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Preparing Your Individual with Angelman Syndrome for General Anesthesia

General anesthesia, also sometimes called a general anesthetic or GA, is where a mixture of medicines is given to keep them a patient in a carefully controlled unconscious state, or 'sleep.' General anesthesia is used mainly for surgery, although in some circumstances your Individual may require a general anesthetic for some non-surgical procedures that require them to hold still for long periods of time, such as dental work, imaging (MRIs or CT scans), and lumbar punctures.

People with Angelman syndrome are special not only because they communicate differently, but also because they have medical issues and often take medications that may impact anesthesia, surgery and recovery. General anesthesia may be required for some non-surgical procedures that other people can safely have without anesthesia. It is important to know that anesthesia for individuals with Angelman syndrome is very safe, and the risk is generally no different than for someone without Angelman syndrome.

When your individual has a procedure requiring general anesthesia, they will be cared for by an anesthesiologist. An anesthesiologist, sometimes called an anesthetist, is a doctor that specializes in giving general anesthesia medicines and monitors their patient closely during the procedure. In some instances, your anesthesiologist might be working with a certified nurse anesthetist (CRNA), who is also highly trained in anesthesia. When your individual receives anesthesia, there will always be an anesthesiologist or a CRNA with them to keep them safe.

Before your individual receives general anesthesia, it is important to communicate with your anesthesiologist and let them know that your individual has Angelman syndrome. By sharing your individual's medical history, you can help the anesthesiologist take the best care of your individual.

Fasting

Your individual will need to fast before their surgery. Fasting before surgery is important to ensure the patient has an empty stomach when under a general anesthetic. Anesthesia medicines reduce the cough or gag reflex. If there is anything in the stomach when a patient is having general anesthesia, there is a risk of food or liquid being breathed into the lungs and causing pneumonia. This is called aspiration. An empty stomach before anesthesia is always preferred. If your individual requires an emergency surgery and they have not fasted, there are precautions that the anesthesiologist can take to reduce the risk of aspiration.



Different foods and drinks require different fasting times. Always check with your doctor about when to have your individual stop eating and drinking before general anesthesia. This is very important, as there is a chance your individual's procedure may be postponed if they are not adequately fasted. Fasting includes:

- Foods and fluids (including breast milk) – although the timing of fasting differs depending on the food or the fluid
- Oral and PEG (Percutaneous Endoscopic Gastrostomy) tube feeds
- Sweets / Lollies / Chewing Gum

One exception to fasting is medication. As a general rule, your individual should continue taking their regular medications at the usual time unless otherwise requested by your doctor or nurse. Medications can be taken with a sip of clear liquid (if in tablet or powder form). Some specific medication-related issues to discuss with your doctor include:

- Medications that can interfere with surgery or procedures. These include medications such as blood thinners (aspirin / warfarin) or medicines for diabetes (insulin). Some medicines might need to be stopped prior to surgery.
- If the medication is a large volume of liquid
- If your individual can only take medication hidden in food or fluids such as juice or applesauce

Before Surgery

The anesthesiologist will:

- Ask you questions about your individual's medical history
- Ask about any prior issues with anesthesia for your individual or your family members
- Explain the plan for your individual during the surgery or procedure
- Answer any questions you may have about anesthesia

Specific issues that the anesthesiologist may want to know include:

- Your individual's seizure history and control, and anti-seizure medication
- A history of gastro-esophageal reflux disease (GERD), and how well-controlled it is
- Medications and drug / food allergies
- The level your individual communicates at – this can include how they communicate pain and distress, and the best methods to communicate with your individual, including the use of Augmentative and Alternative Communication (AAC) devices. This will be especially helpful for the nursing staff in recovery when your individual wakes up.
- Safety measures and your individual's mobility – medical staff may assume (especially for older children and adults) that your individual can be left on a hospital bed without supervision, which may lead to them accidentally injuring themselves.

Some patients are given a medicine to help them relax before surgery – this is called a premedication, and may be called a 'premed'. A premed may be given 15-60 minutes before surgery, but it is not essential for the anesthetic. If your individual spits out the premed or is not keen on taking it, let your anesthesiologist know.



During Surgery

Patients can go to sleep for procedures by one of two ways – your anesthesiologist will talk to you about the best and safest way for your individual to have general anesthesia.

Option 1: Medicine through a drip

- This is where an IV is put into a vein
- A local anesthetic cream may be applied to numb some areas of the skin where an IV is put in
- This cream can take 45-90 minutes to work and will reduce the discomfort associated with having a drip inserted
- The anesthesia medicine is given into this IV
- It takes seconds to go to sleep with this medicine

Option 2: Breathing medicine through a face mask

- Some individuals go to sleep with a vapor (gas) medicine given to them with a mask that is placed over the mouth and nose
- Your individuals will breathe in a mixture of anesthetic gases that may smell funny but not unpleasant
- It takes a minute or two to go to sleep with this method
- It is normal for your individual to wriggle, cough, breathe noisily or snore as they go to sleep

When your individual is asleep, the anesthesiologist will insert a breathing tube. A breathing tube allows the patient to continue to breathe the anesthesia gases and remain asleep throughout the procedure.

After Surgery

The breathing tube is removed at the end of the surgery in the operating theatre or sometimes in the post-anesthesia care unit (PACU, also called recovery). Your individual probably will not remember this tube coming out, but may have a sore throat or a croaky voice for a few hours after. The nurses will call you a littlewhile after your individual has arrived in recovery so you can be with them as they wake up.

Depending on the surgery or procedure, it may take from a day up to a few weeks for your individual to recover. Your individual may need rest, and you may notice a change in your individual's behavior pattern. Your doctor will let you know how long your individual will need to rest at home, and how long it might take for your individual to return to normal activities.

Key Points to Remember:

- General anesthesia or GA is a mixture of medicines given to a patient to keep them asleep during surgery.
- Your individual will need to fast from food and fluid, but not medication, before surgery. Different foods and fluids require different fasting times, so always check with your doctor for specific instructions.
- Individuals can go to sleep for surgery by two ways – medicine can be given through an IV or gas can be breathed through a mask.
- When your individual has general anesthesia, they will never be alone – there will always be an anesthesiologist and/or CRNA with them.
- Anesthesia for people with Angelman syndrome is generally very safe.