



## FREQUENTLY ASKED QUESTIONS OF A SOCIAL WORKER AT AN HD CENTER OF EXCELLENCE



### PERSONS AT RISK

- *Why do I need counseling to get a genetic test?*
- *Can I do the testing anonymously?*
- *Will my insurance pay for testing?*
- *Can I still get life insurance or long term care insurance?*
- *Do I have to bring someone with me for the testing process?*
- *Can I make the appointment for my spouse or friend?*
- *Can the results from my research blood test be released to me or my physician?*
- *Can any of my research results be used to help in my treatment?*

### EARLY STAGE

#### Person with HD

- *What I should take to keep myself healthy?*
- *What clinical trials am I eligible for?*
- *How do I get my family to stop watching my every move looking for symptoms?*
- *Will my HD look the same as that of my affected parent or affected sibling?*
- *I'm worried every little thing could be a sign of HD... how will I know?*
- *What life plans can I make before symptoms start or get worse?*

#### Caregiver/Family Member

- *Is this change in my loved one's mood and behavior HD?*
- *Where is the nearest support group?*
- *How will I know when the HD has started?*

### MID STAGE

#### Person with HD

- *What clinical trials am I eligible for?*
- *Can I continue to be my own payee?*
- *How long can I continue to work?*
- *Is there a problem with taking care of young children?*

#### Caregiver/Family Member

- *I need help finding financial resources*
- *When is time for my loved one to stop driving?*
- *How do I know if this symptom is HD related or something that should be addressed by local MD?*
- *Is choking and swallowing a problem with persons with HD?*

- *Is a change in sleep behaviors an HD problem?*
- *My partner has lost interest in doing things and going out in public, is this HD?*
- *My loved one seems unaware of her/his symptoms, is this part of HD?*
- *My loved one gets frustrated/angry more often, is this HD?*

## **LATE STAGE**

### **Family/Caregiver**

- *When will I know that it is time to find a nursing home?*
- *I need help giving the nursing home information to help my loved one*
- *I want to donate my loved ones brain to research*
- *How do I get my parent extra help in the home so they can avoid a nursing facility?*
- *Is paranoia and psychosis an HD symptom?*

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