Augmentative Communication and Adults with Degenerative Diseases
Degenerative Diseases

An analysis of available data on the diagnoses of adults who use augmentative communication finds that the second most common diagnosis is degenerative diseases. A variety of degenerative diseases was clustered together to compose this group.* Included were Amyotrophic Lateral Sclerosis (ALS, or Lou Gehrig’s disease), Parkinson’s Disease, Multiple Sclerosis, Muscular Dystrophy (MD), Progressive Bulbar Palsy, Progressive Supranuclear Palsy, and some unspecified degenerative diseases.

All of these diseases are characterized by the deterioration of nerve cells in the brain and/or spinal column, resulting in progressive loss of the ability to control muscles. There are also some significant differences, both from one disease to another, as well as within the various forms of a single disease. In particular, the site where the nerve cells degenerate may differ, and, as a result, the pattern of muscle control will differ. The rate of progression is also highly variable.

In spite of the variability just noted, there are strong similarities across the diseases, making it useful to address them as a group. Often the initial symptoms will be noted in control of the limbs. However, any function that is controlled by muscles can be affected, and the impairment may expand to such vital functions as swallowing, breathing, and speaking.

* Although some cognitive changes can accompany these degenerative diseases, conditions whose primary characteristic is cognitive deterioration, such as Alzheimer’s Disease, were not included in the group.

Communication Problems Associated with Degenerative Diseases

Speech production involves use of the respiratory system to provide breath support for speech; control of the larynx and vocal folds to provide voicing and pitch; and control of the mouth, particularly the lips and tongue, to formulate sounds.

Each of these mechanisms relies on muscle control. In degenerative diseases, the musculatures that enable speech weaken. Frequently the tongue is affected first. There may also be changes in volume, rhythm, and inflections. The voice may become breathy or husky. Speech often sounds slurred, resulting in poor intelligibility.

The resulting motor speech disorder is called dysarthria. According to the American Speech-Language-Hearing Association (ASHA), the characteristics of dysarthria may include any of the following symptoms, depending on the location and extent of the lesions: “slurred” speech; speaking softly; slow rate of speech; rapid rate of speech with a “mumbling” quality; limited tongue, lip, and jaw movement; abnormal intonation; changes in vocal quality, such as “nasal” or “stuffy” sounding speech; hoarseness; breathiness; drooling, or poor control of saliva; and difficulty with chewing and swallowing.

As with the progressive loss of muscle control in general, the impact of degenerative diseases on speech production is also progressive. The speech impairment may range from very mild, such as speech that is slow and labored, to very significant, in which the speech is no longer intelligible even to very familiar listeners.

Based on a presentation by Brownlee and Kane, an estimated 830,000 adults in the U.S. have a progressive neurodegenerative disorder. According to Beukelman, Ball, and Pattee (2004), 96% of the individuals with ALS who were included in their data “experienced such severe communication limitations that AAC systems were recommended for them.” Losing the ability to speak was frequently identified as the worst aspect of ALS, according to Hecht et al. (2003).

What is AAC?

AAC, or augmentative and alternative communication, is a set of communication strategies that are intended to either supplement existing communication or, in more severe situations, be used as an alternative to speech production.

AAC strategies can range from “no-tech” and “low-tech” to “high-tech.” No-tech strategies include facial expression, eye blink, directed gaze, yes/no signals, and communication books or manual communication boards. Low-tech options include fairly basic technology such as voice amplifiers and very basic communication devices that provide a limited number of messages. High-tech strategies include speech-generating devices (SGDs) with an extensive capacity for vocabulary as well as a variety of options in how the user accesses the device for communication.
What AAC Can Do for An Individual

AAC can provide the following benefits to an individual who is unable to communicate independently:

- Ability to actively participate in events that are interesting and relevant to them.
- Enable a voice in making personal decisions and choices, including both medical and legal issues.
- Power to communicate with and participate in the lives of family and friends.
- Ability to maintain as much independence as possible.

The guidance of a speech-language pathologist (SLP) is critical in assessing the status of communication and the need for AAC. This guidance may be available in conjunction with an evaluation team such as those specialized in ALS or MD. If team services are not available, contacting a local SLP with expertise in augmentative communication is appropriate. The SLP can work with the individual and family to determine what techniques may be helpful and to identify what AAC device may be useful. Continued contact with the SLP can be helpful in handling changes in communication that occur over time.

To find a local SLP, talk with your physician or home health care service provider. ASHA also maintains a directory of certified SLPs at www.asha.org/findpro/.

“Communication competence and the control it brings ensures that patients will maintain the ability to guide, direct, and influence the management of medical and personal aspects of their lives.” (Yorkston, Miller, Strand, 1996).

BIBLIOGRAPHY

ALS Association. www.alsa.org
About the Author

Annalee Anderson, M.A., CCC-SLP, is a speech-language pathologist with extensive experience in AAC assessment and implementation. She spent 18 years in clinical practice at a university-based school and clinic program that provided services for individuals with cerebral palsy, myelomeningocele, cognitive delay, autism, and cleft lip and palate.

Annalee joined PRC in 1993 and currently serves as Manager of Clinical Programs. She holds a Certificate of Clinical Competency (CCC) from the American Speech-Language-Hearing Association (ASHA), a Wyoming state license, and is certified in neurodevelopmental treatment. She has been recognized for outstanding clinical achievement by ASHA and has received multiple honors from her state professional organization.

About PRC

PRC is a global leader in the development and manufacture of alternative and augmentative communication devices, computer access products, and other assistive technology for people with severe disabilities.

A 100% employee-owned company founded in 1966 and headquartered in Wooster, OH, PRC has enabled thousands of children and adults worldwide with speech disorders to achieve spontaneous, independent, and interactive communication regardless of their disability, literacy level, or motor skills.

In addition to its powerful communication devices – the new Essence™, ECO™2, Vanguard™ Plus, Vantage™ Lite, and SpringBoard™ Lite – PRC provides a wide array of high-quality teaching and implementation ideas, therapy materials, curriculum sequences, funding assistance, and training to speech-language pathologists, health care professionals, special educators, and the families of AAC communicators. For more information, go to prentrom.com or call 800-262-1984.

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