

## DECISION PATH AND ANONYMOUS GENETIC TESTING PATH CHECKLIST

The purpose of the checklist is to provide any individual thinking about starting the genetic testing process with a framework of things to think about. 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.

### 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 to test by someone else. You may want to reflect on your reason for taking the test at this particular point in your life.

### Who do I want to support me in this process?

A very important question. Have somebody in mind whom you trust. Being open about your testing process will allow you to get support from those close to you. Having a support person is very helpful so you don't have to go through the process alone.

### What is anonymous testing?

Anonymous testing means that you can go through the testing process without any of your information being stored where others can see it or shared with any other entity. This can protect you against discrimination issues in the future.

### 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. However, we recommend not going through the process in silence. This can get complex if your result changes the risk of another family member such as a parent. Your counsellor will talk about that with you.

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

Yes, you can stop the process at any time if you change your mind.

### Do I need a referral for testing?

No. HD Reach does not require a referral from an outside medical professional.

### What will the impact on health insurance be?

This is a good question. Under the Affordable Care Act (ACA or ObamaCare) no one with a pre-existing condition can be denied health insurance.

### What will the impact on Life insurance and Long-term care insurance be?

Life insurance and long-term care insurance may be harder to get and the premium may be higher as a result of your test result. If you get insurance before you start the testing process, your insurance won't change even if you test positive, so you are encouraged to sort your insurance out before you start.

### **Will there be an impact on my career?**

The Genetic Information Nondiscrimination Act (GINA), says employers and health insurance companies cannot discriminate based upon genetic test results. However, it has been known to happen.

### **Who will know my results and have access to them?**

You and the counseling team will be the only ones who know the results. Your results are highly confidential and won't be shared with anyone else without your approval.

**This checklist is adapted from the Huntington's Disease Youth Organization's (HDYO) checklist. If you would like to see the original version of this checklist, click the link [here](#).**