

## *Dysphagia and Associated Disorders*

**Guideline:** People who have difficulty swallowing (dysphagia), gastroesophageal reflux disease (GERD), unplanned weight loss or other problems that can affect their nutritional status and overall medical condition should be carefully evaluated and programs should be established to assure that (a) precautions are taken to minimize the risk of aspiration, (b) each person receives proper nourishment in a safe manner that minimizes the risk of aspiration and (c) each person is provided assistance as needed to increase functional independence during meals for a more pleasant and fulfilling dining experience.

### **DEFINITIONS:**

**Aspiration:** The entering of food, liquid, gastric contents and or oral secretions into the airway. Coughing often occurs with aspiration.

**Dysphagia:** Difficulty swallowing. Dysphagia may occur at one or more of the three stages (oral, pharyngeal, esophageal).

**Gastroesophageal reflux disease (GERD):** The backflow of gastric and/or duodenal contents past the lower esophageal sphincter and into the esophagus.

**Helicobacter Pylori (H. Pylori):** A gram-negative bacterium that colonizes in the gastric mucosa causing gastritis and gastrointestinal malignancy.

**Individual's record:** A permanent legal document that provides comprehensive information about the individual's health care status.

**Interdisciplinary Team (IDT):** A team of professionals and direct care staff with knowledge of the individual's overall status and/or knowledge of the causes and treatment of dysphagia, GERD, unplanned weight loss/gain or other problems affecting the consumer's nutritional status. The IDT should meet to discuss evaluation and/or treatment of specific issues affecting the individual's nutritional status and make recommendations as appropriate.

**Medical progress notes:** The section of the individual's record where primary care providers document their findings and provide rationale for treatment plans.

**Primary care providers:** Physicians, nurse practitioners and physician assistants who provide primary care services and are authorized to prescribe medications and treatments for people on their assigned caseloads.

**Silent Aspiration:** Aspiration that occurs with no outward, clinical indication such as coughing.

### **RATIONALE:**

1. Individuals with intellectual and related disabilities are at high risk for problems associated with dysphagia and GERD.
2. Problems associated with dysphagia and GERD can result in aspiration.
3. Aspiration related to dysphagia and GERD, both overt and silent, can result in unplanned weight loss, chronic respiratory disorders, aspiration pneumonia as well as other medical conditions.
4. Aspiration and choking are leading causes of death in people with intellectual and related disabilities.

**Rationale cont'd**

5. Factors that can increase the risk of aspiration related to dysphagia and/or GERD include, but are not limited to:
  - a. Positioning during and after oral intake
  - b. Physical deformity
  - c. Medications
  - d. Behavioral factors (i.e. eating at a fast pace, over packing of mouth, stealing food/liquid)
  - e. Large bolus size
  - f. Dependently feeding an individual at a fast pace
  - g. Enteral feedings
  - h. Pica
  - i. Overall decline in medical and/or functional status related to illness or injury
6. Individuals diagnosed with dysphagia, aspiration, GERD, H. Pylori or other associated conditions may require specific treatment, specialized dining programs and other interventions which may include:
  - a. Positioning
  - b. Adaptive equipment
  - c. Specialized feeding techniques
  - d. Diet/liquid consistency modifications
  - e. Close monitoring of weight
  - f. Monitoring of intake, elimination, respiratory status, skin integrity and/or hydration
  - g. Alternate methods of feeding
  - h. Medication
  - i. Other techniques as needed

**EXPECTED OUTCOMES:**

1. All staff assisting and/or monitoring during any oral intake, whether during meals, snacks or medication administration, etc. should receive training on the basic guidelines for dining and emergencies related to choking.
  - a. Training should occur during new employee orientation.
  - b. Specific guidelines and directions on individual dining programs should be provided prior to staff being assigned specific dining responsibilities.
2. Specialized training may be required for direct support staff depending on the particular treatment options recommended and implemented by the IDT. Training should be provided by appropriate professional staff.
3. Staff should be aware of clinical signs and symptoms of dysphagia, aspiration, GERD and/or H. Pylori which may include, but are not limited to:
  - a. Choking incidents
  - b. Coughing and/or gagging before, during and/or after meals
  - c. Recurrent coughing at night
  - d. Unplanned weight loss or failure to gain weight despite caloric increase
  - e. Refusal of or difficulty managing certain food/liquid consistencies
  - f. Wet/gurgly voice quality before, during and/or after meals
  - g. Frequent respiratory illnesses
  - h. Recurrent pneumonia
  - i. Refusal to eat or drink

**Expected Outcomes cont'd**

- j. Vomiting/regurgitation
  - k. Acute onset of hand mouthing behavior
4. Prompt assessment should be completed by a health care professional and documented when signs and/or symptoms of dysphagia, aspiration or GERD are detected. Further referrals for evaluation and/or diagnostic testing (i.e. modified barium swallow, UGI, esophagram, EGD) may be indicated. Results from evaluations and referrals could result in changes in food/liquid consistency and/or the need for adaptive equipment.
  5. Staff should be made aware of adaptive dining programs as they are developed and modified.

**GENERAL GUIDELINES**

1. Written nutritional management programs should be developed by professional staff and available for staff reference at each meal and whenever food or liquids are given. Alternate therapeutic positioning guidelines should be included in these programs as indicated.
2. General positioning guidelines should be followed during all oral intake of food, liquids, and medications to minimize the risk for aspiration. These guidelines include, but are not limited to:

**During meals:**

- a. Position the person as upright as possible with back supported.
  1. Hips should be flexed and back in the seat of the chair/wheelchair with seatbelt secure when physically possible.
  2. Knees should be flexed to 90 degrees when possible.
  3. Feet should be supported on the floor, wheelchair foot rests or other surface when physically possible, unless otherwise specified.
  4. Positioning devices such as wedges, pillows, bolsters, lap trays, and head rests should be utilized to achieve proper positioning as needed.
- b. For those individuals who cannot be positioned upright, the head of the bed should be elevated 30 degrees or on 6 – 8 inch blocks during feeding.
- c. Encourage proper positioning for adequate airway closure, minimizing the risk for aspiration for those dependently fed. **Food/liquid should be presented at midline with head in a neutral to chin tuck position.**
- d. Individuals who are at risk for aspiration, GERD or other associated disorders (e.g., esophageal dysmotility, esophageal strictures, hiatal hernia, regurgitation, etc.) should NOT be fed in a horizontal/supine position unless medically ordered. If ordered, positional devices should be utilized to encourage a more upright position with head/neck maintained in a neutral to chin tuck position.
- e. Staff assisting with dining should sit on a stool or in a chair at eye level with the individual, when possible, in order to facilitate better communication and monitoring during meals.

**After meals and when in bed:**

- a. Individuals who are diagnosed with dysphagia or who are at risk for aspiration should not lie flat after meals for at least one hour, or longer if ordered, with head of bed elevated as indicated. Position should be maintained as ordered with the head and trunk elevated to avoid aspiration.

**General Guidelines cont'd****After meals and when in bed**

- b. Individuals diagnosed with GERD should remain upright after meals (at least 2 hours, if feasible) to avoid aspiration from incidents of reflux unless otherwise ordered. The head of bed should be elevated at least 30° or on 6 to 8 inch blocks at all times unless otherwise medically ordered.

**REFERENCES**

- Bohmer, C. J., Klinkenberg-Knol, E.C., Niezen-de Boer, M.C. & Meuwissen, S.G. (2000). Gastroesophageal Reflux Disease in intellectually disabled individuals: How often, how serious, how manageable? *American Journal of Gastroenterology*, 95(8), 1868-1872.
- Bohmer, C. J., Niezen-de Boer, M.C. Klinkenberg-Knol, E.C., Deville, W.L., Nadorp, J.H. & Meuwissen, S.G. (1999). The prevalence of Gastroesophageal Reflux Disease in institutionalized intellectually disabled individuals. *The American Journal of Gastroenterology*, 94(3), 804-10.
- de Veer, A. J., Bos, J. T., Niezen-de Boer, R.T., Bohmer, C. J., & Francke, A. L. (2008) Symptoms of Gastroesophageal Reflux Disease in severely mentally retarded people: A systematic review. *BMC Gastroenterology* 8(23), doi: 10.1186/1471-230X-8-23
- Kitchens, D. H., Binkley, C.J., Wallace, D. L. & Darling, D. (2007). Helicobacter Pylori Infection in people who are intellectually and developmentally disabled: A review. *Special Care Dentist* 27(4), 127-33.
- McGowan, K. (July 2013). HRST (Health Risk Screening Tool) Newsletter. The Five Fatal. Available: [http://www.mh.alabama.gov/Downloads/ADSDND/HRST\\_Article\\_Fatal\\_Five.pdf](http://www.mh.alabama.gov/Downloads/ADSDND/HRST_Article_Fatal_Five.pdf)
- Polednak, A. P. (1975). Respiratory disease mortality in an institutionalised mentally retarded population. *Journal of Intellectual Disability Research*, 19(3-4), 165-172. doi: 10.1111/j.1365-2788.1975.tb01270.x