






PATIENT'S CARE PATH	EXPLANATION
<b>YOUR ALS TEAM</b> 	<ul style="list-style-type: none"> <li>Your speech language pathologist (SLP) evaluates your swallowing and can help you to manage swallowing problems.</li> <li>Your physician(s), nurse, physician assistant, and/or nurse practitioner will explain your diagnosis, tests, modifications, medications and general treatment plan(s).</li> <li>Your dietitian can help evaluate and develop a plan to make sure you are meeting your nutritional needs.</li> <li>Your occupational therapist (OT) can help evaluate and provide information on how to better eat and drink if or when upper body weakness is present.</li> <li>The Muscular Dystrophy Association (MDA) and/ or Amyotrophic Lateral Sclerosis Association (ALSA) representatives and/or social worker (SW) can assist with social, emotional, and financial issues.</li> <li>A pulmonologist can help evaluate and manage lung problems (e.g. difficulty breathing, congestion).</li> <li>A gastroenterologist and/or surgeon can help you with deciding about and/or placing a feeding tube.</li> <li>Other medical specialists will help you understand and manage the changes you may experience.</li> </ul>
<b>ASSESSMENTS</b> 	<p>Throughout the disease, your muscle function will change. You may be asked to schedule tests to determine changes in your muscles of swallowing, breathing, and speech. Some specific tests related to your swallowing include:</p> <ul style="list-style-type: none"> <li>A Modified Barium Swallow Study (MBSS), which is a moving picture X-ray of you swallowing food and/or liquid mixed with barium. This test is performed by a SLP and radiologist.</li> <li>A Fiberoptic Endoscopic Evaluation of Swallowing (FEES) views you swallowing food and/or liquid with an endoscope. This test is performed by an SLP.</li> </ul>
<b>INTERVENTIONS</b> 	<p>Your swallowing will likely become worse throughout the course of the disease. There are a variety of eating and drinking interventions that will become important to you throughout the course of the disease. These may include:</p> <ul style="list-style-type: none"> <li>Compensatory strategies (such as different head postures to limit choking)</li> <li>Modified foods or liquids (such as soft blended foods and/or thicker liquids)</li> <li>Adaptive devices (such as different utensils that are easier to use with weak hands)</li> <li>Nutritional supplements (such as high calorie/protein drinks)</li> <li>Medicine to treat increased salivations</li> <li>Changing the ways you eat or drink in order to conserve energy</li> </ul> <p>Unfortunately, exercises do not help strengthen muscles; rather, they cause muscles to become more tired, and can therefore make your swallowing worse.</p>
<b>MEDICATIONS</b> 	<p>In some cases, medications may be available to assist with problems such as increased saliva or changes in muscle mass. Speak with your physician team to help decide what may help for you.</p>
<b>PATIENT EDUCATION</b> 	<p>Staff will explain to you and your family what to expect and how to help cope with changes you may experience. It is important that you ask questions and get information that helps you manage and prepare for changes. Education about what to expect and how to deal with the changes are two of the best tools to help you fight ALS from taking over your life.</p> <p>Swallowing trouble is usually first noticed when you are tired or when you are swallowing items such as pills, tough meats, or thin liquids. Maintaining good nutrition and hydration is helpful in maintaining overall energy. One side effect of swallowing problems is aspiration. Aspiration is when food or liquids enter your airway. Other side effects of swallowing difficulty include: discomfort (e.g. coughing/choking), decreased nutrition/hydration, pneumonia, fevers, or shortness of breath. Your ALS team will work with you to help minimize risk of aspiration and maintain good nutrition. When swallowing becomes unsafe or too difficult, you may need a feeding tube.</p>

We are committed to providing you with the best care possible.

This clinical pathway is a guide for what you can expect as your ability to swallow becomes affected by 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, assessments, interventions, medications, diet changes 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 needs.

We hope to make your care and visits a positive experience. We encourage you to ask your ALS team members any questions about swallowing changes, or options to make eating and drinking safer and easier.

Notes

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SEE INSIDE →

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 for the decision to use the information.

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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

# PATIENT'S CLINICAL PATHWAY FOR SWALLOWING ASSOCIATED WITH ALS

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

[www.dukespeechandhearing.com](http://www.dukespeechandhearing.com)

[www.aac-lerc.com](http://www.aac-lerc.com)

PATIENT'S CARE PATH	Stage 1 Eating habits are normal	Stage 2 Occasional problems with eating/drinking	Stage 3 Swallowing foods and/or liquids is difficult	Stage 4 Swallowing is too much effort and/or maintaining nutrition with oral eating and drinking only is unsafe	Stage 5 Swallowing is too difficult and/or eating or drinking is unsafe
<b>YOUR ALS TEAM</b> 	<ul style="list-style-type: none"> <li>• Speech language pathologist (SLP)</li> <li>• Social Worker (SW)</li> <li>• Nurse/nurse practitioner</li> <li>• Physician(s)</li> <li>• Dietician</li> <li>• Occupational therapist (OT)</li> <li>• Muscular Dystrophy Association (MDA) and/or Amyotrophic Lateral Sclerosis Association (ALSA) representatives</li> </ul>	<ul style="list-style-type: none"> <li>• SLP</li> <li>• SW</li> <li>• Nurse/nurse practitioner</li> <li>• Physician(s)</li> <li>• Dietician</li> <li>• OT</li> <li>• MDA / ALSA representatives</li> </ul>	<ul style="list-style-type: none"> <li>• SLP</li> <li>• SW</li> <li>• Nurse/nurse practitioner</li> <li>• Physician(s)</li> <li>• Dietician</li> <li>• OT</li> <li>• MDA / ALSA representatives</li> </ul>	<ul style="list-style-type: none"> <li>• SLP</li> <li>• SW</li> <li>• Nurse/nurse practitioner</li> <li>• Physician(s)</li> <li>• Dietician</li> <li>• OT</li> <li>• MDA / ALSA representatives</li> <li>• Pulmonologist</li> <li>• Gastroenterologist / surgeon</li> </ul>	<ul style="list-style-type: none"> <li>• SLP</li> <li>• SW</li> <li>• Nurse/nurse practitioner</li> <li>• Physician Team</li> <li>• Dietician</li> <li>• OT</li> <li>• MDA / ALSA representatives</li> <li>• Pulmonologist</li> <li>• Gastroenterologist / surgeon</li> </ul>
<b>ASSESSMENTS</b> 	<p>Your SLP may assess your swallowing and take baseline information about your normal eating habits. Your dietician may assess your nutrition levels with normal eating habits through:</p> <ul style="list-style-type: none"> <li>• Blood work</li> <li>• Calorie estimation</li> <li>• Weight</li> <li>• General discussion</li> </ul>	<p>Your SLP may assess your swallowing through some or all of the following:</p> <ul style="list-style-type: none"> <li>• Discussion</li> <li>• Evaluating the strength and movement of your mouth, tongue, and throat</li> <li>• Observing you eat and/or drink</li> </ul> <p>Your dietician may continue assessing your nutritional, hydration, and overall dietary needs.</p>	<p>In addition to previous assessment methods, your SLP may also perform an objective swallowing test. Two options may include:</p> <ul style="list-style-type: none"> <li>• Modified Barium Swallow Study (MBSS)</li> <li>• Fiberoptic Endoscopic Evaluation of Swallowing (FEES)</li> </ul> <p>See "Assessments" on page 4 for more information.</p>	<p>Your ALS team will further evaluate your abilities, needs, and desires for obtaining nutrition. Evaluations may include:</p> <ul style="list-style-type: none"> <li>• Repeat swallow assessment(s)</li> <li>• Nutritional/hydration assessments</li> <li>• Weight measurements</li> <li>• Pulmonary status assessments</li> <li>• Assessing your preferences regarding the pros/cons of feeding tubes, malnutrition, and/ or aspiration risk</li> </ul>	<p>Your ALS team will continue to work with you to help assess your nutritional and hydration needs as they arise.</p>
<b>INTERVENTIONS</b> 	<p>No intervention is needed as swallowing habits are normal. It is important to stop any exercises targeting your mouth or throat, as these are not helpful for people with ALS. Your team may talk with you about what you might notice as swallowing becomes difficult and discuss interventions that are available. It is important to make sure you are getting enough nutrition and fluids.</p>	<p>Your SLP can help you identify and learn strategies that may make eating and drinking more successful by conserving energy. Strategies include:</p> <ul style="list-style-type: none"> <li>• Eating smaller meals more often throughout the day</li> <li>• Crushing or taking pills in pudding or yogurt</li> <li>• Scheduling/planning activities and lengthy meals to limit fatigue</li> <li>• Taking smaller bites/sips</li> <li>• Increasing concentration while drinking/eating</li> <li>• Limiting talking during meals</li> </ul> <p>Your dietician may help you plan for ways to maximize your nutrition and hydration.</p>	<p>Your SLP and dietician will work with you to change the texture, amount, and content of your foods and/or liquids so eating/drinking can be effective and safe for you. Other helpful tips include:</p> <ul style="list-style-type: none"> <li>• Increasing use of energy conservation (see Stage 2 for specific examples)</li> <li>• Increasing use of strategies/postures that have been identified as helpful</li> <li>• Considering a feeding tube to make sure you are well nourished and hydrated. Good nourishment and hydration can help you have more energy.</li> </ul>	<p>You and your ALS team will continue to discuss treatment options for meeting nutritional needs and decreasing the risk for aspiration. A feeding tube can be helpful in meeting nutrition and fluid needs. This can help optimize your energy and activity levels. There are pros and cons to each option. Discuss these with your ALS team. Options may include:</p> <ul style="list-style-type: none"> <li>• Eating and drinking modified foods</li> <li>• Tube feeding combined with eating and drinking modified foods</li> <li>• Tube feeding only</li> </ul>	<p>Continue to work with your ALS team to plan the best way to meet your nutritional needs. Your team may discuss occasionally eating and drinking some of your favorite things to enjoy the tastes and smells of food.</p>
<b>MEDICATIONS</b> 	<p>Your doctor will work with you to decide whether any medication would be helpful (e.g. to address increased saliva).</p>	<p>Your doctor will work with you to decide whether any medication would be helpful (e.g. to address increased saliva).</p>	<p>Your doctor will work with you to decide whether any medication would be helpful (e.g. to address increased saliva).</p>	<p>Your doctor will work with you to decide whether any medication would be helpful (e.g. to address increased saliva).</p>	<p>Your doctor will work with you to decide whether any medication would be helpful (e.g. to address increased saliva).</p>
<b>PATIENT EDUCATION</b> 	<p>Your ALS team will provide general information on swallowing, including:</p> <ul style="list-style-type: none"> <li>• Changes you may experience with your swallowing</li> <li>• Potential ways to help manage swallowing problems</li> <li>• Tips on saving energy while eating</li> <li>• Ways to avoid dehydration</li> <li>• Ways to ensure you are getting enough nutrition</li> </ul>	<p>Your ALS team will provide information on:</p> <ul style="list-style-type: none"> <li>• Ways to help manage swallowing difficulties</li> <li>• Preparation for future changes in eating/ drinking</li> <li>• Ways to limit potential side-effects, such as: <ul style="list-style-type: none"> <li>– Aspiration (food and/or liquid entering the airway)</li> <li>– Inadequate nutrition/hydration</li> <li>– Discomfort</li> </ul> </li> </ul>	<p>Your ALS team will provide information on:</p> <ul style="list-style-type: none"> <li>• Aspiration precautions</li> <li>• Ways to alter your food/ liquid textures</li> <li>• Techniques to promote safe and less effortful eating/ drinking</li> <li>• Guidelines for when to seek more help from your ALS team</li> <li>• Ways to increase or maintain calories and fluid intake</li> <li>• Ways to minimize weight loss</li> </ul>	<p>Your ALS team will provide information about the importance of nutrition and hydration with ALS. They will continue to discuss options for meeting nutritional needs, and risks and benefits of these options. They may discuss:</p> <ul style="list-style-type: none"> <li>• Nutrition as it affects muscle fatigue</li> <li>• Feeding tubes</li> <li>• Aspiration</li> <li>• Ways to increase calorie intake</li> <li>• Weight loss and gain</li> </ul>	<p>Your ALS team will provide information on:</p> <ul style="list-style-type: none"> <li>• Nutrition options</li> <li>• Benefits and risks of each option</li> <li>• Use, care, and maintenance of a feeding tube, as needed</li> </ul>

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

See back page for explanation →