



HUNTINGTON'S DISEASE
YOUTH ORGANIZATION

Genetic Testing Checklist

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

www.hdyo.org

The purpose of the checklist is to provide any individual thinking, actively engaged in or having been engaged in the testing process a framework of things to think about at various stages of the process. The checklist is to be used as a guide and no one should feel forced to ask any of the questions – it is simply a resource to empower the individual during the process. You may wish to use the checklist to think about questions you want to discuss with a genetic counsellor.

Prior to Starting the Process

What is my motivation for testing?

Is this the right time in my life?

Testing is a major step to take and it is important that it is your choice. No-one should feel pressured in to having a test by someone else. You may want to reflect on your reason for taking the test at this particular point in your life'

What will the impact on my life be/ am I ready for the result?

Getting your results can be a surreal experience and life could change either way for you. It can be hard to adjust and accept either result, and this may take time so consider this before you get tested. Think about how you would like to cope with either result, have a plan of what you want to do but give yourself time to adjust and accept first.

How do I start the process of getting tested and what does the testing process look like?

A good question. The process, according to the guidelines, should involve getting an appointment from your doctor for the genetic clinic local to you. Then you will be assigned a genetic counsellor or clinician in countries with no genetic counsellors who will meet with you at least twice before you would take your blood test. Once the blood is taken it usually takes a few weeks to get your results. You should know arrangements for receiving your result i.e. the date and time and who will be there. It is recommended practice that results are given in person. At any time you may stop the process without finding out your results. To start the process you should go to your doctor and ask for a referral to your genetics clinic to test for HD.



Who do I want to support me in this process?

A very important question. Most genetic clinics will ask you to bring one person with you for the results or for the entire process. Have somebody in mind for that who you trust. Being open about your testing process will allow you to get support from those close to you. This is very helpful to have available, you don't have to go through the process alone with your thoughts.

What is anonymous testing? Is it available to me?

Anonymous testing means that you can go through the testing process without any of your information being put on a database. This can be good and bad. The good part is it can protect you against insurance or discrimination issues in the future (although some countries have safeguards in place so that this should not be the case anyway). The bad part is that anonymous testing can sometimes be done very quickly without speaking with a genetic counsellor and this can mean you are less ready for your results than you would be. Genetic testing is only an option in some countries like the US, in many countries anonymous testing is not necessary.

What are home test kits?

There are some websites where you can get genetic testing kits sent to you. We wouldn't advise you to go via this route, it's not safe for you in terms of accuracy and not having support available.

Are there resources I can gather more information from (websites, books)?

Yes many, HDYO has a good section on [genetic testing](#) which is very useful. There is also a [website](#) specifically for genetic testing info which we recommend.

Is there support outside of the clinics (associations, youth workers etc)?

There may well be depending on where you are in the world. HDYO has a [world map](#) which shows what support is available in your region and also highlights what is available for young people.

Are there any pros or cons to testing?

Testing does potentially impact on life insurance and long-term care insurance, it can lead to discrimination in some places. It can also be emotionally challenging whatever the result.

Are there options for having children if I test positive?

Yes, there are, HDYO has an insightful page on the options for [having children](#).

Is there a cost associated with the test?

Depends where you live in the world. Countries with a national health service tend to provide the process for free on the health service. In countries without a health service you may have to pay hundreds of dollars for the test. Please check in your region what your options are by contacting your [local HD Association](#).

Are there any laws about communicating my results with my family?

The guidelines around genetic testing say that it is your test and you don't have to, by law, share your result with anybody but we recommend not going through the process in silence. This can get complex if your result changes the risk of another family member, a parent for example, the genetic counsellor should talk about that with you.

Can I stop the process at any point during the process?

A great question, yes you can stop the process at any time you want to should you change your mind.

Do I need a referral for testing?

Yes you would usually need a referral from your doctor to the genetics clinic.

Does the team I'm seeing have experience with HD and genetic testing?

They should have lots of experience with genetic testing and HD but that will depend on who you are seeing. Most genetic clinics do this all the time so are very experienced, but if you are getting tested at somewhere more local and small then there is a good chance they don't have an understanding of HD and how the testing process should be done.

Who do I contact with questions throughout the process?

You should speak to your genetic counsellor.

Do I need/should I have insurance first?

What will the impact on insurance be?

This is a good question, depending on where you live insurance can be affected if you test positive. Life and long-term care insurance may be harder to get and the premium you pay may be higher as a result of your test result. If you get insurance before your results then they won't change even if you test positive so it is encouraged to sort your insurance out before you get your results. Speak with your genetic counsellor about insurance for advice.

Will there be an impact on my career?

There may well be. Some countries have genetic discrimination laws which protect you against being treated unfairly as a result of your test. Many countries don't have this law though so you may be open to being treated unfairly. Once again check with your genetic counsellor how protected you are.

What is genetic counseling?

It's a form of counselling which is focused on genetic inheritance of conditions. A genetic counsellor will speak with people who are at risk of getting many genetic conditions, not just HD. They offer advice, education on the genetic implications of that condition and testing to see if you have the condition.

Am I ready for either result?

A huge question to ask yourself. It really is an emotional roller coaster of an experience, try and be as mentally ready as you can be and know it will take time to accept your results and move on forwards. Don't be surprised if it takes you a while to move forwards after your results. Give yourself time.

Who else in my family will be impacted by my results?

Sometimes your result can directly impact a parent's risk status which can make the situation very complex and messy. The genetic counsellor will talk with you about this. Aside from that your results can emotionally impact others in your family who will be thinking about you and your results, and what that means for them too. Try to be aware of this and speak openly with

your family.

Is there counselling available after I get the results?

According to the guidelines this should always be offered as part of the testing process.

Who will know my results and have access to them?

You and the genetics team. Your results are confidential, it shouldn't be shared with anyone else without your knowledge. Often the person giving you your results only opens the test results just before you enter the room so they don't know when they turn up for work that day either.

Who will be there for my results appointment?

You should have someone there for support, at least 1 person. Aside from that there will be the genetic counsellor and/or the doctor delivering the results. This is what the guidelines state.

During the Process

Is there support outside of the clinic?



Yes, there should be, HDYO is a constant support option for you at any stage of the testing process and your [local HD Association](#) is also available. You should also be talking with the genetic counsellor about what support they can offer you post-results.

What is the results day like?

Getting your results can be a surreal experience. It's life changing and yet it is a normal day for everyone else. You will be given your results very quickly once you enter the

room to hear them. Everyone will be there to support you. Once you have the results you will have some time to digest this news and then you will leave the room and are free to do whatever you like. It is a weird experience overall, hard to explain how it will feel until you go through it.

What are CAG repeats?

Will I get to learn my repeat?

CAG repeats is what you are tested for to show if you have the HD gene or not. HDYO has a [whole section on CAG repeats and the genetics of HD](#). You may be told your CAG repeat or you may not. You have a right to know your exact CAG repeat so do ask if you aren't told and want to know what it is. It should be explained to you when you get your results what your CAG repeat means, read the link above to learn about CAG repeats and HD.

Who do I call with questions throughout the process?

The genetic counsellor or their team.

Is there a way to have children without HD if I test positive?

Yes, HDYO's [having children](#) section shows you all the options for having children.

Post Testing

How to cope with either result?

The toughest question. Coping with a gene positive result is challenging. You have to give yourself time to adjust and accept. Make some life goals, your life is far from over, be positive about life and you can achieve whatever you want. Try not to slip into the feeling of being hopeless, being HD positive is not a hopeless position anymore with the way research is progressing there is genuine hope for the future.

As for a gene negative result, people often think this is a simple result to hear but it's not always so simple as you would expect. You can experience guilt for being negative and you may feel lost in terms of who you are now and what do to with your life. The advice is similar to that of testing positive, give yourself time to adjust and make life goals to work towards. HDYO is here to help any time you need us.

What support can I access?

After testing you should still have access to your genetic counsellor should you want to speak with them. HDYO is also here as are your [local HD association](#).

What are my options for having children?

HDYO's [having children](#) section shows you all the options for having children.

What does my CAG repeat mean?

Now you have your results you should know your CAG repeat and understand what it means for you. Any confusion about your CAG repeats should be discussed with your genetic counsellor, but if you aren't sure HDYO is here to help and we have a very good [CAG repeat](#) section on our site.

Should I tell anyone my results?

That is completely your choice. Some share with everyone, others keep it private. Who in your family and friends should know? Usually people are very supportive once you tell them so don't feel you can't share your results.



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