Huntington's Disease Association

Huntington's disease:

Dealing with lack of awareness

What is the problem?

Due to deterioration in the brain, people with Huntington's disease find self-monitoring difficult and have a lack of awareness that the disease is affecting them physically, emotionally and cognitively. The changes to the brain also make it hard for those affected to envision the future and they can be reluctant to consider anything new. This behaviour can be difficult to modify as the person with Huntington's may accept they have the disease but not that they are showing symptoms. This unawareness can become dangerous resulting in the person with Huntington's putting themselves or others at risk. There are a number of strategies you can use to help.

What strategies can we use?

- **Get to know the person -** building a relationship with the person with Huntington's is important and may take time. You may need to assess them over multiple visits and it may take a while for the person to agree to help offered.
- **Visit at home -** this will give you a better idea of the situation as people with Huntington's will often say they are ‘fine’ on the phone when they are not.
- **Use the person’s support network for information -** seek information and advice from family, friends and other professionals who know the person well. Consider joint visits.
- **Carer support** - listen and support those who are caring for those with Huntington's disease.
- **Take your time** - a person's ability to process information is slowed in Huntington's disease. Make sure you give them time to understand, process and respond.

- **Try different methods of contact** - Huntington's affects the person’s ability to plan, organise and initiate activities. They may not always respond to calls, letters or visits. Don’t take this as refusing contact. Try contacting them at different time of the day and using different methods.
- **Reassure about the future** - people with Huntington's find change and picturing a different future (perhaps a life with help in place) difficult. Change can make them anxious and reluctant to accept help. Encourage the person to try something out and see how it works.
- **Start small** - starting with small amounts of help and support early can mean the person gets used to having and accepting it. Even if someone is physically able to do something, they may still need a lot of support with prompting/ monitoring.
- **Don't make insight the main goal** - trying to tell someone they have Huntington's when they are in denial will likely make engagement more difficult. If you are aiming to get the person to accept help or manage the risks associated with their symptoms, it is more practical to address the issues at hand rather than forcing them to confront the fact they have Huntington's disease.
- **Be flexible and creative** - where possible, try to work on what the person will accept help with. If they will accept help with cleaning but not personal care, begin with cleaning support.
- **Seeing it from another perspective** - someone with Huntington's may not accept help for themselves but may accept help for their loved one. For example, they may be able to see that their loved one is overworked and could do with some help with cleaning.
- **Keep trying** - a lot of people with Huntington's will accept help eventually but you may need to wait until the right moment arises.

Once support is in place

Most people with Huntington's disease are anxious to cling on to independence, but with time and a calm approach most will allow some degree of help in time. Once support is agreed and a package of care is in place, there may still be some reluctance by the person to accept help. There are some strategies that can help.

- **Routine is important** - once a care plan has been agreed, a set routine and consistency between carers is important for people with Huntington's disease.
- **Reiterate the plan** - you might consider encouraging the person to use wall planners, reminders on their phone, verbal reminders that them and their carers can refer to about any agreed care and support.
- **Listen and try to understand** - consider why the person is reluctant to do something. For example, do they not want to shower because they feel unsteady when they're in the shower?
- **Consistency** - those with Huntington's find change difficult, Carers arriving late or different carers arriving each day is likely to cause upset and distress. If there are particular carers the person responds best to, look at the methods they use and try to replicate this across the team.
- **Time is important** - people with Huntington's need time. If the person says no, a carer may need to come back a bit later and ask again or rephrase the question. 'No' is sometimes easier for someone with Huntington's to say than 'yes' – it may mean 'not right now', 'I don't want to change what I'm doing' or 'I need a bit more time to process what's happening next'. It's important to make sure there is enough time in the care package for carers to work at the person's pace.

- **Training** - training about Huntington's, particularly on communication and the cognitive features of the disease can help carers support those with Huntington's. Bespoke training is available from the Huntington's Disease Association.

Importance of routine

People with Huntington's disease may seem mentally inflexible. They like to adhere to set routines and behaviour patterns and appear unwilling to adapt to new situations or altered circumstances.

It is important that any care plan incorporates the need for as few carers to provide the care as possible. People with Huntington's struggle with change and facing new challenges. They are unable to instruct new carers to their needs daily and will quickly lose patience. This may cause conflict between them and their carer and lead to a breakdown and engagement and the care service provided.

- **A consistent approach and limited choice** - people with Huntington's need a very clear and set routine as the part of the brain that deals with choice and change is damaged by the disease. Due to the time it takes for people with Huntington's to process information and understand the consequences of any decisions made, it is helpful to keep information clear, concise and choices limited.
- **Moving from one activity to another** - the transition from one activity to another (e.g. watching television to eating) can be difficult for someone with Huntington's. It is important to incorporate time to prepare the person about activities into the routine and make sure all involved follow this pattern.

- **Reinforcing the routine** - once a routine is established, the person with Huntington's may need to be prompted and reminded. This could be through regular verbal or phone reminders that something will be happening or visible visual charts that show the routine and what has been agreed.
- **Stay positive and don't push** - try to keep things positive, friendly and with a good sense of humour! Give time, and return to the issue later if needed. Return to the issue later if they become frustrated or upset.
- **Keep a log** - it is a good idea to record any triggers or changes and share these with those involved with the individual to help maintain a consistent routine and approach.

Further information and support

If you would like to discuss this further or have any questions, please contact your local Specialist Huntington's Disease Adviser at the Huntington's Disease Association.

If you would like to discuss this further or have any questions, please contact your local Specialist Huntington's Disease Adviser at the Huntington's Disease Association. Our advisers operate throughout England and Wales and are able to provide bespoke training to staff working with clients with Huntington's disease. They are also able to discuss individual problems, provide tailored advice and suggest ways of managing certain behaviours. Contact us at:

☎ 0151 331 5444
e info@hda.org.uk

Our website also offers practical advice and sources of help and support, including downloadable information guides:

www.hda.org.uk