Do I Really Need a Primary Care Doctor Too?

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What is Primary Care?

• From American Academy of Family Physicians:

“Primary care includes health promotion, disease prevention, health maintenance, counseling, patient education, diagnosis and treatment of acute and chronic illnesses in a variety of health care settings.”
Who Are PCP’s?

• Internists
• Family practitioners
• Nurse practitioners
• Physician Assistants
• Pediatricians
Primary Care Provider Role in HD

- Genetic testing
- Symptom management
- Non-neurological/non-medical issues
- Care coordination
Genetic Testing
Genetic Testing

• Most PCPs do not work with genetic counselors
• They are not trained in genetic testing
• Often have social work, but not trained to do proper counseling
• HD gene testing can be done by any provider
  – BUT it should be done by a trained individual
  – NEW!!-ly revise genetic testing guidelines recently released by HDSA
Genetic Testing Guidelines

• See HDSA.org and search for:
  – Genetic Testing Protocol for Huntington’s Disease
• Revised 2016
• Geared genetic counselors and providers not at HDSA CoE
Negative Genetic Testing Experience

• Have your PCP connect with an HD expert before mentioning HD in your chart.
  – Once written, disability, life and long-term care insurance may be at risk

• Poor examples:
  – PCP pushed into testing by patient, but PCP unable to interpret testing
  – PCP sent off testing. If negative, “all set.” If positive, will see a neurologist
  – PCP offered to send off predictive testing for small children while everyone was in the office together
Symptom Management

• “No one doctor or one caregiver should attempt to manage all aspects of an HD case without assistance.”

• “Not everyone lives near a HDSA Center of Excellence, however, and there are families who prefer to have their loved one’s care overseen by a trusted family doctor.”
Symptom Management

• HD Neurologist/psychiatrist:
  – Movement disorders
  – Mood disorders
  – Cognitive decline

• PCP:
  – Everything else
    • Includes pain, arthritis, infections, etc.
HD: Primarily a Neurological Disorder

• That lasts years
• PCP will be needed throughout the course of the disease to address general health concerns
• Ex: dental care, cancer prevention, etc.
• Long term relationship with individuals and families
PCP Role

• Coordinate care
• Preventive health
• Management of medical complications in all stages, including late
  – Infections (pneumonia, UTI, etc)
  – Vitamin deficiencies
  – Skin breakdown
  – Fractures
  – Liaise with hospice team
Advanced Directives

• PCP and Neurologist should coordinate to carry out preferences of patients

• PCP often knows family and generations as well as preferences
  – Neurologist may also know family
Non-Neurological Issues

• Insurance
  – Referrals, etc
• Medical transportation
• Personal and family issues pre-, peri and post-testing
• Driving
• Work abilities
  – Disability should be a joint effort
• Parenting
• Legal matters
Coordination of Care

- PCP offices often work with social work, PT, OT, other medical specialists, home care agencies
- Use of medications for patients should be reconsidered and re-examined periodically by PCP and other health care providers
Caregiver’s Guide

• “Conveying the cognitive and behavioral issues to the medical team may not be easy.”

• “You may be told you are ‘overreacting’ to events.”
Summary

• PCP’s remain the foundation of care
• It is critical to have a provider who knows HD involved in your care
• Trust is a key aspect of care and should be a part of the relationship you have with your provider, PCP and neurologist.