

Guidelines for Huntington's disease hospice eligibility

Hospice referral for those with late-stage Huntington's disease should weigh experienced clinical judgement, [Functional Assessment Staging](#) (FAST scale) guidelines and input from family members.

Patients will typically be considered to be in the terminal stage of the disease if they meet both 1 and 2 below:

1. Stage 7 or beyond according to the Functional Assessment Staging Scale with all of the following:

- Inability to ambulate without assistance
- Inability to dress without assistance
- Urinary and fecal incontinence, intermittent or constant
- No consistent meaningful verbal communication

AND

2. Has had at least one of the following conditions within the past 12 months:

- Aspiration pneumonia
- Pyelonephritis or other upper urinary tract infection
- Septicemia
- Multiple stage-3 or stage-4 decubitis (pressure) ulcers
- Toxoplasmosis unresponsive to therapy
- Fever, recurrent after antibiotics
- Inability to maintain sufficient fluid and caloric intake with one or more of the following during the preceding 12 months:
 - 10% weight loss during the previous six months
 - Serum albumin < 2.5 gm/dl
 - Significant dysphagia with associated aspiration measured objectively, for example, swallowing test or a history of choking or gagging with feeding

In the absence of one or more of these findings, rapid decline or comorbidities may also support eligibility for hospice care.

Tarolli CG, Chesire AM, Biglan KM. ["Palliative Care in Huntington Disease: Personal Reflections and a Review of the Literature."](#) Tremor and other hyperkinetic movements. 2017 7:454. Epub 2017 Apr 11.

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