Parent's Guide to Blood Draws for Children with Autism











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A Parent's Guide To Blood Draws for Children with Autism

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INTRODUCTION TO AUTISM SPECTRUM DISORDERS

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. Individuals with ASD may have absent or limited speech. If they have speech, they may use it to recite or repeat words. They would 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. People 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

- Discuss what will happen using words and pictures that your child can understand.
- Try to avoid focusing on the most unpleasant/painful aspects before the visit if it will make your child more anxious.
- 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, or scheduling with someone familiar with ASD.
- 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.
- 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

- 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.
- Muscle Tensing/Relaxing.* Have your child relax by focusing on different muscles of the body and alternately tensing and relaxing them one at a time.
- 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.
- 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.
- Music. Play your child's favorite music or sing a silly song.
- 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:

- 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 some-thing good will follow, just as it has during practice sessions.
- 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.
- 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 medical procedures such as blood draws.

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

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.

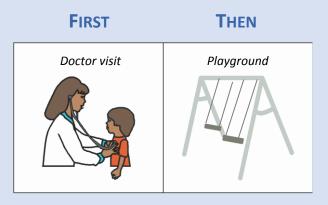
☐ First-Then Board

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.

- 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. 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").
- 2) 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.

First-Then Board

Feel pinch Play with cars



□ Visual Schedule

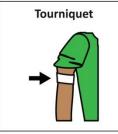
A visual schedule is a display of what is going to happen throughout the day or during an activity. A visual schedule is helpful during blood draws to decrease anxiety and difficulty with transitions by clearly letting your child know when certain activities will occur.

- 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.
- 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.

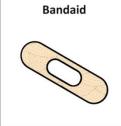
VISUAL SCHEDULE

















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.

☐ 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 just before the visit (for example, in the car on the way) or when you are at the appointment (for example, in the waiting room) to share the story. Have your child read the parts of the story that explain what is happening at each particular step during the visit.

Social Stories[™] were created by Carol Gray.
For more information visit 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 before the visit to practice strategies, such as relaxation, that will help. 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.

☐ 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 brief statements or a visual that tell 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.

> 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.

➤ Tips For Writing A Social Story[™]

- 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).
- Focus on important social cues, events that might occur, reactions that might be expected, and why the event is occurring.
- 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...").
- Use positive, concrete language.
- 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".
- Write the story specifically for your child and his or her experience with blood draws.
- 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.

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. Also, remember to visit our website at kc.vanderbilt.edu/asd bloodwork/ 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 Harbiner.
- 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 docto r.html
- www.helpautismnow.com/blood draw.html

RESOURCES ON AUTISM SPECTRUM DISORDERS

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

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Appendix

APPENDIX A: DEEP BREATHING

Instructions for Belly Breathing:

- 1. Get comfortable. Lie on the floor or sit up straight.
- 2. Put one hand on your chest and the other hand over your belly.
- 3. Breathe in through your nose, 1...2...3...4. When you breathe in, feel your belly rise like a balloon blowing up. Watch your hand on your belly rise, while the hand on your chest stays still.
- 4. Breathe out slowly through your nose 1...2...3...4. Feel your belly go back in, like a balloon deflating.
- 5. Keep breathing like this a few more times.
- 6. The more you practice...the easier it will become!

Giving your child a visual—like a picture to go along with belly breathing, blowing bubbles, or blowing a pinwheel—will help make practicing deep breathing more enjoyable and easier for your child to follow. This can also provide a distraction during stressful doctor's visits.

Blowing Bubbles

- This technique is simple, yet soothing. Have your child get comfortable (for example, lean back in a chair). Have your child first try blowing bubbles using quick, shallow breaths. Watch how the bubbles pop immediately.
- Now have your child practice blowing the bubbles using slow, deep breaths.
 The slower your child breathes out, the more bubbles he or she will make. Have your child focus on watching all the bubbles fall and repeat the process.

Pinwheel

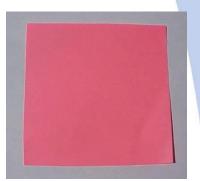
Have your child take a deep breath and blow out slowly on the pinwheel. See how long your child can make the pinwheel move – the longer he or she exhales, the longer the pinwheel will spin! Make your own pinwheel using the instructions on the following page.





APPENDIX B: MAKE YOUR OWN PINWHEEL

Step 1. To get started making your own pinwheel, cut a 4-inch x 4-inch square out of a piece of paper.



Step 2. Draw diagonal lines across your square to join up the corners. Then, mark the center of the square with a dot and draw an additional dot at each of the corners.



Step 3. Use a pair of scissors to cut along the diagonal lines. Then, use a hole punch or punch a hole through each of the dots.



Step 4. Line the dots on the outer edge of your pinwheel up with the dot in the center. Push a tack through the dots to hold everything together. Then, push the tack into the side of a pencil eraser or straw.



Your pinwheel is now ready to use!





APPENDIX C: MUSCLE RELAXING TRAINING SCRIPT FOR PARENTS TO USE WITH THEIR CHILDREN

When you feel tense, upset, or nervous, muscles in your body tighten. By practicing tensing certain muscles in your body, you will learn to relax them. Now get comfortable!



Hands and Arms: Squeeze a Lemon

Pretend you have a whole lemon in each hand. Now squeeze it hard. Try to squeeze all the juice out! Feel the tightness in your hand and arm as you squeeze. Squeeze hard! Don't leave a single drop. (Hold for 10 seconds.) Now relax and let the lemon drop from your hand. See how much better your hand and arm feel when they are relaxed.



Arms and Shoulders: Stretch Like a Cat

Pretend you are a furry, lazy cat and you just woke up from a nap. Stretch your arms out in front of you. Now raise them way up high over your head. Feel the pull in your shoulders. Stretch higher and try to touch the ceiling. (Hold for 10 seconds.) Great! Let them drop very quickly and feel how good it is to be relaxed. It feels good and warm and lazy.



<u>Shoulders and Neck:</u> Hide in Your Shell

Now pretend you are a turtle. Try to pull your head into your shell. Try to pull your shoulders up to your ears and push your head down into your shoulders. Hold it tight! (Hold for 10 seconds.) Okay, you can come out now. Feel your shoulders relax.

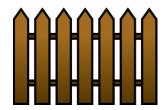


Back: Swing up High

Pretend you are on a swing at the park. Swing your upper body back and forth, back and forth. To get really high, use your arms to help you swing! Keep swinging! (Hold for 10 seconds.) Great. You're all done on the swing. Sit back and relax.







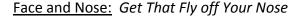
Stomach: Squeeze through a Fence

Now pretend that you want to squeeze through a narrow fence. You'll have to make yourself very skinny if you're going to make it through. Suck your stomach in, try to squeeze it against your back bone. Get it real small and tight. Hold it as tight as you can! (Hold for 10 seconds.) Okay, you've made it! You got through the fence. Settle back and let your stomach come back out where it belongs.



Jaw: Chew that Carrot

Now, pretend that you are trying to eat a giant, hard carrot. It is very hard to chew. Bite down on it. As hard as you can. We want to turn that carrot into mush! Keep biting. (Hold for 10 seconds.) Good. Now relax. You've eaten the carrot. Let yourself go as loose as you can.



Here comes a pesky old fly and he has landed on your nose! Try to get him off without using your hands. Wrinkle up your nose. Make as many wrinkles in your nose as you can. Scrunch up your nose real hard and hold it just as tight as you can. Notice that when you scrunch up your nose, your cheeks and your mouth and your forehead and your eyes all help you and they get tight too. (Hold for 10 seconds.) Good. You've chased him away. Now you can just relax and let your whole face go smooth.



Legs and Feet: Squish your Toes in the Mud

Now pretend that you are standing barefoot in a big, fat mud puddle. Squish your toes down deep into the mud. Try to get your feet down to the bottom of the mud puddle. You'll probably need your legs to help you push. Squish your toes down. Push your feet, hard! (Hold for 10 seconds.) Okay, come back out now. Relax your feet, relax your legs, and relax your toes. It feels so good to be relaxed. No tenseness anywhere. You feel warm and tingly.





APPENDIX D: MUSCLE RELAXING PICTURE CHARTS

Squeeze a lemon	Stretch like a cat	Chew that carrot
		Salar
Hide in your shell	Swing up high	Squeeze through a fence
Get that fly off your nose	Squish your toes in the mud	Relax
your mose	in the made	





APPENDIX E: IDEAS FOR DISTRACTION

Characteristics of Good Distraction Supplies:

- Familiar to child or something you know that they like
- Something stimulating and novel
- Portable
- Allowed in hospital or clinic rooms
- Can be used with minimal movement by child (and with one hand, if possible)
- Able to sustain child's attention.

Tips:

For medical appointments involving blood draws, the following distraction tools may be helpful:

- Sensory objects to put near the site of the blood draw (for example, cold pack, vibrating toy)
- Ask your doctor about availability of EMLA cream or sprays (which numb pain)
- Some hospitals or doctors' offices will have additional, specific tools for blood draws, for example, "Buzzy" (buzzy4shots.com)

Examples of Good Distraction Supplies:

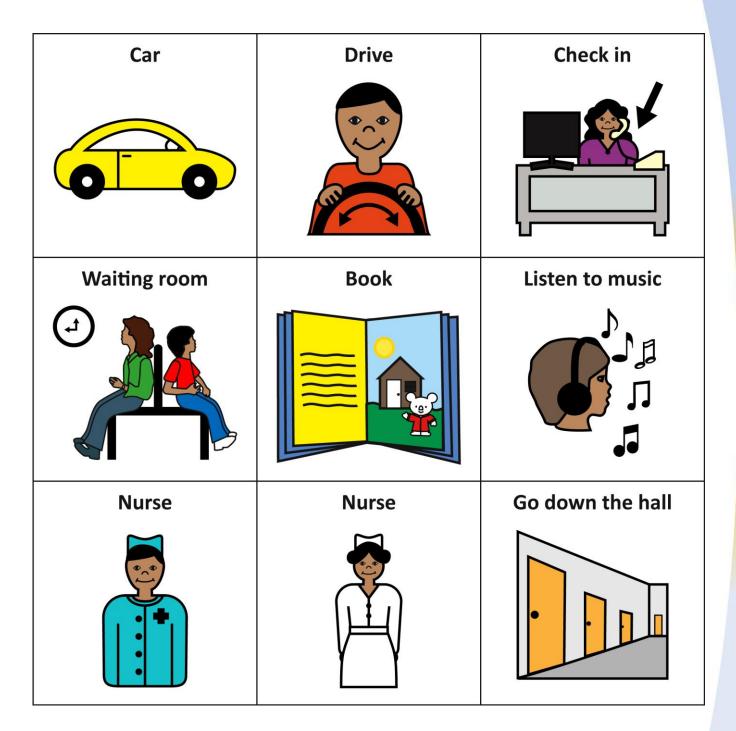
- Portable device to play videos or music that the child likes
- Games that require little or no movement that the child likes (for example, Paper, Rock, Scissors)
- Laughter (for example, a game where you think of different types of laughter and imitate what they might sound like)
- Favorite toys or stuffed animals that can sustain their attention
- Toys that are visually stimulating (for example, toys that light up, pin wheels, colorful toys)
- Tactile toys or objects (for example, toys with interesting textures, stress squeeze balls, toys that vibrate)
- Novel toys that are visually interesting, make innocuous noise, or are tactile (for example, rain sticks, glow sticks, relaxation toys, bubbles)
- Relaxation techniques (for example, deep breathing or progressive muscle relaxation) also can be distracting. Just be sure to check with the health care provider that these techniques are safe and appropriate to use during your child's medical procedure.
- Topics of interest to your child. Often children with ASD will have a restricted interest. Engaging the child in conversation about this topic can be distracting (for example, trains, elevators, or a particular television show or movie).





APPENDIX F: VISUAL SUPPORTS

Here are some pictures you might find helpful to use with your child before and during a blood draw as part of their visual schedule or first-then board.













Squeeze ball	Feel pinch	Cotton balls
Cotton ball on arm	Bandaid	All done
Нарру	Doctor visit	Keep arms at sides
Blood pressure	Please wait	Doctor visit

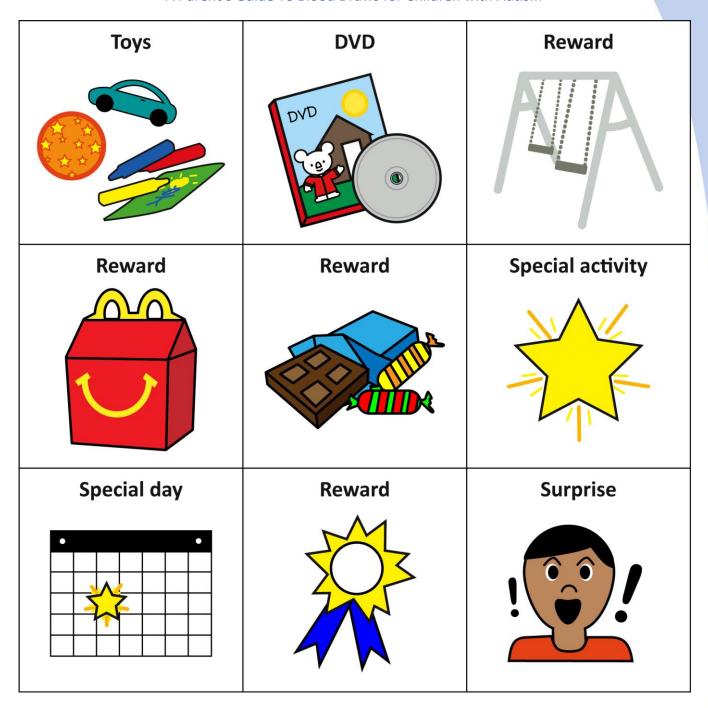


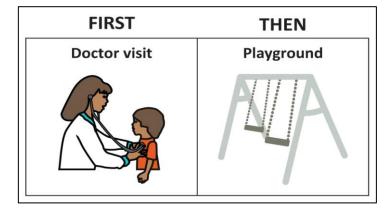


Laugh	Pinwheel	Change channel
Take deep breath	Belly breathing	Stretch
	→	
Think	Blow	Blow bubbles













APPENDIX G: SAMPLE SOCIAL STORY TM

For children with lower reading levels, consider using short, descriptive sentences when creating a Social Story™.

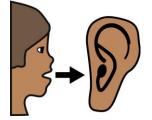
An example of a Social Story™: Going to the Doctor



I am going to the doctor. The doctor keeps me safe and helps me when I am sick.

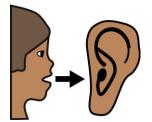


I may have to wait with my _____ (mom, dad, etc). I can play with my _____.





When I am with the doctor, I will try to listen and sit in my chair.





My mom will be happy if I listen and have nice words and hands.





When the doctor is all done, I get my reward.





A Parent's Guide To Blood Draws for Children with Autism

An example of a Social Story $^{\mathrm{IM}}$ for older children: Getting My Blood Taken

I am going to the doctor. People go to the doctor for lots of reasons. Sometimes, people go to the				
doctor when they are not sick. When I get to the doctor's office, I may have to wait my turn. While I				
am waiting, I can (talk to my mom, watch TV, read a book, or think about something				
else, etc.). When it is my turn, a nurse may call my name. A nurse is someone who helps the doctor.				
I will go with the nurse into another room. This is a safe thing to do and my (mom, dad,				
etc.) can come in with me. The nurse may ask me to answer a question and follow her directions.				
The nurse will like it if I listen. I will try to follow her directions and stay calm. My				
(mom, dad, etc.) will be very proud if I listen to the nurse and do what the nurse says.				
Sometimes the nurse needs to take some of my blood to make sure I am healthy. I can give some				
blood away because I have lots of blood in my body. The nurse may ask me to push up my sleeve				
and may put a band around my arm. The nurse may also spray something on my arm or use other				
things to make it feel better. The nurse will use a needle to take blood from my arm. The needle				
may feel like a pinch. I will try to stay very still while the needle is in my arm. This is the safe thing to				
do. While the nurse is doing this, I can (talk to my mom, look at my book, or think				
about something else, etc.). The needle will come out of my arm when the nurse is finished. After				
that, the nurse may put a cotton ball and bandage on my arm. When the nurse is finished, I can				
have (reward). My mom and dad will be very proud of me for sitting still and				
staying calm!				



