HUNTINGTON'S DISEASE YOUTH ORGANIZATION

EUROPEAN HUNTINGTON'S DISEASE NETWORK

GENETIC TESTING CHECKLIST

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 a 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.

PRIOR TO STARTING THE PROCESS

- What is my motivation for testing?
  - Is this the right time in my life?
- What will the impact on my life be/ am I ready for the result?
- When do I become a "patient"?
- Who do I want to support me in this process?
- What is anonymous testing? Is it available to me?
- What are home test kits?
- Are there resources I can gather more information from (websites, books)?
- Is there support outside of the clinics (associations, youth workers etc)?
- Are there any pros or cons to testing?
- Are there options for having children if I test positive?
- Is there a cost associated with the test?
- Are there any laws about communicating my results with my family?
- Can I stop the process at any point during the process?
- Do I need a referral for testing?
- Does the team I'm seeing have experience with HD and genetic testing?
- Who do I contact with questions throughout the process?
- Do I need/should I have insurance first?
  - What will the impact on insurance be?
- Will there be an impact on my career?
- What is genetic counseling?
- Am I ready for either result?
- Who else in my family will be impacted by my results?
- Is there a way to have children without HD if I test positive?
- What is the process for testing?
  - Am I going to get counselling?
  - Who will I see at the clinic?
  - How long are appointments?
  - How long is the whole process?
- Is there counselling available after I get the results?
- Who will know my results and have access to them?
- Who will be there for my results appointment?



DURING THE PROCESS

- Is there support outside of the clinic?
- Are there any pros or cons to testing?
- Are there options for having children?
- What are CAG repeats?
  - Will I get to learn my repeat?
- What could the results be?
  - What is the grey zone? Low penetrance?
- Who do I call with questions throughout the process?
- Do I need/should I have insurance prior to testing?
- What is genetic counseling?
- Am I ready for either result?
- Who else in my family will be impacted by my results?
- Is there a way to have children without HD if I test positive?
- Who will know my results/have access to the information?
- Can I stop the process once I'm in it?



POST TESTING

- What support can I access?
- What are my options for having children?
- What does my CAG repeat mean?
- Who else in my family will be impacted by my results?
- Is there a way to have children without HD if I test positive?





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