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Aspiration Prevention in Angelman Syndrome

A Practical Guide for Caregivers and Care Teams

What is Aspiration?

Aspiration happens when food, liquid, saliva, or other substances are not swallowed correctly and enter the airway instead of going down the esophagus to the stomach. In individuals with Angelman syndrome (AS), aspiration may go unnoticed (silent aspiration) and can lead to:

- · Recurrent pneumonia or respiratory infections
- Chronic coughing or choking
- Poor weight gain or nutrition challenges

Why Individuals with AS Are at Higher Risk:

- Low muscle tone (hypotonia)
- Poor coordination of swallowing and breathing
- · Oral motor challenges or excessive drooling
- · History of seizures, reflux, or feeding difficulties
- Lack of verbal communication may delay detection

ASPIRATION PREVENTION CHECKLIST

1. Know the Signs

- Coughing or choking while eating or drinking
- Wet or gurgly voice after swallowing
- Frequent respiratory infections
- Excessive drooling
- · Refusal to eat or very slow eating
- Unexplained fever or breathing changes







2. Feeding Best Practices

- Ensure upright positioning during and after meals (at least 30–60 minutes after eating)
- Use adaptive utensils and slow pacing
- · Offer appropriate textures (thickened liquids or pureed foods if recommended)
- Eliminate distractions during mealtimes
- Encourage small bites and sips

3. Involve Your Care Team

- Get a swallow study (Modified Barium Swallow or FEES) to assess risk
- Consult:
 - Speech-language pathologist (SLP) for feeding support
 - Occupational therapist (OT) for positioning
 - Gastroenterologist if reflux is present
 - Discuss options like thickening liquids or alternate feeding methods (e.g., G-tube)

4. Safe Sleep & Medication

- Sleep with head of bed slightly elevated (if medically appropriate)
- Review all medications for side effects that may increase secretions or impact swallowing
- Manage seizures, as aspiration risk increases postictally

5. Train Your Team

- Educate all caregivers, school staff, nurses, and respite providers
- Document your child's safe feeding plan in an IEP, medical binder, or care notebook
- Use tools like the ASF Care Binder to organize info and instructions

WHEN TO CALL THE DOCTOR

- New or worsening coughing/choking
- Refusal to eat or drink
- Recurring respiratory symptoms
- Fever without a clear cause

Remember: Aspiration prevention is not about fear — it's about awareness and proactive support. With the right strategies and care team in place, individuals with Angelman syndrome can eat, drink, and enjoy life more safely. For more resources, visit: www.angelman.org



Angelman Syndrome Foundation angelman.org

