

## **QUESTIONS ASKED OF CLINICIANS ACROSS THE HD DISEASE TRAJECTORY**

### **PRE “CLINICAL”/AT RISK**

- *Do my mood changes (irritability, depression, anxiety) mean I (or my at risk family member) have/has HD?*
- *Are our marital problems due to HD onset in my partner?*
- *Should I get the genetic test?*
- *Will I be able to emotionally handle the results?*
- *Will my partner leave me if I have the gene?*
- *How will I tell my children if I have the gene? When do I tell them?*
- *If I have the gene, what does this mean for my family planning, career and educational goals?*
- *How will my affected sibling deal with my possibly negative (no gene) test result?*
- *What do I need to do to get ready for the genetic testing process?*
- *How do I talk with my family member whose behavior has changed about my belief that they have HD?*

### **EARLY STAGE**

- *I have the clinical diagnosis. How do I feel about it? What has changed in my life?*
- *Should I reduce my hours at work or my work responsibilities?*
- *What should I tell my children about my diagnosis?*
- *What should I tell my neighbors, extended family, and my insurance company?*
- *When do I apply for SSI?*
- *What resources (support groups, community agencies, information) are available for me and my family?*
- *My affected family member does not think s/he is affected, despite mild symptoms and a clinical diagnosis. How do I take over some household responsibilities without causing upset and embarrassment?*
- *Are there treatments? Is there a cure?*
- *Is it time for me to develop legal documents such as powers of attorney, wills, and living wills?*
- *What will the course of the disease be like?*
- *How do I get involved in research studies?*

### **MIDDLE STAGE**

- *When do I need to stop driving?*
- *Is it time for me to stop work?*
- *How will I make it financially?*
- *Am I able to take care of my children without assistance?*
- *Am I able to live independently?*
- *What can I do to maximize my quality of life and my health?*

## **LATE STAGE**

- *Will my care be provided at home with my family or in a nursing facility?*
- *How will I pay for my care?*
- *Will the nursing facility or my family carry out my wishes regarding my life extension if I become acutely ill?*
- *Will I be emotionally able to provide care for my loved one who has HD?*
- *Is it ok if I get help?*
- *What if my family member refuses outside help, but really needs it?*

- *Randi Jones, Ph.D.*