



Huntington's
Disease
Association



Stop. Think. Act.

Top ten tips for caring for someone with Huntington's disease in hospital.

*"As a family we very much hope that these tips will help relieve anxiety
for Huntington's patients and their relatives - and that difficulties
like those my mum faced in hospital will be avoided."*

Huntington's disease family member



Think Huntington's.

Huntington's disease is a genetic, progressive, neuro-psychiatric disorder. It has physical, cognitive and behavioural symptoms. Hospital can be very challenging for someone with Huntington's. Understanding more about Huntington's can help make the situation much easier. Take time to read information provided.

Think about assumptions.

Don't make assumptions based on the diagnosis of Huntington's. Establish what symptoms are new – they may not be Huntington's. People with Huntington's can struggle to express what they are feeling. There can often be an unmet need – such as pain, hunger, feeling too hot or cold. Medical staff asking the right questions is crucial.

Think environment.

Hospitals are busy places. Coping with distractions is hard for someone with Huntington's. Can anything be done to reduce the amount of stimulation and keep things simple?

Think communication.

How does the person usually communicate? Do they use any equipment? Keep on one topic at a time; speak clearly; keep information simple; visual cues help; **give extra time for answers as processing is slowed**. If you can't understand, ask to repeat, spell or write the word if they can. Changes in facial muscles may give a bored or angry look but this may not be how they are feeling.

Think carers.

Lack of insight and communication difficulties may prevent the person from providing accurate information. Consult the people who know them best e.g. family members or professional care staff. Have any advance decisions about care been made?





Think nutrition and hydration.

Swallowing problems are common. Choking may be a risk. Establish how the person usually eats and drinks. Consider position whilst eating; consistency of food; and minimising distractions. Is prompting or assistance needed? Small frequent meals may be better. Take lids and wrappers off food. Some people with Huntington's require a high-calorie diet to maintain weight. Do alternative feeding methods need to be considered? Poor nutrition and hydration can exacerbate other symptoms.

Think routine.

Routine and consistency are really important. Establishing a person's preferences in daily routine, personal care and diet can prevent upset. Rigid thinking could affect ability to adapt to new surroundings and new routines. Consider the impact of staff rotations for someone who finds change very difficult.

Think comfort.

Support needed to sit or lie in a comfortable position or to prevent injury due to involuntary movements? Temperature dysregulation (feeling too hot or too cold) is common in Huntington's but rule out infection, medication side effects and hormonal problems.

Think mobility.

Involuntary movement may make a person appear unsteady. They may have big bursts of movement. Find out what is normal for them and consider this when assessing falls risk. Do they usually use equipment? Think before stopping medication prescribed for movement.

Think further information.

The Huntington's Disease Association has a helpline you can contact for advice **0151 331 5444**.

Our website has a professional's area full of information that will help you in providing good care for your patient. www.hda.org.uk

Get in touch

For advice and support or
to speak to a Specialist
Huntington's Disease
Adviser

Email: **info@hda.org.uk**

Phone: **0151 331 5444**

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