

Related Conditions and Complications

Not all conditions listed below will be applicable to every individual who has AS. Not all have epilepsy, some might sleep really well, many have no behaviours that require management, and some might only have mild problems with reflux and constipation. However, when the following conditions are present, they need to be carefully monitored and managed.

Some of these conditions can cause pain, stress and disruptions to family life and can even become life threatening if not treated appropriately.

1. **Epilepsy:** [read more here](#)

2. **Sleep disorder:**

- “...Serious sleep disorders are one of the symptoms of AS. These can be so serious that the children must sleep in special crib-like beds to keep them from wandering or harming themselves at night.” Read more here: [Circadian clock linked to Angelman syndrome](#).
- “...A significantly high frequency of disorders of initiating and maintaining sleep, prolonged sleep latency, prolonged wakefulness after sleep onset, high number of night awakenings and reduced total sleep time were found in our AS patients, as compared to age-matched controls. We also found other types of sleep disorders, never reported before, such as enuresis, bruxism, sleep terrors, somnambulism, nocturnal hyperkinesia, and snoring.” Read more here: [Sleep disturbances in Angelman syndrome: a questionnaire study](#)
- Review, Sep 2020 study: [Angelman syndrome and melatonin: what can they teach us about sleep regulation](#). Read full article [here](#).
- “...According to Angelman-related literature, sleep problems with our children can’t just be put to bed. The degree to which sleep evades children with AS is enormous, and can include everything from difficulties with falling asleep to reduced sleep time, bedwetting, waking during the night, terrors, and even sleep walking. Like typical children, youngsters with AS also don’t like to stay in bed and often try to escape their beds or rooms to seek stimulation via toys, electronics, water, and even outside spaces. My son, as well as many other children with AS, sleeps in a specialized safety bed that keeps him enclosed and safe during the night.” Read more here: [Why My Child’s Sleep Problems Just Can’t Be ‘Put to Bed’](#)
- Read more here: [Angelman syndrome children and adults have serious sleeping disorders](#)

3. **Dysphagia and Gastrointestinal (GI) issues:**

'Angelman Patients Frequently Have Gastrointestinal Problems': read more [here](#).

GERD and Cyclic vomiting: Read more here: [GERD and Cyclic vomiting \(CVS\)](#)

Reflux and constipation are common and can become serious if left untreated. Ideally GI issues should be treated holistically with an appropriate diet plan, correct

positioning during and after meals, physical activity, as well as medical intervention when necessary.

Dysphagia (swallowing problems): Some people with dysphagia have problems swallowing certain foods or liquids, while others can't swallow at all. Signs include [coughing](#) or choking when eating or drinking, bringing food back up, sometimes through the nose, a sensation that food is stuck in your throat or chest, persistent drooling of saliva. Over time, dysphagia can also cause symptoms such as weight loss and repeated chest infections.

Eosinophilic Esophagitis (EE): Read more here - [An Update on EE.](#)

[Eosinophilic esophagitis is a chronic allergic inflammatory condition of the esophagus, characterized by symptoms such as solid-food dysphagia \(difficulty swallowing\) and food impaction in adults, and feeding intolerance and GERD symptoms in children. An EGD \(Esophagogastroduodenoscopy\) is a procedure that examines the esophagus, stomach and first portion of the duodenum \(small intestine\) using a long flexible tube with a camera at the end of it. The scope is inserted into the mouth and advanced to the small intestine.](#)

Constipation can be an ongoing issue and is best treated by adapting the diet, encouraging exercise, massage, and the intake of fluids. Medication should be used sparingly, only when really necessary.

Elevated ammonia levels: Constipation and certain Epilepsy medications, eg. Epilim/Depakote (also known as valproic acid) can be causes of elevated ammonia levels, which can cause a variety of problems. Ammonia is a nitrogen waste compound that is normally excreted in the urine. Elevated blood ammonia levels can affect a person at any age and happens for a variety of reasons. Read more [here](#).

4. **Anxiety and aggressive behaviours:**

Watch on YouTube: [Anxiety and Behavior Concerns with Christopher Keary, MD](#)

Read more on the [Informational Series on Angelman Syndrome Behaviors.](#)

It is also important to access and model an appropriate communication system/device as early as possible to model [‘self- talk’ with AAC systems](#) - as a tool necessary for self-regulating emotions.

[Video modelling](#) and the use of personal social stories on a tablet have also been known to help.

Current research study on: [Anxiety in Angelman syndrome](#)

[Behaviours that Challenge Associated with Frustration Related to Communication Difficulties](#)

[Behaviours that Challenge Related to Anxiety](#)

5. **Cyclic Vomiting:**

Cyclic vomiting syndrome (CVS) can cause dehydration, injury to the food tube (sometimes the esophagus becomes so irritated it bleeds), and tooth decay. The acid in vomit can corrode tooth enamel. If episodes occur more than once a month or

require hospitalization, your doctor may recommend preventive medicine, such as amitriptyline, propranolol (Inderal), cyproheptadine and topiramate. Read more [here](#).

['Guidelines on management of cyclic vomiting syndrome in adults'](#)

['Treatment of Cyclic Vomiting Syndrome'](#)

6. Orthopedic conditions:

Scoliosis & Skeletal - see [Management of Angelman Syndrome - A Clinical Guideline](#)

Gait and movement disorders: Physical therapy is essential to help improve ambulation. Sometimes bracing (AFOs) or surgical intervention may be needed to properly align the ankles, feet and knees.

Osteopenia - [Bone mineral density in Angelman syndrome](#)

7. Vision/Strabismus and CVI:

Angelman syndrome and Vision: read more [here](#)

Management of strabismus requires evaluation by an ophthalmologist who will advise on a course of action. Read more on [Cortical Visual Impairment Symptoms and Causes](#).

[Click on link here to watch](#) a 2019 documentary about CVI, with explanations by Professor Gordon Dutton and Dr Cathy Williams, Ophthalmologist from the CVI Project.

8. Pica

[The term pica originates in the Latin](#) word for [magpie](#) (Picave), a bird that is famed for its unusual eating behaviors, where it is known to eat almost anything. [Pica](#) is the repeated or chronic ingestion of non-nutrient substances. In children with developmental delay, pica occurs in 10–33%.

Although many people with AS are picky eaters, they might still be impulsive when it comes to chewing, biting and swallowing objects that are not food, eg. Foam stuffing, small objects, plastics, small toys, gravel, balloons, etc. This can cause choking and/or obstructions in the throat and digestive system that can become serious and at times, lethal.

9. Anaesthetics and Surgery recovery:

Aspiration and respiratory distress: Though most people with AS are very resilient and seem to withstand anaesthetics and extensive surgeries well, many do struggle with recovery in the first few days after surgery. It is most important to achieve good pain control while closely monitoring for [aspiration](#) and [respiratory distress](#).

Read more here: [FAQs About Anesthesia in Angelman Syndrome](#)