Huntington's Disease Association

Hospital passport

My name is:

If I have to go to hospital this book needs to go with me, it gives hospital staff important information about me. It needs to hang on the end of my bed and a copy should be put in my notes.

This passport belongs to me. Please return it when I am discharged.

Personal details

Name:

What I like to be called if this is different:

Address:

Phone number:

NHS number:

Date of birth:

Support

Next of kin

Name:

Relationship:

Address:

Phone number:

Main carer

Name:

Address:

Phone number:

My support needs:

Medical

GP

Address:

Phone number:

Any other services/professionals involved with me:

Any other medical conditions?

What other medical conditions apart from Huntington's disease is it important to know about?
For example diabetes, epilepsy, allergies.

Current medication:

Medical history and treatment plan:

Communication

How I communicate / what language I speak

What helps with communication?

For example - short clear sentences, giving time to process.

What makes it more difficult e.g. busy environment?

Eating and drinking

How I eat:

e.g. tube feeding, softer foods, adapted cutlery, support needed

How I drink:

e.g. thickened fluids, adapted cups, support needed

Special diet / allergies:

My likes and dislikes:

Getting around

How I move around:

e.g. walking aid, wheelchair, help needed to mobilise

Getting dressed

How I get dressed:

e.g. support needed, prompting needed, a specific routine

I like to wear:

Getting washed

How I wash:

e.g. support needed, prompting needed, a specific routine

Using the toilet

How I use the toilet:

e.g. continence aids, assistance to get to the toilet

Sleeping

I sleep well when:

e.g. a specific routine, a specific position, sleeping pattern

I don’t sleep well when:

My feelings

What makes me feel anxious, irritable or upset:

e.g. is there anything to avoid saying or doing? Is it important that things are done in a certain way? How well do I cope if I am rushed for time? How do I react if something unexpected happens or if there is a lot going on?

What makes me feel calm and relaxed:

e.g. are there things that help my mood? Are there things that help if I become upset? What do I find relaxing?

About me

Things I'd like you to know about me:

e.g. religion, specific routines, my background, my likes and dislikes

Notes

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

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**