Nutrition

By Sara Baker, RD, LD

As ALS progresses, the ability to enjoy the foods that provide us with the basic nutrients diminishes as the risk of aspiration and level of fatigue for uncomplicated tasks increases. Dysphagia, or difficulty in swallowing, is a condition that can cause malnutrition and life-threatening aspiration pneumonia. Nutrition can be improved using simple techniques to help manage everyday symptoms of ALS, alter food textures to ease chewing and swallowing, as well as increase calories and protein to maintain weight.

Managing Everyday Symptoms

Daily obstacles encountered with ALS can include dehydration, constipation and diarrhea, which can be diminished by following a few guidelines.

Humans in general have a weak sense of thirst; the signs and symptoms of dehydration can include dry skin, dry mouth and fatigue. A simple indication of adequate hydration is the pee test. If your urine is light in color and slight of odor than your body has plenty of fluids, if your urine is dark in color and has a strong smell you will want to increase your fluid intake. Adequate hydration is individual for everyone, but you should aim for at least 50-60 oz of fluids a day or about 7-8 glasses a day. Try to limit caffeinated beverages to a minimum as they can also cause some additional loss of fluids. Adequate hydration can also help prevent swelling as well as constipation.

Dealing with and preventing constipation and diarrhea are often difficult to talk about, but what goes in must come out. The number of bowel movements a person has is very individual. Normal can be three times a day to every three days. Finding what is comfortable for your body is important.

Incorporation of high fiber foods, which add bulk to stool, and drinking plenty of fluids, can help you increase the chances of a “regular” bowel movement thereby reducing constipation. High fiber foods include fruits, vegetables and whole grains. Unfortunately these are often also the hardest to chew. Cooked or canned fruits and vegetables, hot whole grain cereals, and legumes are high fiber choices that can be added to your everyday diet. Words of caution, if you are attempting to increase your fiber intake, do so slowly. Add one new high fiber food per day to help reduce any abdominal discomfort.

Another option is a fiber laxative that can be added to beverages like juice to aid in bowel regularity. These provide additional bulk and will help prevent constipation. Benefiber is the fiber laxative that I most often recommend as it mixes very easily and does not cloud the liquid that you add it to making it easier to drink. Start with 1-2 tablespoons per day and do not exceed 6 tablespoons per day for optimal results and comfort. You need to consistently use these along with drinking plenty of fluid for these laxatives to help reduce the risk of constipation. Stimulant laxatives are used for immediate relief of constipation.

Flaxseed oil can also be used as a preventive measure against constipation as a means to “lube the tube”. Whether taking flax oil capsules or adding flax oil or ground flaxseeds to whole foods the beneficial oils will help to reduce constipation. Another remedy for many includes prunes and prune juice to get the bowels moving. “Power Pudding” is a tasty recipe that uses prunes to aid in regular bowel function. Puree together 3 ¼ cups cooked prunes, 2 cups apple juice, 2 cups prune juice, 1 cup bran and refrigerate
the mixture. Start with 2 or 3 ounce servings 3 to 7 days a week and adjust amount and frequency to achieve a normal stool pattern.

At the other end of the spectrum, diarrhea is just as uncomfortable. If a new medication has recently been added, check with your doctor to see if diarrhea can be a side effect of the drug. Several foods can help to bind stools, which are included in the Brat diet (see Table 1). Also, watch your hydration level as diarrhea persists. Include fluid replacement drinks like Gatorade or Powerade if it persists for more than a day. Medications that can help reduce your symptoms include Imodium or Lomotil.

<table>
<thead>
<tr>
<th>Tips for prevention of:</th>
<th>Table 1</th>
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| DEHYDRATION             | ▪ Keep a water bottle with you throughout the day filled with your favorite drink.  
▪ Take small sips of liquids between bites of food at mealtimes.  
▪ Drink fluids that provide added calories, ie. Fruit juice, Ensure, milkshakes, etc. |
| CONSTIPATION            | ▪ Increase intake of high fiber foods: add whole fruit to smoothies, add cooked vegetables to casseroles or soufflés, eat oatmeal or cream of wheat, and Power Pudding.  
▪ Drink plenty of fluid.  
▪ Fiber Laxatives: Citracel, Metamucil, Benefiber  
▪ Stool Softeners: Colace  
▪ Stimulant Laxatives: Milk of Magnesia, Lactulose |
| DIARRHEA                | ▪ “BRAT” diet- Increasing consumption of bananas, rice, applesauce and tapioca can help to bind stools.  
▪ Increasing intake of yogurt with active cultures can aid in increasing the “good” bacteria in your gut. |

Mealtimes

Food provide your body with the carbohydrates, protein and fat which is the fuel for your cells. They also provide vitamins and minerals that help your cells to function properly. Thereby, foods are the means in which we nourish our body to sustain daily life. Unfortunately, as the anxiety around mealtimes increases, related to extended periods of time to eat meals and increased risk of choking, the ambiance of meals has evaporated.

Starting to set the mood can reduce anxiety related to mealtimes. Treat yourself as if you are at a four star restaurant for every meal. Limit distractions by turning off the television and playing relaxing music. Sit at the table and enjoy the company of those who are nourishing their bodies with you. Find a comfortable chair with maximum support and padding which enables you to sit upright. Add eye appeal to your plate! Serve food on colorful dishes, add garnishes for an added touch, and attempt to vary the color palate of the foods served in an effort to tempt the tastebuds.

Once you have created a peaceful environment in which to eat, now comes the hard part – eating. Improved swallow function can be accomplished by really focusing on the food in front of you. As you chew your food and start to swallow, visualize the food safely traveling down to your stomach. Once you have swallowed your food, swallow one more time for good measure. Alternate small bites of food with small sips of liquids to push the food along to the stomach. Positioning of the head is also important,
keeping your chin down or parallel to the table is the best angle for the food to make it safely through the esophagus. Foods moistened with sauces or gravies will be the easiest to swallow. Straws can be useful especially for those who have lost muscle tone around the mouth. But, it can also pose difficulty if the liquid is drawn into the mouth to quickly and your mouth is unable to handle the liquid appropriately. Use straws with great caution. And lastly, just like your mama always told you, do not talk with food in your mouth!

**Food Consistency**

The consistency of the food is also a factor in the ability to safely swallow. Foods with differing consistencies like broth soups and cold cereals can be difficult for the mouth and tongue to handle. The thin liquid of the broth or milk could easily be aspirated while chewing the contents of the soup or cereal. Highly textured foods, red meat or raw vegetables, can be very difficult to chew and create quick fatigue of the jaw muscles. Particles from dry foods, pretzels or chips, can easily be choked on. Stringy textures from vegetables like celery or spinach can be hard to chew as well as difficult too completely swallow. And sticky foods, such as peanut butter or refried beans, can be difficult to handle as well. These foods will likely need to be avoided as swallow difficulty progresses, see the Table 2 for new options.

<table>
<thead>
<tr>
<th>Problem Foods</th>
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<tr>
<td><strong>Instead of:</strong></td>
<td><strong>Try:</strong></td>
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<tr>
<td>Broth-based soups</td>
<td>Cream soups</td>
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<tr>
<td>Cold cereal and milk</td>
<td>Hot cereal</td>
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<tr>
<td>Red meat</td>
<td>Chicken, fish, eggs</td>
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<tr>
<td>Raw vegetables</td>
<td>Steam/boil vegetables</td>
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<tr>
<td>Peanut butter</td>
<td>Flavored butter/yogurt</td>
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<tr>
<td>Nuts, pretzels, chips</td>
<td>Dried fruit, cookies</td>
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The following is a Swallow Self-Assessment Survey, from the National Parkinson Foundation, if you answer yes to any of the following questions you will want to consider changing the consistency of your diet. Seeing a Speech and Language Pathologist will help you to determine the appropriate texture to help minimize your risk of aspiration.

1. I have recently experienced an unintentional loss of weight.
2. I have a tendency to avoid liquids.
3. I occasionally run a fever for unexplained reasons.
4. I have a tendency to drool.
5. I notice excess pocketing of food around my gum line.
6. I have increased occurrence of coughing or choking before, during or after eating or drinking.
7. I have frequent heartburn or persistent sore throat.
8 I have difficulty keeping food or liquid in my mouth.
9 It takes me a long time to eat a meal.
10 I get the sensation of food being stuck in my throat.
11 I sometimes have difficulty swallowing pills.
12 I have had recent changes in my eating habits or loss of appetite.
13 I notice changes in my voice quality after eating or drinking.

Once you have made a determination of your swallow function, changing the consistency of your diet is likely to be an option. There are three classifications of altered textures as termed by the National Dysphagia Diet guidelines. These can provide general guidelines for alteration of foods. A Speech and Language Pathologist can provide further food specifics.

The first step is transitioning to soft foods, which you might already be following if the length of mealtimes has increased, to ease exhaustion from chewing. These foods are ground, easily chewed, and are not rough in texture. Foods to avoid include hard, crunchy breads or those with nuts, hard fruits and vegetables, corn skins, nuts, seeds and peanut butter. (See sample menu below.)

Mechanically altered foods should be considered when length of meals continues to increase and control of foods is becoming difficult. These foods should minimize chewing, are ground, fork mashable, and moist. Appropriate textures will easily form a bolus (masticated food mass) that is easy to swallow. Meats should be ground or finely diced and moistened with gravy or sauce. Choose canned or cooked fruit and fresh bananas, and soft cooked vegetables. Avoid dry bread, dry cake, rice, cheese cubes, corn, peas, skins, dry fruit, coconut, and seeds. (See sample menu below.)

Pureed foods are the easiest to chew and swallow and should be considered when food is often getting stuck in the throat or is pocketing in the cheeks (leftover food between the cheek and gums after one has swallowed). These foods offer a smooth consistency, do not require much chewing, do not fall apart when eaten and should be a pudding consistency. Avoid Jell-O, fruitied yogurt, peanut butter, unblenderized cottage cheese, scrambled, fried or hard cooked eggs. Once foods have been blenderized, thickening agents might be useful to get foods to the appropriate texture. Finding new recipes for soufflés, blenderized casseroles and smoothies will be helpful to enhance the eye appeal of these meals. Two cookbooks of mention include: Puree Pizzazz by Becky Dorner can be ordered through Amazon.com or your local bookstore and Non-Chew Cookbook by J. Randy Wilson available at www.nonchewcookbook.com. (See sample menu below.)
Sample Menus:

<table>
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<tr>
<th>Soft Diet</th>
<th>Shredded Lettuce with Dressing</th>
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<tbody>
<tr>
<td></td>
<td>Cream Soup</td>
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<tr>
<td></td>
<td>Turkey Sandwich with Mayonnaise</td>
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<td></td>
<td>Fresh, Ripe Melon</td>
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<td></td>
<td>Chocolate Chip Cookie</td>
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<tr>
<td>Mechanically Altered</td>
<td>Scrambled Egg</td>
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<tr>
<td></td>
<td>Pancake Moistened with Syrup</td>
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<tr>
<td></td>
<td>Wheaties with ¼ cup 2% Milk</td>
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<tr>
<td></td>
<td>Banana</td>
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<td></td>
<td>Orange Juice</td>
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<tr>
<td>Pureed</td>
<td>Pureed Chicken</td>
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<td></td>
<td>Mashed Potatoes with Gravy</td>
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<tr>
<td></td>
<td>Pureed Carrots</td>
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<tr>
<td></td>
<td>Applesauce</td>
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<tr>
<td></td>
<td>Chocolate Pudding</td>
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Increasing the consistency of liquids will also help to reduce the risk of aspiration. If you frequently experience a gurgly voice or frequent coughing and choking after drinking liquids you will likely need to change the consistency of liquids consumed.

Liquids are defined in 4 categories: thin, nectar-thick, honey-thick, and pudding-thick. Thin liquids are the consistency of water, juice and tea. Nectar thick liquids are the consistency of fruit nectar or tomato juice. Honey-thick liquids flow easily at room temperature like honey. Pudding-thick liquids should be spoon-thick and smooth. Use the packaging guidelines of the specific commercial thickener you choose for obtaining your required consistency as different liquids and temperatures require different amounts of thickener. Maximum thickening of the liquid can take 1-2 minutes, so allow time for full thickening before adding additional thickener. Refrigeration of thickened liquids will cause further thickening. Except for thickeners like cornstarch, which actually bind water and can cause dehydration, drinking thickened liquids will result in the same hydration as unthickened liquids if used appropriately. Food thickeners include:

- Commercial Food Thickeners: Thick It, Thick & Easy, Simply Thick
- Instant Cereal
- Baby Strained Bananas or Banana Flakes
- Potato Flakes
- Powdered Skim Milk or Heavy Milk
- Finely Chopped Crackers or Bread Crumbs
- Flavored or Plain Yogurt
- Unflavored/Flavored Gelatin
- Cottage Cheese or Cream Cheese

Maximizing Calorie and Protein Intake

As food consistencies change and the difficulty with eating meals increases, weight loss can become a problem. Therefore you will want to make the most out of the foods you eat. Calorically dense foods will give you the most calories and protein in the smallest quantity of food. This calorie-rich way of thinking
is often difficult as many of us have been on and off diets for many years. But, maintaining one’s weight is often a high predictor of longevity with ALS and therefore very important. Below is a list of several ways to maximize your intake. Choose those that best suit your current eating habits. Disclaimer: This list is not an attempt to discount the advise from your MD. If they have advised you to avoid certain types of foods due to other medical conditions, please continue to follow their advice.

- Try pancakes as an alternative to regular bread.
- Serve cooked cereal and rice with extra margarine.
- Choose full fat dairy products.
- Mix 2-3 tablespoons of nonfat dry milk into soups, puddings or hot cereals.
- Try malted milk and eggnog.
- Add ice cream and/or whipped cream to desserts and milk beverages.
- Add grated cheese to eggs, vegetables or casseroles.
- Add cottage cheese or ricotta cheese to gelatin, pudding-type desserts and pancake batter.
- Try vegetables with cream or cheese sauce.
- Serve mashed potatoes with gravy, margarine, shredded cheese or sour cream.
- Include banana or other fruit on cereal.
- Add brown sugar to hot cereal.
- Choose fruit packed in heavy syrup.
- Drink liquids with calories: Ensure, Boost, Milkshakes, Juices.
- Choose higher grades of meats, which have more marbling and more calories.
- Choose oil packed tuna.
- Beat eggs into mashed potatoes, vegetable purees and sauces.
- Add jelly, jam, or preserves to cheesecakes, pudding or other desserts.
- Serve gravy on meats.
- Add extra margarine.
- Try nondairy liquid creamers or heavy cream instead of milk in recipes.

Oral supplements, like Ensure or Boost, are convenient and easy snacks that can add an extra calorie punch and will keep you hydrated as well. Experiment with adding ice cream, yogurt, and fruit to your favorite supplement for a tasty smoothie. Commercial thickeners can also be added to supplements, but can often create lumps. To reduce these, add the thickener to a small amount of water before adding to the supplement.

Oral supplements include several varieties of Ensure and Boost, some with fiber, some without. Ensure Plus or Boost Plus have additional calories and protein compared to the original Ensure or Boost. Carnation Instant Breakfast and Slimfast also count as oral supplements and have many more flavors to choose from. In fact, Carnation Instant Breakfast has more calories and protein when added to whole milk than the original Ensure or Boost and is cheaper than both.

Other options for supplements can include Benecolacite and protein powder. Benecolacite is an odorless, colorless liquid that can be added to smoothies, applesauce, mashed potatoes, or oatmeal. It can be
purchased at the drug store and if not kept on stock, the pharmacy will likely purchase for you or you can order through the Internet. Protein powders can be used in much the same way as Benecolite. Find one at your local drugstore, supermarket, or nutrition center that fits your taste buds, as well as your price range. An alternative for commercial protein powders is non-fat dry milk. It mixes easily with most foods and is tasteless, as well as very inexpensive. Below is a recipe for a tasty supplement alternative:

“Katie Drink”

1/3 cup vanilla ice cream
1/4 cup cottage cheese
1/4 cup flavored jello
Blenderize in blender until smooth, refrigerate until firm.