Patient Information about Huntington's Disease
http://www.neurologychannel.com/patient-information-huntingtons-disease/index.shtml

Huntington's disease (HD), or Huntington's chorea, is a progressive, incurable, genetic (inherited) disease that results in the deterioration of nerve cells in the brain. Huntington's disease symptoms include uncontrolled movements, personality changes, memory loss, and impaired cognitive functioning, usually beginning in middle age.

Healthy lifestyle choices, such as getting enough sleep, regular exercise, and eating a well-balanced diet, can help people with HD feel better mentally and physically, and treatment involves medications to manage symptoms. Ongoing Huntington's research continues to shed light on how the disease progresses and may lead to additional treatment options in the future.

Here are some questions to ask your doctor (e.g., neurologist) about Huntington's disease. **Print this page**, check off the questions you would like answered, and take it with you to your doctor appointment. The more information you have about your condition, the easier it will be to make important decisions about your medical care.

Questions to Ask Your Doctor about Huntington's Disease

- ☐ What is Huntington's disease?
- ☐ What are Huntington's disease causes?
- ☐ What other conditions can cause symptoms similar to Huntington's disease?
- ☐ How will you determine if I have Huntington's?
- ☐ What kinds of examinations and diagnostic tests will be performed?
- ☐ What do these exams and tests involve?
- ☐ What are the risks and benefits associated with these tests?
- ☐ How should I prepare for these exams and tests?
- ☐ Will I need special help at home following the tests? How soon after the tests will I be able to return to my normal activities? **Restrictions**:
- ☐ Should I call for my test results or will someone contact me? **Date to call**: **Telephone number to call**:
- ☐ Who will discuss the results with me?

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- ☐ Will other members of my family be tested? Why or why not?
- ☐ How will Huntington's disease affect my daily life?
- ☐ How will my condition be monitored? Will I need to have diagnostic tests on a regular basis from now on?
- ☐ Why did HD symptoms appear at this time in my life?

Questions to Ask Your Doctor about Treatment for Huntington's Disease

- ☐ What are Huntington's disease treatments?
- ☐ What type(s) of HD treatment do you recommend?
- ☐ Why do you recommend this treatment?
- ☐ What are the benefits, risks, and side effects of this treatment?
- ☐ How quickly do you suspect my condition to progress?
- ☐ What other symptoms might I experience?
- ☐ How might my lifestyle choices, such as diet and exercise, affect progression of the disease?
- ☐ Is it possible to slow or stop Huntington's disease from progressing? If so, what might this involve and how can I accomplish this?
- ☐ Do you recommend medication(s) to manage my HD symptoms? Why or why not?
- ☐ What are the benefits, risks, and side effects of these medications?
- ☐ What should I do if I experience serious side effects?
  Telephone number to call:
- ☐ What if I forget to take a dose of my medication?
- ☐ Will I need to take these medications for the rest of my life?
- ☐ Might I need to see a specialist? If so, what kind of specialist(s)?
  Specialist(s): **Telephone number(s) to call:**

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- ☐ What kind of additional therapies will I need? Where can I go for these services?
  Practice/Therapist(s): **Telephone number(s) to call:**

Questions to Ask Your Doctor about Caring for a Person with Huntington's Disease

- ☐ What can I expect as a caregiver of someone with Huntington's disease?
- ☐ What symptoms indicate that I should call the doctor?
- ☐ What medications will I need to give and how often will I need to give them
- ☐ What warning signs should I look for regarding medication side effects?
- ☐ What should I do if these warning signs occur?
  Telephone number to call:
- ☐ What signs indicate that the prescribed medications are helping?
- ☐ What kinds of resources are available for caregivers?
- ☐ Do you recommend that I join a caregiver support group?
- ☐ What signs indicate that it might be time for my loved one to be placed in a long-term care facility?
- ☐ What should I look for in a long-term care facility?
- ☐ How can I get more information about long-term care, including how to pay for it?

Notes/Additional Information

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