HUNTINGTON'S DISEASE
YOUTH ORGANIZATION

Things to Consider When Adopting a Child at Risk of HD

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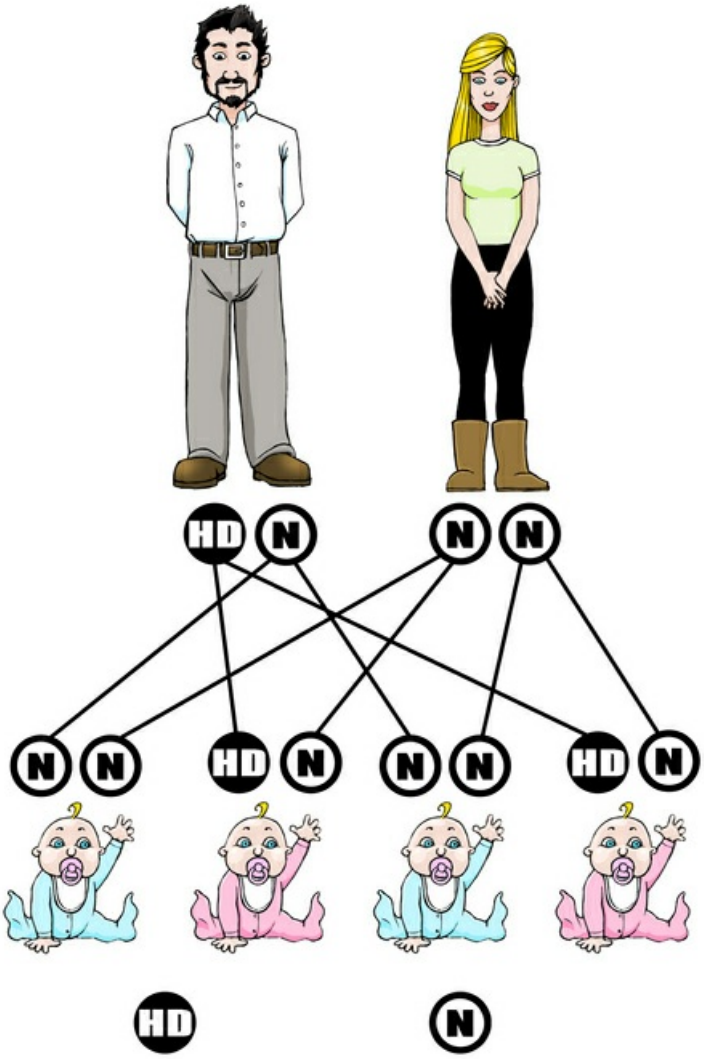
HDYO has more information about HD available for young people, parents and professionals on our site:

www.hdyo.org



For those considering adopting a child who could be at risk for Huntington's Disease there are some key things that you should take into account to help shape your decisions. Adoption is a long and difficult process for anyone to embark on like all aspects of building a family unit. If Huntington's Disease is a factor in the life of a child you are adopting then we have put together a simple factsheet to help shape the research you should do to help make an informed decision and to help you support your child as they grow up.

Adopting a child who is at risk of HD is a serious decision for anyone to make. For those that might be in such a position we have provided some advice below to help you make your decision.

Understanding what HD is

Huntington's Disease is a complex neurological condition therefore it is important that you understand both the symptoms of the disease and the impact of the disease on those at risk. A good starting point to understand the symptoms and genetics of HD can be found here.

A very important thing is to begin to understand what HD is. You will almost certainly be

starting from a position of not knowing anything about HD unless it's entered your lives somehow previously. Therefore, to get into any position to make a decision you need to learn quite a bit about what HD is, the way it affects people and the genetics of HD are all good areas to learn as much as you can. HDYO is full of great content to learn about HD so have a good read of our content and/or watch our videos.

Future risk for child

Understanding what risk your child is at is really important. You might want to speak with a Genetic Counsellor to help you understand the risk better but the general points would have been covered in the genetics article. This video may also be helpful for you.

If one of the child's biological parents carries the genetic expansion for HD then the child has a 50% risk of inheriting that mutation also. If the parent had interventions to remove this risk before having the child then that would mean the child is not at risk of inheriting the mutation that causes HD.

If the child is at 50% risk then it is their right to choose to get test after they turn 18 years old. The only exception to this is if there is a concern that the child could be symptomatic prior to 18. This is a very rare form of HD known as Juvenile onset HD. The testing process for this should only be considered if EVERYTHING else has been ruled out and in consultation with an HD specialist centre of Doctor.

As HD is a genetic condition the child will likely be at risk. If the child has a parent with HD then their own risk is 50%. There's just as much chance they will get HD as there is that they won't. Another important thing to state is that you can't have the child tested as within the HD community it is the child's right to choose to test when they are over 18, so this risk will always be there as they grow up with you.

Talking about HD and their risk

Similar to disclosure about adoption there are different ways to approach this. Evidence would suggest that open, honest age and stage appropriate conversations introducing HD to the child as they develop works best for most children.

You are also not alone in this journey. There is a huge amount of support within the HD community to help you talk to your child but also to help you cope with their risk and the impact that can have on you as a family.

At some point you will have to explain to the child that they are at risk too. You will need to understand it enough to be a support as they get older and learn more about their risk of HD and where that came from. Talking about HD as a family is one of the most challenging aspects for HD families with many not having good communication about HD because of stigma within the family. However, HDYO highly recommends being open and honest with young people about HD in their lives and research shows young

people cope better when told as early as they can. We provide a lot of great content on talking to children about HD in our parent section.

The progress of HD research

Another important aspect when considering whether to take on a child at risk of HD is how treatable is the condition if the child does have it. At the moment there's no treatment to stop HD and it is a fatal condition. But research is going in a very positive direction and speed. There is a lot of money invested in finding treatments for HD and gene therapy is in human trials right now (2019) and look to be showing some positive results, it may not be a cure but it will be useful. The good news is that there are more gene therapy drugs and other treatments being worked on our on their way to trial soon too. There is a lot in the pipeline and there's a strong case that treatments will be around to change how HD impacts people's lives in the next 10 years.

Support

We hope this section has been useful. If you would like to talk to HDYO about this decision please contact us, we're happy to help. Below, we have the thoughts of an adoptive parent to a child at risk of HD on their experience.

> **If we all allowed the "What ifs..." to influence our decision making, I suspect that many of us would never become parents. Adoptive or otherwise.**
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> **What if I can't cope with all the sleepless nights? What if our adopted baby doesn't seem to attach to us? What if the baby has your eyes and my nose? Whether through adoption or a different means, starting a family is a huge decision. And at first, I'll admit, adopting a child with the potential to inherit an incurable disease was not something that I was all that willing to do.**
>
> **So we did some research. We read up on Huntington's. The causes, the symptoms, the current medical thinking. And what we found out was the HD**

is the most curable of all the incurable diseases. Researchers know what causes it. They just haven't worked out how to prevent it. Yet.

We met a paediatrician who talked to us about juvenile Huntington's and DNA and family history and statistics... and by the end of it, it really did seem like a no brainer. Because there are no guarantees in life. None of us knows how long we've got. But, we do know that ACEs (adverse childhood experiences) can impact on a person well in to adulthood. The statistics around care experienced young people and the links to under achieving in school; becoming NEET (not in education or employment); drug addiction; becoming criminalised; spending time in prison; becoming homeless... each these circumstances is more likely to happen to a young person who has been in care, compared to a young person who has not.

My son is 12 years old. He has no idea that Huntington's could be a factor in his life. At present, we feel we need to protect him from this because he is not in a place where he could process this information. The complexity of his special educational needs, the trauma he has suffered in the womb and in the first few weeks and months of his life mean that he would be unable to contemplate the magnitude of Huntington's being anywhere close to his life.

His biological mum has it. So he has a 50% chance of developing it.

But there are far more pressing and urgent issues that we need to address and support him with right now. His anti social, aggressive and violent behaviour and keeping us all safe. That's the priority.

Parenting is an unpredictable journey. Arguably, more so for adoptive parents. But adopting a child with Huntington's in the family should not be a barrier to starting a family. Because there is always so much to value and cherish in life. When things get tough and I find myself struggling, I have to remind myself that I am privileged to be a parent. My eldest child is my Treasure Trove. He provides me with countless opportunities to practise forgiveness and tolerance, patience and acceptance.

And my youngest is my saviour. Because no matter how dark and twisty my world becomes (which it does from time to time), I have a duty. So he saves me from myself.

Recently, I was fortunate to attend a Huntington's support group, where I met some incredible people with the most amazing stories to tell. I met people with a diagnosis of HD who were well in to their 60s. The group also included husbands and wives of those with HD - some still with us and some

who have sadly passed away.

Being the the company of these people was very special. It is something I will always remember. I left the group feeling buoyant. Uplifted. Because, despite the suffering that these people have endured, they continue to see the positives and find happiness.

Huntington's Disease is incurable. For now. But medical advancements continue to reduce the truism off that statement. For anyone considering adopting a child with a family history of HD, I would advise that you speak to friends and family, do your research and make an informed choice. But don't let HD be the deciding factor. Being a parent is the most wonderful, the most challenging and the most fulfilling element of my life. I can say that about both of my children. Only one of them has a family history of HD.