

Guidance note:

Inspecting homes where people affected by Huntington's disease are cared for

Summary

This is the précis of a document produced for us by the Huntington's Disease Association (HDA), which describes the disease and offers advice on signs of good and poor practice in the care of people affected by it. Inspectors are asked to be aware of this advice when inspecting and reviewing homes where those with the disease are cared for.

Advice from HDA

Huntington's disease is a hereditary disorder of the central nervous system which usually develops in adulthood (between the ages of 30-50 years). The neuro-degenerative nature of the disease means that people affected by it experience intensifying physical, cognitive and psychological challenges, and ultimately lose the capacity to make most of their own decisions.

In the care of those affected by the disease, good practice may be observed in the following:

- Staff who are knowledgeable, caring and committed
- The use of flexible communication strategies to involve people, and their families, in decisions about their care
- Regular assessments to make sure that changing care needs are addressed
- Proper attention to the nutritional needs of those affected
- Multi-disciplinary co-operation among providers to make sure that the right knowledge and expertise is applied
- Awareness of safeguarding issues and vigilance for signs of abuse – many people with the disease are classified as vulnerable adults
- Availability of specialist equipment that is safe and appropriate to the needs of the patient.

Issues to watch out for, and areas where poor practice may be a concern include:

- Nutrition, swallowing and PEG feeding (via a tube into the patient's stomach)
- Cognitive impairment and communication issues
- Properly managed medication
- Movement disorder including involuntary movements and rigidity.

For more detail please consult the HDA website.

The Huntington's Disease Association (HDA)

The HDA provides support to people affected by the disease and also provides information and advice to professionals.

References and resources

- Website of the [Huntingdon's Disease Association](#).