

CJD: Communication, Swallowing, Memory

As you're probably aware, Creutzfeldt-Jakob Disease (CJD) is a neurological condition that causes fast deterioration of motor and cognitive skills. Three of the most highly concerning areas for patients and their families who are dealing with CJD are:

Swallowing, Communication, and Memory.

Speech-Language Pathologists (SLPs) are experts of swallowing, communication, and the cognitive-linguistic processes related to memory, and you may work with one during the rapid decline of skills that happens with CJD.

Swallowing

Eating and drinking is key for life, and when the body and brain are dealing with a neurodegenerative disease, the natural, typical process of swallowing gets impacted, too.

There are three stages of swallow – oral, pharyngeal, and esophageal – and breakdown can occur at any of these steps. Most commonly, because of a combination of nerve control and sensation, and even memory, the oral and pharyngeal phases are the ones impaired with CJD.

The medical term used to describe impairments of the swallowing process is *dysphagia*.

The biggest risk of dysphagia is aspiration of the airway, and *Aspiration* is when food, drink, and even one's own secretions get breathed into the airway and ultimately into the lungs.

Aspiration can then cause *aspiration pneumonia*, which is generally a difficult condition to get rid of, especially when involving a neurodegenerative disorder like CJD.

Typically, there are obvious signs/symptoms of aspiration, such as throat clearing or coughing while eating/drinking, even a change of voice during or immediately after eating, although sometimes there can be *silent aspiration*, which is when there are no outward signs of something going wrong with a body's swallow process and into the lungs.

Because of all these considerations, your doctor and SLP may have you change your diet in ways to make it easier and safer to eat and drink. Food may be ground like meatloaf, or pureed like smooth mashed potatoes. Drinks may be thickened to give greater control over the liquid, possibly to a “mild” thickness (like tomato juice consistency – also called nectar-thick) or to a “moderately” thick consistency (like honey moves slowly off a spoon, also called honey-thick). You may also participate in a special swallowing study done in a radiology suite, called a Modified Barium Swallow, to help determine the safest consistencies for food and drink, and whether or not there’s aspiration occurring.

Communication

Speech and language are key methods of communication for all peoples, and in CJD, these are going to be negatively affected. Speech is the motor act of communicating, typically through the mouth to articulate words, called talking. Because of the CJD’s impact upon the body and brain, talking will be affected, also, and speech can decline very quickly.

That said, a person with CJD can still communicate, but it’s just going to be different than before. An SLP can help fit a patient with Alternative Augmentative Communication (AAC) – such as paper and pencil if handwriting isn’t yet effected, or a paper communication board (can be homemade or found online). A more advanced (but often easier to use during the progression of disease) is a kind of AAC called a Speech-Generating Device (SGD). SGDs work with the tap of a button or even a person’s eye gaze, and there are many apps available for computer devices, including tablets and smartphones. You’re welcome to do your own research to find a good fit for an app or dedicated SGD, but oftentimes working with an experienced SLP will make things much easier on you and your family.

Dementia

While there isn't much in the form of direct therapy that SLPs can offer for patients because of the memory changes, aka dementia, that occur during CJD, there are some things that you can do as someone who cares for them:

- Take time to reminisce together while you can!

Memories matter, and it can be highly fulfilling to take a walk down memory lane together. Try to talk about the good times, how you all got through difficult times, and family history. Talk about the foods that are special to you, who made the best (or worst!) recipes, and how your family celebrates holidays and special events.

- Make a Memory Book together

Yes, memories matter, and pictures are said to be worth a thousand words! Looking through the family scrapbook, photo album, childhood artwork, or creating a new story/picture book together can be a unifying and comforting experience for all involved. Plus, having gone through these stories together can make for cherished memories for the whole family.

- Record it!

If you're comfortable with it, consider recording some of your time spent together while reminiscing or looking through a photo album. A simple and effective way to record yourselves is to use an audio recorder or video camera. Many people have smartphones these days, which can make it even easier to record a movie and then play a recording back when you want to.

Recordings can be a very special thing to do together – both in creating them and listening/watching them together later on – for the patient and for family members, in life, as well as after they're gone.