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.

**PATIENT’S CLINICAL PATHWAY FOR SWALLOWING ASSOCIATED WITH ALS**

**Notes**

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**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

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

- www.dukespeechandhearing.com
- www.aac-erc.com

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<table>
<thead>
<tr>
<th>Patient's Care Path</th>
<th>Stage 1</th>
<th>Stage 2</th>
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**Your ALS Team**

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:

- Blood work
- Calorie estimation
- Weight
- General discussion
- Your SLP may assess your swallowing through some or all of the following:
  - Discussion
  - Evaluating the strength and movement of your mouth, tongue, and throat
  - Observing you eat and/or drink

Your dietician may continue assessing your nutritional, hydration, and overall dietary needs.

**Interventions**

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.

Your SLP can help you identify and learn strategies that may help you make eating and drinking more successful by conserving energy. Strategies include:

- Eating smaller meals more often throughout the day
- Crushing or taking pills in pudding or yogurt
- Scheduling/planning activities and lengthy meals to limit fatigue
- Taking smaller bites/sips
- Increasing concentration while drinking/eating
- Limiting talking during meals

Your dietician may help you plan for ways to maximize your nutrition and hydration.

**Medications**

Your doctor will work with you to decide whether any medication would be helpful (e.g. to address increased saliva).

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:

- Increasing use of energy conservation (see Stage 2 for specific examples)
- Increasing use of strategies/postures that have been identified as helpful
- Considering a feeding tube to make sure you are well nourished and hydrated.

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**Patient Education**

Your ALS team will provide general information on swallowing, including:

- Changes you may experience with your swallowing
- Potential ways to help manage swallowing problems
- Tips on saving energy while eating
- Ways to avoid dehydration
- Ways to ensure you are getting enough nutrition

Your ALS team will provide information on:

- Ways to help manage swallowing difficulties
- Preparation for future changes in eating/drinking
- Ways to limit potential side-effects, such as:
  - Aspiration (food and/or liquid entering the airway)
  - Inadequate nutrition/hydration
  - Discomfort

Your ALS team will provide information on:

- Aspiration precautions
- Ways to alter your food/liquid textures
- Techniques to promote safe and less effortful eating/drinking
- Guidelines for when to seek more help from your ALS team
- Ways to increase or maintain calories and fluid intake
- Ways to minimize weight loss

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:

- Nutrition as it affects muscle fatigue
- Feeding tubes
- Aspiration
- Ways to increase calorie intake
- Weight loss and gain

Your ALS team will provide information on:

- Nutrition options
- Benefits and risks of each option
- Use, care, and maintenance of a feeding tube, as needed

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**ASSESSMENTS**

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:

- Blood work
- Calorie estimation
- Weight
- General discussion
- Your SLP may assess your swallowing through some or all of the following:
  - Discussion
  - Evaluating the strength and movement of your mouth, tongue, and throat
  - Observing you eat and/or drink

Your dietician may continue assessing your nutritional, hydration, and overall dietary needs.

In addition to previous assessment methods, your SLP may also perform an objective swallowing test. Two options may include:

- Modified Barium Swallow Study (MBSS)
- Fiberoptic Endoscopic Evaluation of Swallowing (FEES)

See ‘Assessments’ on page 4 for more information.

Your ALS team will continue to work with you to help assess your nutritional and hydration needs as they arise.

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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.

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See back page for explanation.