

Explain Briefly and Simply.

- Explain briefly and simply while proceeding calmly with the procedure.

Beware!!

- When anxious, individuals with Autism can exhibit aggressive behaviors toward objects, themselves or others such as hitting, biting, head butting, scratching, kicking, etc.
- Tantrums can include damaging equipment, screaming, falling to floor, etc.
- Notify other staff to be prepared to assist as needed.

Your Next Patient Has Autism...

A practical guide for the health practitioner for effectively meeting the special needs of patients with disorders on the Autism Spectrum



Developed by the Autism Steering Committee, North Shore-LIJ Health System
www.northshorelij.com/autism

AUTISM IS....

Autism is a severe developmental disorder of neurobiological origin that begins in early childhood and results in seriously impaired social interaction, communication and behavioral functioning. The following diagnoses all fall within Autism Spectrum Disorder:

- Pervasive Developmental Disorder (PDD)
- PDD NOS
- Childhood Disintegrative Disorder
- Autism
- Asperger's Disorder
- High Functioning Autism

Persons with Autism have significant difficulty understanding, sometimes resulting in inappropriate behavior. Unusual and challenging behaviors are often present, such as extreme reactions to minor changes, unusual sensitivities to particular sounds, sights or textures, compulsive routines and repetitive motor behaviors. Problems in communication, inflexibility and extreme sensitivity could make any encounter with a health care provider a challenge for both the patient and the provider. This brochure is intended to offer some quick suggestions for the practitioner and staff. For more information about Autism visit: www.northshorelij.com/autism

THE HEALTHCARE VISIT

It is essential that the health care team be creative, keep their sense of humor and, when possible, prepare in advance. Below are some steps to follow to make an office visit a success for a child with Autism.

- **Assessment/Parent Interview.** A 15- or 20-minute phone conversation before the visit could make all the difference.
- **Consult** with the parents or caregivers for tips that work. They are your greatest allies and the best experts on this particular child. Questions to ask include: What is the child's response to crowds? Is the child verbal? How much language does the child understand?
- **Planning,** based on this child's strengths and sensitivities. For example, a quiet waiting area for a child who is sensitive to noise, or a particular reward on hand that is familiar to this child.
- **Be familiar** with behavioral protocols to increase compliance: modeling, rewards and shaping for example, and know which ones are used with this child at home and school.
- **Implement** the plan you have so carefully worked on with all staff and the patient's parents or caregivers.

Assessment can be done over the phone, with the parent, for 15 or 20 minutes the day before the visit. Ask about the child's strengths, limitations and previous experiences with similar appointments. Ask what has worked in the past.

Make a plan for how the visit will be handled by the providers. Decide where the patient will wait, how the wait can be minimized or eliminated altogether, what procedures will need to be done, who will do the procedures, and what behavioral techniques will be employed, if any, to make it easier for the patient to comply.

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Modeling and rewards are two simple behavioral techniques that are easy to implement in clinical practice. Modeling, or imitation, is simply providing an example of the behavior you would like the child to perform. When the child performs the behavior, after following your model, you would reward him or her with a reward you have previously discussed with the parent during your assessment. This reward may simply be verbal praise, but if it is a food item that the child likes, remember to ask the parent to bring it to the appointment. You are unlikely to have a particular brand of snack food available, and these patients sometimes have very particular wants.

Suggested strategies and behavioral techniques are described below. In addition, your patient's treatment team may be able to provide more specific recommendations.

Measurements	Choice, Distraction, Imitation, Rewards, Visuals, Easy/Then Difficult Request
Heart, Lung, Abdomen	Choice, Distraction, Imitation, Rewards, Visuals
Eye Exam	Choice, Distraction, Imitation, Rewards, Visuals, Easy/Then Difficult Request
Ear, Nose, Mouth Exam	Choice, Distraction, Imitation, Rewards, Visuals, Easy/Then Difficult Request, Body Hold Techniques
Painful Procedures (e.g. venipuncture)	Distraction, Imitation, Rewards, Visuals, Body Hold Techniques
Temperature	Choice, Distraction, Imitation, Rewards, Visuals, Easy/Then Difficult Request
Reflexes	Choice, Distraction, Imitation, Rewards, Visuals, Easy/Then Difficult Request
Blood Pressure	Choice, Distraction, Imitation, Rewards, Visuals, Easy/Then Difficult Request

Techniques to use with patients who have disorders on the Autism Spectrum:

Choice

If possible, offer a choice; for example, "Would you like me to look in your right ear or your left ear first?"

Distraction

Questions: Ask questions about things they might logically be interested in, like pets or other family members. If the child has a special set of interests, such as trains, ask the child to tell you about these.

Toys or Objects: Encourage the child to play with toys or objects they enjoy. Offer a safe object to explore.

Counting and Singing: If the child will count or sing, these are excellent distraction techniques. If the child is less related or has language difficulties, other techniques may be more appropriate.

Imitation and Role Modeling

Using a doll and other objects to represent the patient and medical apparatus, the child could be reassured about the procedure and given mastery over it. For instance, a pen could stand for a syringe and a vaccination could be modeled using the pen and the doll. Then the child could give a "vaccination" to the doll, and then the clinician could give the actual vaccination to the patient. This is an effective technique, particularly if the child has a tendency to imitate already.

Rewards

Reward the child for complying with a request. **Do not assume** you know what is rewarding to the child. Children with Autism or a disorder on the spectrum may find upsetting what other children find rewarding. Ask the parent or caregiver what is rewarding to this particular patient. Reward any attempt at the behavior you are asking for from the child, and ignore any behavior that makes the target behavior impossible.

Easy Request, then Difficult Request

Ask the child to do something you know she/he can do and is willing to do before you ask for a more difficult behavior. For instance, say to the child, "Show me your ears," if you are sure the child can do that. Then follow with your request, "Open your mouth and stick out your tongue."

Visuals

Since some children with Autism or disorders on the spectrum have language difficulties, the procedures could be explained to them using pictures showing what will happen and what will be expected of them. This is particularly effective if the child is already used to communicating through pictures.

Body Hold Techniques

Many parents or caregivers are already well trained in these techniques, and will know what techniques work well with their child. They can be enlisted for those procedures where the child needs to be immobilized.

Pain Management

Offer analgesia such as EMLA cream for venipuncture or injections; this requires 45 minutes for maximum effectiveness. Offer distraction, i.e. cover with shirtsleeve to prevent child from removing.

Remember

Waiting is the Hardest Part of the Visit!

- Minimize waiting: Try to perform procedure/visit immediately without wait.
- If impossible, allow parent to leave area and notify them when to return.

They have EXCEPTIONAL Memories.

- A good experience will result in more cooperation at the next visit; a negative one will make future visits very difficult!

The Parent Knows Best!

- Always ask what works best and what to avoid.
- Ask about social, communication, behavioral abilities/limits, sensitivities (sound, touch, smell, etc.), response to anxiety, previous similar experiences and what has worked.
- Use parents' approach as a guide when interacting; encourage their participation.
- Parents have tremendous daily struggles; be kind and supportive.

Accepting Attitude is Critical.

- Bend down to speak with child.
- Be prepared to work from floor, parent's lap or wherever child seems comfortable.
- Use gentle tone of voice; minimize words and touch; respect their individual personal space (it is likely wider than yours); expect no eye contact.
- Allow child to touch and hold equipment whenever possible; use a second set to perform the procedure.

Adjust the Physical Environment Whenever Possible.

- Lower lights if light-sensitive.
- Lower volume on overhead page speaker.
- Substitute cloth sheet or drape for paper on exam table.
- Remove white lab coat whenever possible.

Focus on the Positive.

- Compliment child for all cooperative behavior.
- Ignore behaviors that appear odd (e.g., unusual vocalizations or body movements).