HUNTINGTON'S DISEASE YOUTH ORGANIZATION

Know Your Rights

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

www.hdyo.org

Knowing your rights may seem a bit dull for some people, but it's actually really important to know and be confident about what human rights you have and what you should expect from those people around you. This section looks at your rights in relation to HD.

The United Nations is an international organization founded to encourage global cooperation between countries, they also work to create human rights and encourage countries to have a good level of human rights for people in that country. One of the rights the UN have created is called the UN Convention on the Rights of the Child (UNCRC for short). This was created in 1989 to highlight basic rights for every young person under 18 that countries should all try to provide. There are similar rights, human rights, that cover everyone, but they decided to create some special rights for children because they are sometimes more vulnerable to having their rights abused. All but two countries involved with the UN have agreed to the UNCRC, so it is a global standard. It covers very basic rights about support, having food and shelter etc. What we are going to look at is how these rights work in situations for young people impacted by HD. How do these rights impact you?

#1: Education

Young people impacted by HD have the right to have access to educational information so that they can learn about HD. This is such an important point and although it seems easy now to have access to information about HD with the internet, it is not always a good or safe experience for young people to learn about HD. If you are on HDYO's site whilst reading this then you are already in a place to safely learn about HD with factual information. But it wasn't always like that for young people and it was one of the reasons we created HDYO – so we could do our own educational content especially for young people to learn about HD. Otherwise young people had little options especially for them, and had to try their luck on search engines, which can be a terrifying experience for some. So, HDYO has helped make education for young people impacted by HD accessible, but not everyone has access to us. But, it is your right that you should have access to information about HD that is appropriate for your age – whether that comes from HDYO or anyone else. In a family with HD for instance, sometimes people think that they can protect their family or children from HD by not talking about it and not educating young people in the family about HD. This is generally not a good approach anyway, but it's actually your right to have access to learn about HD. So in this situation you could argue that you have a basic human right to know more about HD.

#2: Decision maker

Leading on from education, young people have the right to make their own decisions about HD. Being informed about your choices (through education) is a first step to being able to make the best decisions for you, but it is only you who can make those decisions for yourself, nobody else. What kind of decisions are there to be made when it comes to HD? The big ones with HD are things like genetic testing and having children. Only you

can make a decision about whether you want to go for genetic testing, and only you (and your partner in this case) can make a decision about what option to go for with having children. Sometimes young people's right to decide whether they want genetic testing is taken away from them, often by a family member who feels that they want to know if the child (or children) have HD so get them tested. This is usually done as a protective move by the family member, but it doesn't actually protect anyone from anything and only ends up causing problems in the future. So not only is this generally a bad move, but it takes away your basic right to make your own informed decision about genetic testing.

#3: Discrimination

Discrimination is something we should all have protection against but many of us don't. There are many forms of discrimination due to race, gender or class for instance, but genetic discrimination is becoming more of an issue in modern day life as testing for genetic conditions such as HD becomes easier. Some countries have laws in place to stop genetic discrimination, or at least make it illegal to do it, but many countries do not and in those countries there is a risk that people with genetic conditions like HD may be treated poorly or sacked from work just because they have HD (or even are at risk for it). Many people work hard to change laws in countries where they don't have genetic discrimination protection, but it is often a long process, be aware of what protection you have in your area. If you feel that you are being discriminated against because of HD, and you have genetic discrimination laws in your region, use them!

#4: Support

Just like with education, young people impacted by HD have a right to support to help you cope with HD in your life. Often this is an area which is lacking for young people, they may have some level of support from family and friends, but access to professional support focused on them or events especially for young people are quite rare in the HD community. But, it is your right to have this support, and we should always be fighting to improve support available for young people. HDYO's other main reason for being created, aside from education, is support. We do offer a basic level of online support where young people can speak privately with us about concerns or questions they have and we will do our best to help or direct you to those who can. We are increasingly offering events for young people globally and looking to work with other HD Associations to provide those more often so that young people globally truly have access to the support they deserve. If you don't feel you have good support available to you, let us know and we will look to help.

#5: To participate and be listened to

Finally, young people impacted by HD have the right to participate in any decisions that affect them and be listened to by those around them, whether that be family who may be making care decisions for other family members who have HD, or it could be HD Associations (HDYO included) in your region who should listen to what you have to say and take your feedback seriously. Young people should not be ignored, you are just as deserving as everyone else is of having good support and educational opportunities when it comes to HD, fight for those rights if you don't feel what is available is enough. Let us know too, we want to help young people globally so no matter where you are it is our goal to improve services in your area.

I hope this short article has been useful for you in feeling more confident about the rights you have as young people impacted by HD. If you have any questions about these rights or feel your rights are being abused contact us.
