



# Huntington's Disease Society of America

## Social Security Disability: How to Choose your Disability Onset Date

### What is the disability onset date?

The disability onset date is the date that your disability became severe enough that you could no longer work.

### Why do I need to choose an onset date?

Everyone who submits a Social Security Disability Insurance (SSDI) application or Supplemental Security Income (SSI) application has to choose an onset date.



Social Security does not use the phrase "onset date" but asks: What is the date you became disabled?

### Why is the onset date important?

The onset date is incredibly important because that is the date Social Security uses to determine if you were actually disabled. All of the medical records, work history, and supplemental evidence you submit with your claim have to support your chosen onset date. Choosing the wrong onset date could have very negative consequences for your application and could result in a denial.

### How do I choose my disability on-set date?

**Your disability onset date should reflect when you stop working AND when you have medical evidence to support your claim.**



Social Security will tell you that your onset date is when you stop working, but this is not accurate. If you have no medical proof of the symptoms and limitations you experience from your Adult Onset Huntington's Disease (HD), you WILL NOT be found disabled.

### What kind of medical evidence will support my claim?

You need medical evidence that includes symptoms and limitations related to Adult Onset Huntington's disease, which can be physical, cognitive, or behavioral. Medical evidence can come from any kind of medical provider – neurologist, psychiatrist, physical therapist, primary care physician, nurse practitioner, psychologist – as long as the evidence includes HD related symptoms. You do not need a gene test to apply for Social Security disability.

Elizabeth:

Elizabeth has a history of HD in her family and she tested positive for the HD gene in 2015. Elizabeth was not symptomatic at the time of her gene test results so she continued working as an accountant and she started treatment with a neurologist at an HDSA Center of Excellence in 2015. Elizabeth continued to see her neurologist at least once a year while she continued working. In 2019, Elizabeth began to have trouble working, she was not able to get to work on time, she struggled with deadlines and multi-tasking, she began making errors at work, and she started having difficulty working with others. In 2020, Elizabeth and her neurologist decided it was time for Elizabeth to stop working due to her HD symptoms and apply for disability. Elizabeth stopped working on March 27, 2020 and has started a Social Security disability application. **What should Elizabeth choose as her onset date?** \_\_\_\_\_



Elizabeth should choose March 28, 2020 as her onset date because it reflects both when she stopped working and when she has supporting medical evidence. Elizabeth has been getting specialized care for her HD for 5 years so she can choose the date she stopped working as her onset date.

Tom:

Tom has a history of HD in his family, but he decided that he did not want to get genetic testing and he has not been getting medical care of any kind. Tom stopped working in October 2016 because he was no longer able to keep a job, no matter how hard he tried. Tom finally went to a neurology appointment on July 29, 2019, and was clinically diagnosed with stage II HD based on his family history and presentation of symptoms. He had a follow-up appointment on January 15, 2020. The neurologist recommended that Tom apply for disability due to the symptoms and limitations he was experiencing from HD. **Tom has started a Social Security disability application, what date should he choose as his onset date?** \_\_\_\_\_



Tom should choose July 29, 2019 as his onset date because it reflects the existence of supporting medical evidence and it is after he has stopped working due to his HD symptoms and limitations. If Tom chose October 2016 for his onset date he would get denied because he does not have *any* medical evidence at that time.

### Choose your Disability Onset Date

Date you stopped working: \_\_\_\_\_

Date you first started getting medical care for HD: \_\_\_\_\_

Disability Onset date = the later of the two dates

**Your Disability Onset Date:** \_\_\_\_\_