

This is Luna!



Luna has medical PTSD, autism, ADHD, and a rare genetic syndrome that causes mild physical and cognitive impairments.

We appreciate you being on her care team.

It is important to know that any clinic environment, and virtual visits, are triggering and stressful to her.

Your compassion in helping her stay regulated is appreciated, and will help this and future visits go more smoothly!

Here's how you can help:

Please Don't:

- ★ Please don't talk to Luna more than necessary for her care.
- ★ Please don't involve more people in her care than necessary.
- ★ Please don't offer choices or information she hasn't asked for, or use talk as a distraction.
- ★ Please don't take her behavior personally.

Please Do:

- ★ Address questions and conversations to her parent. Luna will chime in if she likes!
- ★ Allow Luna to stay calm by focusing on her favorite videos with headphones.
- ★ Focus on the goal of the visit, and omit conversation and tasks that aren't necessary.
- ★ Grant Luna every reasonable request that you can.

Examples of some that help her feel safe:

- Sitting in a chair vs exam table. At minimum, staying as upright as possible vs lying down.
- Wearing her own clothes vs a hospital gown
- If she declines an intervention, temporarily acquiescing is more likely to be successful than insisting.

☆ **Please know we her parents are VERY grateful for the care she receives.** Because Luna has experienced **medical trauma** (waking up intubated in the ICU after open heart surgery, forcibly restrained for deep suction), as well as having **autism**, her reaction to her care is very different. **We hope that by working together to support her self-regulation and autonomy, we can heal some of her response to the healthcare environment.**

Please see the reverse side if you are interested in more information on the rationale behind our requests!

Why talk as little as possible? Social interaction is work for Luna, as it is for many people with autism. She is already putting considerable resources into holding it together during a stressful experience.

In addition, many routine questions asked of children (what grade are you in? Who's your best friend? What do you like to read?) highlight difficulties and challenges, rather than build rapport.

On the flip side, if she opens up to you about snakes, Minecraft, or YouTube, it will go a long way to show interest and enthusiasm rather than negativity (like "eww, snakes!" or "I hope you're not getting too much screen time").

Why limit the number of people in the room? Luna already has extra challenges with receiving medical care, and large groups or being used as a teaching tool is overwhelming.

Why not ask her friendly questions, or offer her small choices? These use up mental bandwidth, contribute to stress and frustration, and don't increase her level of comfort or control.

What do you mean don't take her behavior personally? Aren't you teaching her how to be polite to people? When she is dysregulated, manners and social skills are not accessible to her brain. The best approach is to take this in stride and allow her parents to set a few boundaries if needed.

Sounds like she just needs firmer boundaries/more rules/more instruction/to "know who's boss." Actually, research on trauma and our own experience with Luna show that this type of approach is like throwing gasoline on the fire of her nervous system's dysregulation. **We also use up capital needed for cooperation during the exam if we touch off a power struggle over something that could have been granted without compromising her care.**

Thanks for your commitment to high quality care!