

Treatment algorithms can help you become a Huntington's disease "Symptom Survivor"

For most patients and families, receiving the best treatment for symptoms of Huntington's disease is challenging. Huntington's disease (HD) experts have years of experience treating HD symptoms, but most patients don't receive care from these doctors. Many patients and families live far away from specialty HD care centers; and lengthy travel becomes more difficult as illness progresses. In addition, HD experts have limits to how many patients they can effectively manage. For this reason, the majority of HD families receive most, if not all of their medical care from general physicians. These physicians often have little knowledge of specific HD symptoms, and lack training in how to treat them. This leads to frustration for patients, families, and doctors alike. Unfortunately, this frustration may lead to the conclusion that HD symptoms are not treatable.

This "no-treatment" perception about HD needs to change. Though we can't beat all of HD, and the drugs we have for symptomatic treatment aren't perfect, and can't "cure" the symptom -- they can significantly reduce the severity of many symptoms. There are steps you can take to help your general doctor help you to be a HD "symptom-survivor"!

Step 1: *Before your office visit, you and your care partner should identify the treatable HD symptoms that cause you the most trouble.* Tell your doctor about your depression, anxiety, and insomnia; these are symptoms common in general practice that your doctor may already know how to treat. However, he or she may be less knowledgeable about other symptoms in HD like irritability, obsessive compulsive behaviors, and chorea. Telling your doctor about all of your symptoms will help him or her understand Huntington's disease and how these symptoms affect you and your family.

Step 2: *Ask for treatment* for all symptoms that cause trouble. Recently an international group of HD experts has developed treatment guides as an aid for you and your doctor specifically for those HD symptoms for there may be less experience. These treatment guides -- called algorithms -- provide information for treating chorea, irritability and obsessive-compulsive symptoms, and recommend medications that most general doctors prescribe frequently. Dose ranges are provided for those they may be less familiar with. If you are prepared for your visit, a discussion about your symptom, and treatment can fit into your doctor's schedule, where the average time spent with a patient is about 16-18 minutes. You can find the individual algorithms and more family-friendly summaries on the pages to follow.

Step 3: *Don't expect that one visit will result in the best treatment for your symptom.* This is the tough part! Experts say it often takes several tries to find the best drug, dose of drug or drug combination that fits your unique situation. You won't get better if you don't keep seeing your doctor -- on a frequent basis -- for drug management. Don't give up or stop asking your doctor for help until you get the best drug treatment for all your treatable symptoms. You can be an HD symptom survivor!

Treatable Symptoms of Huntington's disease:

- Sadness, depression
- anxiety, worry or feelings of tension
- trouble sleeping
- crankiness, impatience, easy irritability, anger
- chorea movements
- paranoid feelings
- rumination, getting stuck on ideas, worry about the same thing over and over
- aggressive actions, including damage to property, threatening to strike another person, or assaultive behavior
- thoughts of suicide or suicidal actions