

PATIENT'S CLINICAL PATHWAY FOR COMMUNICATION CHANGES WITH ALS

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.

Medications, activity, and patient education that you may receive. This clinical pathway is only a guide. Your care may be changed to meet your individual needs. Please let us know if you have any special requirements.

We hope to make your care and visits a positive experience. We encourage you to ask your team members any questions about speech changes, options to make communication easier, or ways to enhance your communication.

Notes

1. _____
2. _____
3. _____

DISCLAIMER

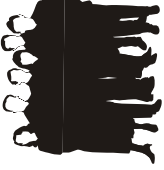





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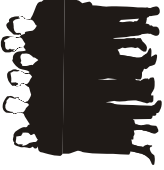





Any comments or input related to this clinical pathway should be directed to Frank DeRuyter, PhD at frank.deruyter@duke.edu

The most recent PDF version of this pathway can be downloaded from the following websites:

www.dukespeechandhearing.com
www.aac-rerc.com

PATIENT'S CARE PATH	EXPLANATION
<p>YOUR ALS TEAM</p> 	<p>Some or all of the following members may be a part of your team:</p> <ul style="list-style-type: none"> Your physician(s) and nurses will explain your diagnosis, tests, and treatment plan(s). Other medical specialists will help you understand and manage the changes you may experience. A speech-language pathologist (SLP), occupational therapist (OT), physical therapist (PT), rehabilitation engineer (RE), and/or dietitian (RD) will work with you to prepare for and address any problems related to speech, swallowing, walking, and daily living activities. Assistive technology (AT) specialists help with using technology to meet communication needs. Myotrophic Lateral Sclerosis Association (ALSA)/Muscular Dystrophy Association (MDA) representatives(s) and/or a social worker (SW) assist with social, emotional, and financial issues. Vendors and insurance company case managers will work with the professionals on your team to assist with acquiring appropriate adaptive equipment. Patient family and friends
<p>ASSESSMENT</p> 	<p>Throughout the disease, your muscle function changes. You may be asked to schedule tests to determine changes in your muscles and ways to maximize the use of your muscles. This will likely include muscles of speech, swallowing, and respiration.</p>
<p>TREATMENTS/ INTERVENTION</p> 	<p>There are a variety of treatments that will become important to you throughout the course of the disease. These may include compensatory strategies, adaptive devices, breathing equipment, and/or procedures to treat increased salivations and maintain nutrition. Exercises to target strengthening muscles DO NOT help, rather they cause muscles to become more tired.</p>
<p>MEDICATIONS</p> 	<p>In some cases, medications may be available to assist with problems such as increased saliva or changes in muscle mass. You will need to speak with your physician.</p> <p>At some point, you may notice problems swallowing when you are tired or stressed. Refer to the "Patient's Clinical Pathway for Swallowing Associated with ALS" for more information.</p>
<p>ACTIVITY</p> 	<p>You will want to continue participating in enjoyable activities. Work with your ALS team to identify ways to conserve energy and manage stress so you are able to remain as independent as possible.</p>
<p>PATIENT EDUCATION</p> 	<p>Staff will explain to you and your family what to expect and how to cope with changes in communication and/or swallowing. It is important that you ask questions and get information that helps you plan and prepare for changes. Refer to the "Patient's Clinical Pathway for Swallowing Associated with ALS" for more information.</p>

SEE INSIDE →

PATIENT'S CARE PATH	STAGE 1 NORMAL SPEECH PROCESSES	STAGE 2 DETECTABLE SPEECH DISTURBANCE	STAGE 3 REDUCTION IN SPEECH INTELLIGIBILITY	STAGE 4 USE OF AUGMENTATIVE AND ALTERNATIVE COMMUNICATION (AAC)	STAGE 5 NO FUNCTIONAL SPEECH
YOUR ALS TEAM 	<ul style="list-style-type: none"> • Speech-language pathologist (SLP) • Social Worker (SW) • Nurse, nurse practitioner • Amyotrophic Lateral Sclerosis Association (ALSA)/ Muscular Dystrophy Association (MDA) representative • Physician(s) • Patient family and friends 	<ul style="list-style-type: none"> • SLP • SW • Nurse, nurse practitioner • Occupational Therapist (OT) • Physical Therapist (PT) • Assistive Technology (AT) Specialist • Rehabilitation Engineer (RE) • ALSA/MDA representative • Physician(s) 	<ul style="list-style-type: none"> • SLP • SW • Nurse, nurse practitioner • OT/PT • AT Specialist • RE • ALSA/MDA representative • Physician(s) • Vendor 	<ul style="list-style-type: none"> • SLP • SW • Nurse, nurse practitioner • OT/PT • AT Specialist • RE • ALSA/MDA representative • Physician(s) • Insurance Case Manager • Vendor 	<ul style="list-style-type: none"> • SLP • SW • Nurse, nurse practitioner • OT/PT • AT Specialist • RE • ALSA/MDA representative • Physician(s) • Insurance Case Manager • Vendor
ASSESSMENT 	<p>A team member will:</p> <ul style="list-style-type: none"> • Listen to your speech to evaluate for any changes • Explain or ask you about changes that you or others might begin to notice • Discuss factors which may impact speech (e.g., fatigue, time of day, exercise) 	<p>Your SLP will listen to your speech and examine your speech muscles for changes that might include:</p> <ul style="list-style-type: none"> • Slowness • Low volume of speech • Slurring • Harsh sounding voice quality • An increase in nasal sounds 	<ul style="list-style-type: none"> • 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 help you find funding for the system, if necessary. 	<ul style="list-style-type: none"> • 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. 	<ul style="list-style-type: none"> • You and your ALS team will continue to assess your changing communication needs.
TREATMENTS/ INTERVENTION 	<ul style="list-style-type: none"> • You will learn more about communication changes that can occur with ALS and options to help preserve communication. • See Patient Education section below. 	<p>Your SLP will work with you and your communication partners to identify speech techniques that will be successful for you. This may include:</p> <ul style="list-style-type: none"> • Ways to make speech easier to understand • Changing your surroundings • Energy saving ideas • Using non-verbals to add to your speech 	<p>Your SLP will teach you to use a communication system that adds to your natural speech. This may include:</p> <ul style="list-style-type: none"> • Using strategies to improve speech understandability • Using simple technology ideas (e.g., communication boards, writing system) • Using a speech amplifier or palatal lift • Beginning to investigate high technology speech devices 	<ul style="list-style-type: none"> • Your ALS team will work with you to learn and use your system to communicate with partners who can't understand your speech. 	<ul style="list-style-type: none"> • You and your ALS team will continue to modify your communication system to ensure it meets your changing needs.
MEDICATIONS 	<p>Your ALS team physician or nurse practitioner will work with you to decide whether any medication would be helpful.</p>	<p>Your ALS team physician or nurse practitioner will work with you to decide whether any medication would be helpful.</p>	<p>Your ALS team physician or nurse practitioner will work with you to decide whether any medication would be helpful.</p>	<p>Your ALS team physician or nurse practitioner will work with you to decide whether any medication would be helpful.</p>	<p>Your ALS team physician or nurse practitioner will work with you to decide whether any medication would be helpful.</p>
ACTIVITY 	<ul style="list-style-type: none"> • ALS causes muscles to easily get tired. <i>Energy conservation</i> 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. • Continue to participate in life activities as much as possible. 	<p>Begin to <u>use</u> energy saving ideas, including:</p> <ul style="list-style-type: none"> • Eliminate all strengthening exercises, including tongue and lip exercises • Schedule and plan activities around energy level • Plan lengthy conversations for a time when you feel you have the most energy • Focus energy on enjoyable activities 	<p>Your SLP will discuss more ways to enhance your communication, which may include:</p> <ul style="list-style-type: none"> • Making your natural speech easier to understand • Learning to use low technology strategies • Preparing for high technology devices for verbal and/or written communication 	<ul style="list-style-type: none"> • Continue working with your ALS team to <u>develop</u> and use energy-saving strategies. 	<ul style="list-style-type: none"> • Continue working with your ALS team to <u>develop</u> and use energy-saving strategies.
PATIENT EDUCATION 	<ul style="list-style-type: none"> • Your ALS team will give you information about possible changes in speech and communication. Other services and resources are available (e.g. local MDA/ALSA clinics, chapters, and support groups. Information in print and on the web). 	<p>Your SLP will provide information about:</p> <ul style="list-style-type: none"> • Ways to make your speech more understandable • Ways to enhance your written and verbal communication • Planning and preparation for further changes in communication 	<p>Your SLP will discuss more ways to enhance your communication, which may include:</p> <ul style="list-style-type: none"> • Making your natural speech easier to understand • Learning to use low technology strategies • Preparing for high technology devices for verbal and/or written communication 	<p>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:</p> <ul style="list-style-type: none"> • Your natural speech, gestures, and facial expressions • Low and/or high tech equipment <p>If it is difficult for you to use the device with your fingers, different options are available and will be investigated.</p>	<p>You 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.</p>

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

See back page for explanation ➔