver. Due to the fact that she was getting more involved.

Molly

I was 16, and my mum told me ‘your Dad has Huntington’s disease’ my mind went blank, my eyes welled up and the worst part, my heart broke.

I can honestly say I have never felt a pain like that before. Then she continued to explain what it was because my initial thought was ‘what the hell is that, he’s going to die’. As soon as she said his memory would fade I broke down, I looked next to me and seen my sister in shock, I think she was scared, scared of it being hereditary, scared of having it and passing on the gene to her kids, thinking if she should even have kids. We both had so many questions.
For weeks, months I didn’t leave my bed. I didn’t want to eat, think or talk, I just wanted to lay there and indulge in all of my sadness. I questioned ending it all, was there to live for I asked myself.

If your reading this looking for an easy way to deal with the pain then quit while you are ahead, there is no way. It’s been two years since I found out about my father and honestly…it doesn’t get any easier. Some days everything’s fine, it doesn’t even cross your mind. But then you get the days where you don’t care about anything, you just feel emptiness, the tears won’t stop streaming and you can literally feel your heart breaking over and over and over.

The only way I have found to at least try and control my emotions, is to do everything I can to make what my dad has left of his life the most amazing time of his entire life. I have taken over everything for him, I’ve found him a nice care home, I’ve made sure he has everything he could possibly want. But mostly, I’ve gave him my time. I’ve seen a lot of posts saying ‘you’ll find you struggle to find time to visit when their in a home’ it’s a load of rubbish, there is always time for loved ones. Especially when they have such a devastating condition like Huntington’s.

One advise I can give you, write a diary, it sounds silly but if you’ve watched the notebook then you’ll understand. Not only can you write what you feel you can’t tell another person, you can read it back to your loved one, spark memories. Do everything you can, but trust me...don’t give up.

It won’t get any easier then how you feel today, each day your loved one will deteriorate, and each day it will get harder and you’ll feel worse and worse.

All you need to think is, Huntington’s is breaking my loved one, I wont let it break me.

Alyssa

I have always been considered a “daddy’s little girl” until he suddenly changed. My parents divorced when I was six years old. After I had chosen to live with him, he consumed more and more alcohol. Eventually, I became aware of these issues and got use to his actions. When I was 14, my mother lightly mentioned the “H” word. I had absolutely no clue what was coming. His alcohol usage got worse and worse as my anxiety got worse and worse. I felt alone. I felt paranoid. I felt sick. I felt tired of being a parent to a parent. I didn’t understand the implications behind every action he was conducting. I am at risk. I am at risk.....

I love my father. I love my mother. All I can say to change the world—is that I wish they would have involved me throughout this process in life. This would begin with the essentials of learning acceptance and adherence towards those with any form of disability. In essence, this would eventually lead to learning tools to help with everyday complications and processes (including Medicare!). As you can imagine, I am still a young adult with full-time obligations to fulfill for my single parent. Even though I am currently facing this disposition with a high probability—all I am forced to think about is how my father will be comfortable.

Carla

My father is suffering from HD and I’ve known this for a few months now. My parents are divorced and I see my father once every two weeks. My father and I used to fight a lot and I was very cruel to him and his wife. When I came home to my father’s house the other day, they wanted to sit down and talk, but they seemed a bit nervous. They told me my father has HD. I was, and still am, very sorry about that. I knew a little about HD, since my father’s mother also had HD, and his brother too. But I didn’t know that much about it then.

Now I do know what HD is. At first, I didn’t notice anything about him, but now I do (my father is in his forties). Sometimes when he is tired, his walk is a bit awkward and he forgets a lot. But that doesn’t matter. My fathers likes sports very much and that’s what he does a lot. It always makes me sad when I realize that within a few years, he might no longer be able to do so. It is really awful to see someone you love very much decline. I also have a lovely 2-year-old brother (he is the son of my father and stepmother). I also always get really sad when I realize that when he is my age, he may not have a father anymore. I worry a lot about this. When I’m outside and I see an old man, I always think about my father and the fact that I will never know him like that. Since my father’s illness I look at life differently. I try to enjoy life even more and I try to get everything out of life. I enjoy it even more when I’m with my father. I notice that I’m quite angry about him being ill and I think it’s not fair. I sometimes take it out on my mother, by calling her names and things like that. I’m not that much of a talker, that makes it even more difficult. My advice for parents is to just listen and don’t say things like ‘everybody dies’. My advice for kids is just to enjoy the time you still have left together and not to worry too much, since you will only regret that later on.

Yasmine

After he came back from the hospital, he simply smiled and said “I have bad news, just tell me when you’re ready to hear it.” My father has been working as a paramedic, then as a fireman and later as a demining expert. He spent his whole life caring for others and there safety. So, at that moment I knew, because of this nervous smile we share, that what was coming would shake my whole life. Then, I went out with a friend to have some beers and got back home. We sat down, he talked, I listened. On the 3rd of March 2017, my
father told my brother (20 years old) and I (23), he had HD.

And just like my father, I smiled, I told him I would be there and he should count on me, and that he shouldn’t be afraid to talk to me. I hugged him, which I hadn’t done in years. Then I quietly went to my room. I stuck myself in front of the mirror and, staring at myself, I silently cried my heart out.

We suffered so much from my mother’s toxicomania. I was 17 at the time when I decided to put her in rehab. I quit my job, my studies and decided to go and live in the mountains to try and find myself again. Just a few days ago, I was celebrating my 23rd birthday, being happy to be back home with my father and brother, glad to be surrounded with incredible friends, proud to have just a few months to go before graduating. My life was already planned in its every instants. Now, my path, I can see it collapse right in front of me. I am strong but not invincible, I am brave, but also weary.

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