Your ALS Team

- Your speech language pathologist (SLP) evaluates your swallowing and can help you to manage swallowing problems.
- Your physician(s), nurse, physician assistant, and/or nurse practitioner will explain your diagnosis, tests, modifications, medications and general treatment plan(s).
- Your dietitian can help evaluate and develop a plan to make sure you are meeting your nutritional needs.
- 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.
- The Muscular Dystrophy Association (MDA) and/or Amyotrophic Lateral Sclerosis Association (ALS) representatives and/or social worker (SW) can assist with social, emotional, and financial issues.
- A pulmonologist can help evaluate and manage lung problems (e.g. difficulty breathing, congestion).
- A gastroenterologist and/or surgeon can help you with deciding about and/or placing a feeding tube.
- Other medical specialists will help you understand and manage the changes you may experience.

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:

- 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.
- A Fiberoptic Endoscopic Evaluation of Swallowing (FEES) views you swallowing food and/or liquid with an endoscope. This test is performed by an SLP.

Compensatory strategies (such as different head postures to limit choking)
Modified foods or liquids (such as soft blended foods and/or thicker liquids)
Adaptive devices (such as different utensils that are easier to use with weak hands)
Nutritional supplements (such as high calorie/protein drinks)
Medicine to treat increased salivations
Changing the way you eat or drink in order to conserve energy

Unfortunately, exercises do not help strengthen muscles; rather, they cause muscles to become more tired, and can therefore make your swallowing worse.

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 with what may help for you.

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

1. ____________________________
2. ____________________________
3. ____________________________

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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.

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### Assessments

- Blood work
- Calorie estimation
- Weight
- General discussion

### Interventions

- Your SLP can help you identify and learn strategies that may 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 eating/drinking
  - Limiting talking during meals

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 strategies/postures that have been identified as helpful
- Considering a feeding tube to make sure you are well-nourished and hydrated. Good nourishment and hydration can help you have more energy.

### Medications

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

### 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
  - Dysphagia

### See back page for explanation