

Taking the Work Out of Blood Work: Helping Your Child with an Autism Spectrum Disorder

A Parent's Guide

INTRODUCTION TO AUTISM SPECTRUM DISORDERS (ASD)

The purpose of this pamphlet is to present ways for you and your child to cope with the stress and worry that may come with blood draws. It provides strategies to make these appointments go more smoothly. Although completing blood draws with children with ASD is the main focus, the information and techniques presented here also apply to other aspects of a clinic visit.

These may be helpful for individuals of any age or with other conditions. For more detail, examples, and printable tools, visit kc.vanderbilt.edu/asdbloodwork/

What Are Autism Spectrum Disorders (ASD)?

ASD are a group of developmental disabilities that affect the brain. They make communicating and interacting with other people difficult. Because ASD affect people differently, they are referred to as “spectrum disorders.” They can range from mild to severe. Not everybody with ASD has the exact same symptoms or the same skills.

All people with ASD are likely to experience challenges in three main areas:

- **Communication.** People with ASD may have absent or limited speech. If they have speech, they may use it to recite or repeat words. They may have limited ability to use words to convey their wants or needs and limited ability to use them in conversation and social interaction.
- **Social Interactions.** Persons with ASD usually have trouble with social interactions. They may have difficulty understanding social cues, such as tone of voice or facial expressions. They may also have a difficult time maintaining eye contact.
- **Play and Routines.** Individuals with ASD are likely to engage in repetitive behaviors. Routines are also important and may play a role in daily activities. Another characteristic of ASD is what some describe as “sensory overload.” For these individuals, sounds seem louder, lights brighter, or smells stronger.

TIPS TO HELP YOUR CHILD HAVE A SUCCESSFUL BLOOD DRAW

Before The Visit

- 1) **Discuss what will happen** using words and pictures that your child can understand.
- 2) Try to **avoid focusing on the most unpleasant/painful aspects** before the visit if it will make your child more anxious.
- 3) **Talk with your child's providers** before the visit. Ask what they can do to make the blood draw go more smoothly, such as requesting a certain time of the day, assuring no wait time, completing multiple blood draws at one time, or scheduling with someone familiar with ASD.
- 4) Plan to **bring toys or visual supports** that you use every day to help your child remain calm and happy.

During The Visit

- **Share your suggestions** with medical staff.
- **Remain calm and reassuring.** Controlling your expressions and emotions will help your child do the same.
- **Resist the “white lie.”** If your child asks, say it may hurt. It is better to prepare your child than to say it will not hurt if it could hurt. You could describe a needle for a blood draw as a “strong pinch.”
- **Explain what is happening** in simple, direct language.
- **Acknowledge feelings, but avoid long conversations** and avoid using words like “scared” or “worried.”
- Help your child **see medical staff as helpers.**
- Allow your child **time to explore** certain items that they may have a strong reaction to before it has to be used. For example, allow them to see what the alcohol smells like, what the texture of the tourniquet feels like, etc.
- **Prioritize what you need to accomplish** during the visit. Focus on what is most important to complete.
- When possible, **provide choices** to help your child feel more in control. For example, let your child pick where to sit, the color of a bandage, or a reward to follow the visit.
- **Praise your child's** ability to complete the visit. Praise specific compliant behaviors.

RELAXATION AND DISTRACTION FOR CHILDREN WITH ASD

Why Do Relaxation And Distraction Matter?

When children with ASD think about going to the doctor, many become worried about the visit. You can help by teaching your child simple relaxation techniques.

Distraction may help by taking your child's mind off stressful events, thoughts, or emotions and putting attention on positive thoughts or activities.

Strategies For Relaxation And Distraction During Blood Draws

- 1) **Deep Breathing.*** Teach your child to take a deep breath, hold the breath for a few seconds and then release it. For young children, using a pinwheel or bubbles to practice can help them focus on their breathing and distract from their stress.
- 2) **Muscle Tensing.*** Have your child relax by focusing on different muscles of the body and alternately tensing and relaxing them one at a time.
- 3) **Visualization.** Encourage your child to imagine something pleasant and to visualize that scene with eyes closed. Suggest thinking about smells, sounds, and touch of what is imagined. Using pictures or objects to remind your child of favorite places or activities can help this strategy be more successful.
- 4) **Favorite Toys/Activities.** Involve your child in distracting activities before the procedure begins and, if possible, before your child begins to become upset. Use a favorite toy, a particularly engaging topic of conversation, or a game that does not require movement.
- 5) **Music.** Play your child's favorite music or sing a silly song.
- 6) **Laughter.** Find ways to make your child laugh.

*If your child has lost consciousness during prior blood draws, check with your physician before using deep breathing or muscle relaxation.

Tips For Using Relaxation And Distraction

Parents may find that typical approaches to using relaxation are not always effective for children with ASD. Certain changes can be made in order to effectively use these strategies with your child:

- 1) **Practice makes perfect.** Try to teach relaxation strategies at scheduled times in the day instead of when your child is already anxious. Reward your child immediately after practicing relaxation. This encourages continued practice and adds another positive connection with relaxation. Later when you use these strategies because your child is worried, he or she will connect it with something positive. Your child will trust that something good will follow, just as it has during practice sessions.

- 2) **Prevent instead of react.** Try to use these strategies before your child becomes worried, instead of only using them to calm your child down after becoming upset. It is best to use these beforehand (for example, at home before going to the doctor's office, in the car before going in to the office, in the waiting room) or when mild signs of anxiety are noticed.
- 3) **Use visual supports or concrete tools.** It is important to use visual supports (for example, pictures) or other concrete cues while putting relaxation strategies in place. Use them as a quick reminder to your child that it is time to use these strategies. This will be more helpful than trying to explain through talking.

VISUAL SUPPORTS FOR CHILDREN WITH ASD

What Are Visual Supports?

A visual support refers to using a photograph, drawing, object, or list to communicate with a child who has difficulty understanding or using language. Visual supports can be especially helpful when your child has to participate in medical procedures such as blood draws.

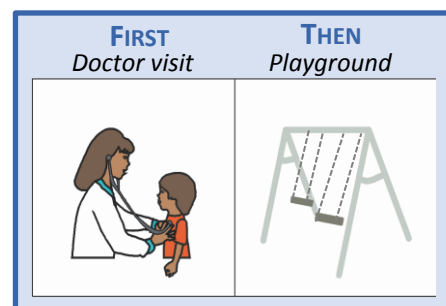
Why Are Visual Supports Important?

The main features of ASD involve challenges in interacting socially, in using language, and having limited interests or repetitive behaviors. Visual supports help in all three areas before, during, and after blood draws or other medical procedures.

Two kinds of visual supports that might help your child with ASD more successfully complete blood draws are **First-Then Boards** and **visual schedules**.

First-Then Board

A First-Then board is a visual display of something preferred that will happen after completing something that is not as preferred. During blood draws, a First-Then board can help motivate your child to take part in an activity that is not enjoyable by clarifying a preferred activity that will occur after it is over.



Continued on the next page...

("First-Then" Board continued...)

To Create A First-Then Board:

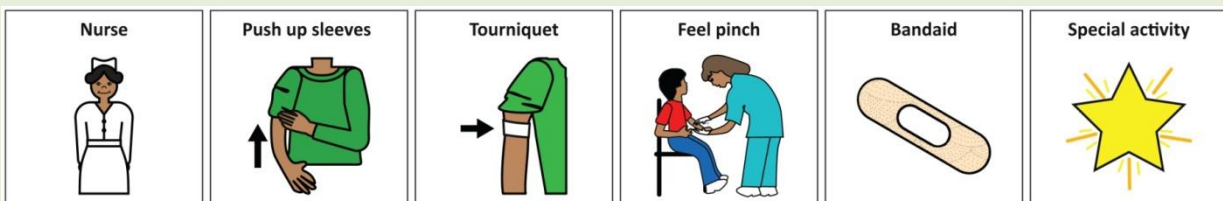
- 1) **Decide what task you want your child to complete** first (what goes in the "First" box) and the preferred item or activity (what goes in the "Then" box) that your child can have as soon as the "First" task is done.
- 2) **Put a visual on the board** for each "First" and "Then" activity. The board can refer to the general overall procedure ("First go to the doctor, Then playground"). The board can also refer to specific steps during the process that can each be paired with reinforcement. For example, "First sit in waiting room, Then lollipop." Next, change the board to "First take temperature, Then sticker" and so forth through the blood draw.
- 3) **Show the board to your child** with a very brief statement ("First sit in waiting room, Then lollipop") before starting the "First" task. If needed, refer to the board while your child is doing the task ("One more minute, Then lollipop").
- 4) **As soon as the "First" task is over, refer back to the board** ("All done with the doctor, now the playground!") and immediately provide access to the "Then" activity.

Visual Schedule

A visual schedule is a display of what is going to happen throughout the day or during an activity. A visual schedule is helpful during blood draws to decrease anxiety and difficulty with transitions by clearly letting your child know when certain activities will occur.

- 1) **Decide the activities that you will put on the schedule.**
Try to mix in preferred activities with non-preferred ones.
- 2) Put the **visuals that stand for the activities that you have identified on a portable schedule** (on a binder or clipboard) and bring it to the visit. The schedule should be available to your child from the beginning of the first activity. It should continue to be visible through all of the activities.
- 3) **When it is time for an activity** on the schedule to occur, let your child know with a brief verbal instruction before the next activity begins. When that task is completed, tell your child to check the schedule again and transition to the next activity. Some children may respond best when each task during the procedure is broken down in a detailed way. If this makes your child more anxious, a more general schedule might be better.

VISUAL SCHEDULE



- 4) **Provide praise and/or other rewards** for following the schedule and completing the activities. Put a preferred activity at the end of the schedule to give your child something positive to look forward to after completing all the items on the schedule.

SOCIAL STORIES™ FOR CHILDREN WITH ASD

What Is A Social Story™?

Many people with ASD benefit from having a written guide for situations that may be new, scary, or confusing. A Social Story™ is a helpful way to provide this guide for blood draws. A Social Story™ helps your child understand the situation and decreases anxiety that comes from entering an unknown situation.

Tips For Writing A Social Story™

- 1) Accurately describe the situation in detail. Focus on aspects of the situation your child may find difficult (for example, meeting new people, waiting, lights, smells).
- 2) Focus on important social cues, events that might occur, reactions that might be expected, and why the event is occurring.
- 3) Write from your child's perspective ("I will go to the doctor. I will...") or third person ("Kevin is going to the doctor. He will...").
- 4) Use positive, concrete language.
- 5) Do not write in absolutes. For example, instead of "The doctor will use cold spray on my arm," write "The doctor may put something on my arm to make it feel better."
- 6) Write the story specifically for your child and his or her experience with blood draws.
- 7) Some children may respond best to breaking down each task that will occur during the procedure in a detailed way. This may make other children more anxious and, for that child, a more general story might be better.

When To Read The Social Story™

If your child needs to know the details about the blood draw ahead of time to relieve anxiety, then have your child read the story a few days prior to the visit. Use this as a time to briefly answer your child's questions about the visit.

If reading the story ahead of time will make your child more anxious, wait until before the visit (for example, in the car on the way) or when you are at the appointment in the waiting. Have your child read the parts of the story that explain what is happening.

Social Stories™ were created by Carol Gray.
For more information www.thegraycenter.org

REINFORCEMENT FOR CHILDREN WITH ASD

Why Does Reinforcement Matter?

Because of the difficulties many people with ASD have with communication and social interactions, typical ways of using reinforcement may not work well.

It is important to use specific reinforcers when asking your child with ASD to participate in blood draws and when practicing strategies, such as relaxation. Doing this will help your child with ASD connect these activities with other enjoyable things. This may make the process less stressful for your child and will let your child know that his or her hard work will be rewarded.

Tips For Using Reinforcement During Blood Draws

- Choose a reward that your child does not always have available and is different enough to be motivating during something like a blood draw.
- If your child is undergoing several medical procedures, have a few different rewards so that your child remains motivated throughout the entire visit.
- Give reinforcement as soon as you can. If this is not possible, provide some type of visual way to let your child know that the reward is coming soon (for example, a picture of the activity, a token).
- Be clear about what the reward is and exactly what your child did to earn it (for example, sat still, walked in without help).
- Always follow through with providing the reward you promised.

What If Challenging Behaviors Occur?

Continue to focus on the task and praise the parts of the procedure your child is completing. Instead of shifting attention to the challenging behavior, provide a visual or a brief statement that tells your child what you would like for them to do (for example, “Hold your arm out”).

If you think challenging behaviors may occur, introduce your child to the strategies in this pamphlet before the visit and practice them during daily activities he or she enjoys.

REFERENCES AND RESOURCES

Want more tips for helping prepare your child with ASD for doctor’s visits? Below are some links and resources that might be helpful. Visit kc.vanderbilt.edu/asdbloodwork/ for more detail, examples, and printable tools!

- Allen, J., & Klein, R. (1996). *Ready...Set...R.E.L.A.X.: A Research-Based Program of Relaxation, Learning, and Self-Esteem for Children*. Watertown, WI: Inner Coaching.
- Culbert, T., & Kajander, R. (2007). *Be the Boss of Your Pain: Self-Care for Kids*. Minneapolis, MN: Free Spirit.
- Davis, M., Eshelman, E. R., McKay, M., & Fanning, P. (2008). *The Relaxation & Stress Reduction Workbook*. Oakland, CA: New Harbinger.
- Gray, C. (2010). *The New Social Stories Book* (10th ed.). Arlington, TX: Future Horizons.
- Gillis, J. M., Natof, T. H., Locksin, S. B., & Romanczyk, R. G. (2009). *Fear of routine physical exams in children with Autism Spectrum Disorders*. *Focus on Autism and Other Developmental Disabilities*, 24, 156-168.
- Huebner, D., & Matthews, B. (2005). *What to Do When You Worry Too Much: A Kid’s Guide to Overcoming Anxiety* (What to Do Guides for Kids). Washington, DC: Magination Press.
- Thorne, A. (2007). *Are you ready to give care to a child with autism?* *Nursing*, 37, 59-61.
- www.helpautismnow.com/going_to_the_doctor.html
- www.helpautismnow.com/blood_draw.html

RESOURCES ON AUTISM SPECTRUM DISORDERS

- www.autismspeaks.org
- www.autism-society.org
- kc.vanderbilt.edu

This publication was developed by Leadership Education in Neurodevelopmental Disabilities (LEND) long-term trainees Whitney Loring, Psy.D., Kristen Reeslund, Ph.D., Dwayne Dove, M.D., Ph.D., Michelle Reising, M.S., and Melanie McDaniel, B.A., and LEND faculty members Evon Batey Lee, Ph.D., Associate Professor of Pediatrics, Psychology, & Psychiatry at Vanderbilt University and Psychological Assessment Coordinator, Vanderbilt Kennedy Center, and Cassandra Newsom, Psy.D., Assistant Professor of Pediatrics & Psychiatry at Vanderbilt University and Director of Psychology Education, Vanderbilt Kennedy Center, The Treatment and Research Institute for Autism Spectrum Disorders.

It was edited, designed, and produced by Autism Speaks Autism Treatment Network / Autism Intervention Research Network on Physical Health and the Dissemination and Graphics staff of the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities. We are grateful for review and suggestions by many, including by families associated with the Autism Speaks Autism Treatment Network site at Children’s Hospital Los Angeles. This publication may be distributed as is or, at no cost, may be individualized as an electronic file for your production and dissemination, so that it includes your organization and its most frequent referrals. For revision information, please contact atn@autismspeaks.org.

These materials are the product of on-going activities of the Autism Speaks Autism Treatment Network, a funded program of Autism Speaks. It is supported by cooperative agreement UA3 MC 11054 through the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Research Program to the Massachusetts General Hospital. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the MCHB, HRSA, HHS. Printed August 2011.

 **VANDERBILT KENNEDY CENTER**
LEND—LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL DISABILITIES