

April 2018

Social work is about talking and listening. Social workers are supposed to do more listening then talking but my profession is very chatty. But what would happen if I couldn't communicate well? What would people think if my speech slurred, or was slow, or too loud, or too soft? In this month's newsletter communication, speech, and tips to help communicate better with your loved one with HD will be discussed. The information outlined has been adapted from the HDSA publication: *Understanding Behavior in Huntington's Disease: A Guide for Professionals*.

Communication problems become more pronounced as HD progresses. In the earlier stages a person with HD might notice difficulty with organization of speech and thoughts. As the disease progresses, the person might experience problems with initiation, understanding, and articulation.

Speech therapy can be a useful tool for persons with HD who are having trouble with articulation. Loss of regulation of the mouth and tongue, as well as breathing, can lead to speech difficulties.

The strategies for dealing with communication issues listed below are basic and, when used, help address the four underlying factors leading to problems with communication: articulation, initiator, understanding, and organizing.

- When asking questions, allow the person with HD enough time to answer or express their thoughts. It is not necessary to speak slowly to the person with HD. Keeping directions or commands to one or two steps can be helpful as working memory is often diminished by HD.
- Advise family members and caregivers to practice patience when requesting a response from the person with HD.
- Offer cues and prompts to help the person with HD to start speaking or answer a question but pay attention to how the person with HD is

responding to the assistance – if it is creating tension, try giving a little more time for the answer.

- When asking a question offer, offer limited choices instead of asking openended questions. Questions can be phrased in a "yes or no" or a "this or that" format. For example would you like, "Italian or Mexican tonight?" instead of "What do you want to eat tonight?"
- If the person with HD is confused by a conversation, modify what is being said. Make it simpler and shorter.
- When delivering a task or a set of instructions, break it down into small steps. Remember, many seemingly basic tasks are actually very complex activities. Modify the steps of a request as the person with HD becomes more impaired.
- As communication becomes more impaired for the person with HD, consider using simple words and short sentences. Be careful not to talk down to the person with HD or use baby talk.
- In late stages or HD, alphabet boards, yes-no cards or other technical communication devices can be considered. Due to chorea in HD, these tools are not appropriate for all.
- Once a person with HD loses the ability to verbally communicate, do not stop talking to them. This only intensifies feelings of isolation that accompany the loss of the ability to speak.
- A person with late stage HD may not speak, but may still hear what is said and be able to take in information and process it, albeit at a slower rate.

Communication and speech are an integral part of our life. If you need help finding a Speech and Language Pathologist, I can help you locate one within your community. If you are struggling with communicating with your loved one with HD, we can work on expanding these tips to make them more specific to your unique situation. Feeling lonely at home because you have no one to talk to? You can call or email me and I will be so happy you reached out. If you do not have my phone number by now, 901-609-9127, program it into your phone so you will be ready to call me when the time is right. Save my email address into your contacts, mbradley@hdsa.org so you will be able to connect with me when needed.

Until next month,

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