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.