We are committed to providing you with the best care possible.
This clinical pathway is a guide for what you can expect as communication changes with ALS. The changes you may experience are divided into stages for you to understand what help is available when these changes occur. There is no proven therapy that cures the disease; however, managing the symptoms can help reduce some of the challenges you may face. This pathway identifies your team, assessment, treatments, and intervention options to make communication easier, or ways to enhance your communication.

Notes
1. ____________________________________________
2. ____________________________________________
3. ____________________________________________

DISCLAIMER
By using this document, the user understands and agrees that the information provided is intended for educational purposes only. Use of this information does not create a consulting relationship or a provider/patient relationship. This document is intended to provide general information about health-related matters and is not intended to create a practice of medicine. All information provided is subject to ongoing review and revision, and a more current version may be available. The user is solely responsible for validation against other resources and the decision to use the information.

Duke University, Duke University Medical Center, the Division of Speech Pathology and Audiology, and all associated employees, staff, and providers accept no liability for the use of information from this document.

Any comments or input related to this clinical pathway should be directed to Frank DeRuyter, PhD at frank.deryt@duke.edu

The most recent PDF version of this pathway can be downloaded from the following websites:
www.dukespeechandhearing.com
www.aac-rerc.com

© 2002, Duke University Medical Center (Trautman, Ourand, Bardach, Vess, Caves, DeRuyter)
Version 5.3 (3/9/2004)
## Patient's Care Path

<table>
<thead>
<tr>
<th>STAGE 1</th>
<th>STAGE 2</th>
<th>STAGE 3</th>
<th>STAGE 4</th>
<th>STAGE 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>NORMAL SPEECH PROCESSES</td>
<td>DETECTABLE SPEECH DISTURBANCE</td>
<td>REDUCTION IN SPEECH INTELLIGIBILITY</td>
<td>USE OF AUGMENTATIVE AND ALTERNATIVE COMMUNICATION (AAC)</td>
<td>NO FUNCTIONAL SPEECH</td>
</tr>
</tbody>
</table>

### YOUR ALS TEAM

- **Speech-language pathologist (SLP)**
- **Social Worker (SW)**
- **Nurse, nurse practitioner**
- **Amyotrophic Lateral Sclerosis Association (ALS Association)/Muscular Dystrophy Association (MDA) representative**
- **Physician(s)**
- **Patient family and friends**

### ASSESSMENT

- Listen to your speech and examine your speech muscles for changes that might include:
  - Slowness
  - Low volume of speech
  - Slurring
  - Harsh sounding voice quality
  - An increase in nasal sounds
- Your ALS team will initiate a formal augmentative and alternative communication (AAC) assessment. No matter how difficult it is to "talk," you can still communicate.
- Your ALS team will complete an AAC assessment and help you identify a communication system that best meets your needs. This may include trying out different devices and systems to determine what best meets your needs.
- Your ALS team will help you find funding for the system, if necessary.
- You and your ALS team will continue to assess your changing communication needs.

### TREATMENTS/INTERVENTION

- You will learn more about communication changes that can occur with ALS and options to help preserve communication.
- See Patient Education section below.
- Your SLP will work with you and your communication partners to identify speech techniques that will be successful for you. This may include:
  - Ways to make speech easier to understand
  - Changing your surroundings
  - Energy saving ideas
  - Using non-verbatim to add to your speech
- Your ALS team physician or nurse practitioner will work with you to decide whether any medication would be helpful.
- Your ALS team will work with you to learn and use your system to communicate with partners who can't understand your speech.
- You and your ALS team will continue to modify your communication system to ensure it meets your changing needs.

### MEDICATIONS

- Your ALS team physician or nurse practitioner will work with you to decide whether any medication would be helpful.
- Your ALS team will give you information about:
  - Ways to make your speech more understandable
  - Ways to enhance your written and verbal communication
  - Planning and preparation for further changes in communication
- Your SLP will provide information about:
  - Ways to make your speech more understandable
  - Ways to enhance your written and verbal communication
  - Planning and preparation for further changes in communication
- Your ALS team will provide you and your communication partners with information and resources about your communication system. This system will likely consist of both:
  - Your natural speech, gestures, and facial expressions
  - Low and/or high tech equipment
  - Your SLP will discuss more ways to enhance your communication, which may include:
    - Making your natural speech easier to understand
    - Learning to use low technology strategies
    - Preparing for high technology devices for verbal and/or written communication
- You and your ALS team can help provide information and ways to change and alter your communication system. The ways you use your communication system will change based on the time of day, your position, communication partners, and the disease progression.

### ACTIVITY

- ALS causes muscles to easily get tired. Energy conservation techniques help save energy by preserving your muscle strength. This is important for many activities, including communication.
- You will begin to learn ways to save your energy and remain active.
- Your SLP will provide information about:
  - Ways to make your speech more understandable
  - Ways to enhance your written and verbal communication
  - Planning and preparation for further changes in communication
- Your ALS team will work with you to decide whether any medication would be helpful.
- Your ALS team physician or nurse practitioner will help you find funding for the system, if necessary.
- You and your ALS team will continue to assess your changing communication needs.

### PATIENT EDUCATION

- Your ALS team will give you information about possible changes in speech and communication. Other services and resources are available (e.g., local MDA/ALS clinics, chapters, and support groups, information in print and on the web).
- Your SLP will provide information about:
  - Ways to make your speech more understandable
  - Ways to enhance your written and verbal communication
  - Planning and preparation for further changes in communication
- Your ALS team will provide you and your communication partners with information and resources about your communication system. This system will likely consist of both:
  - Your natural speech, gestures, and facial expressions
  - Low and/or high tech equipment
  - Your SLP will discuss more ways to enhance your communication, which may include:
    - Making your natural speech easier to understand
    - Learning to use low technology strategies
    - Preparing for high technology devices for verbal and/or written communication
- You and your ALS team can help provide information and ways to change and alter your communication system. The ways you use your communication system will change based on the time of day, your position, communication partners, and the disease progression.

---

Your "Stage" (see column heading) is dependent on your speech symptoms. Your ALS team will help you understand the stages.