

PFA Tips

Going to the Hospital

According to a study in the journal *Pediatric Emergency Care*, children on the Autism Spectrum are nine times more likely to visit an emergency room for mental health problems than their neurotypical peers, and were 20% more likely to be hospitalized for injuries than typically developing children. So how can we best prepare either for emergency or planned hospital visits?

Practice with toy doctor equipment

You can help familiarize your child with some of the equipment he or she will be exposed to in the hospital by playing “hospital” at home with a toy doctor’s kit. During your play, reinforce that doctors help us and make us feel better.

Fill out an Emergency Information Form ahead of time

Fill out an Emergency Information Form for Special Needs by American College of ER Physicians (see Additional Resources at the end of the article) during a non-crisis time and have copies available to take with you as needed. It might even be a good idea to keep a copy or two in the car. Another helpful tool is the *Grab and Go Emergency Book*. Also, bring a list of surgical procedures if the individual has a complex history.

Pack Ahead

If you have a planned hospital visit, or you have the benefit of time (a noncrisis emergency), you may want to pack a bag with the following:

- Medications – the hospital may not have the exact medication your child takes
- Favorite toy, fidget, or other comfort/sensory item
- Favorite blanket and pillow
- Favorite activity – music, headphones, movies, tablet, DVD player, books, toys, puzzles, etc.
- Loose fitting clothing and a change of clothes
- Communication device(s)
- Pull-ups/diapers, especially if the child is

between toddler and adult sizes

- Favorite snacks and drinks
- Chargers for electronic devices

For emergency trips, you may want to have a bag packed with essentials that’s ready to go.

Make arrangements for your other children

This might sound easier than it is. But the hospital might be upsetting to them, or they may react to the distress of your child being treated. Many hospitals will not allow siblings back in patient care areas and these restrictions may be more tightly enforced during the winter months (cold/flu season).

Ask your primary care doctor/ pediatrician to call ahead

It will most likely not benefit you to call the ER to say you are on the way. It may actually backfire on you as the ER staff may interpret this as your way to bypass their triage system. Rather, ask your child’s doctor to call-in the patient.

Advocate, advocate, advocate

No one knows your child better than you. You know your child’s triggers and calming strategies. You may need to request accommodations if you know that certain practices may escalate your child’s behaviors. For example, ask if your child can wear his own clothing if a gown or paper scrubs will send him into a meltdown. If you have concerns or questions, speak up.

Ask if the hospital has Child Life Specialists on staff

Child Life Specialists are pediatric health



care professionals who work with children and families in hospitals and other settings to help them cope with the challenges of hospitalization, illness, and disability.

Use visual supports

Pictures and visual tools can be great supports both for preparing for and during your hospital visit. Download *Visual Supports for Hospital Visits for PECS* symbols for common hospital terms, “How I feel,” and “I need help.” (See Additional Resources) Social stories can also help prepare a child for an upcoming hospital visit. Download the sample social story *Going to the Hospital*. This tool will be most useful if you can use pictures of your child. You can even request the local ER allow you to come and take photos to use for your book.

“It hurts this much”

We’ve all been asked to describe our pain on a scale of 1-10. During our normal course of teaching communication skills to our children, this scale likely doesn’t make the priority list. But it can be invaluable not only for use in the hospital, but at home with something as common as a headache.

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Practice this with each cut, scrape, ache, injury, and illness. Visit Visual Supports for Hospital Visits for a common Faces Pain Management Scale.

Ask for pain reducers

Talk with your doctor about the different options that may be available depending on your child's procedure. Topical (skin-based) medications are most suitable for numbing, such as an IV injection site. Oral medications can be used to reduce pain and anxiety. For longer or more painful procedures, you may want to discuss the possibility of partial or full sedation.

See if certain routine procedures can be done at the same time

Call your child's pediatrician and/or psychiatrist and state, "I am on the way to an ER for _____. Are there any labs he/she needs, any immunizations, or anything else that needs to be done that may require sedation?" You might even think to take scissors to clip nails/toenails while under sedation.

Request earlier morning procedures if anesthesia is used

If an individual is having anesthesia (for

surgery, MRI, etc.), they will be required to fast (typically eight hours for solids, four for clear liquids). Request early morning surgery and explain why. Most surgical times are arranged by age, with youngest first. That can make for a long day if missing both breakfast and lunch, and ramp up anxiety and behavior.

Take care of YOU

You can't be at your best, or be the best help to someone else if you don't take care of you. Take breaks, even if it's just routine visits to the cafeteria. If you are looking at an extended stay, create a family relay team so you can do shift rotations. And make sure you bring YOUR comfort items – book, tablet, music, chargers, etc.

Crisis Intervention

If you enter the ER for behavior crisis, your child will first need to be medically cleared before seeing a psychiatrist. If the plan for your child is inpatient placement, understand that this can be a long process as there can be a wait time of days for a bed to become available. Your child will be asked to change into paper scrubs for safety, and may be placed in a locked unit, especially if there is a flight/elopement risk.

The admitting physician or psychiatrist may use medication to try and calm your child's behavior.

Additional Resources

Emergency Information Form for Special Needs by American College of ER Physicians <http://pathfindersforautism.org/wp-content/uploads/2017/01/Emergency-Information-Form-for-SpecialNeeds-by-American-College-of-ER-Physicians.pdf>

Grab and Go Emergency Book by the Louisiana Office for Citizens with Developmental Disabilities and modified by The Arc of Frederick County <http://pathfindersforautism.org/wp-content/uploads/2017/01/Grab-and-Go-Emergency-Book-from-The-Arc-Frederick.pdf>

Visual Supports for Hospital Visits for PECS symbols <http://pathfindersforautism.org/articles/healthcare/visual-supports-for-hospital-visits/>

Going to the Hospital social story <http://pathfindersforautism.org/wp-content/uploads/2017/01/sample-social-story-going-to-the-hospital.pdf>

Autism and Hospital Visits: How to Prepare Your Child or Support Your Staff to Improve Outcomes <http://www.rchsd.org/documents/2015/03/autismspeakstoolkit.pdf>

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