

Family Tip Sheet: For Families of Children with Autism Spectrum Disorders

Eleven Great Ideas to get the Best from Your Child's Health Care Visit



Oregon Family to Family
Health Information Center
www.oregonfamilytofamily.org

Before the Visit:

1. Make sure you have a comfortable working relationship with your child's health care provider. Does your child's doctor:

- Fully explain treatment choices to you and check to make sure you understand?
- Provide you with written information when needed?
- Involve you in all decisions about treatment?
- Provide enough time to talk so you don't feel rushed?

It is ok if your doctor does not know everything about autism as long as he or she is willing to listen and work with you and is willing to learn.

2. Be a good health care consumer and advocate for your child by:

- Speaking up at appointments. Don't exaggerate symptoms, but don't be afraid to tell your provider the truth about what your child is experiencing, even if it is embarrassing or seems silly.
- Asking questions and asking again until you understand the answer.
- Sharing your child's and family's service and support needs. For example, if transportation to therapy is a problem, say so.
- Discussing any disagreements you may have. If you and your child's health care provider disagree, work to negotiate a mutually acceptable compromise.
- Sharing your family's medical history honestly, including any mental health or substance abuse issues that you feel are relevant.

3. Know what works best for your child in a health care visit and ask for them. Some things to consider:

- The time of day and length of appointments. For example, does your child do better in the morning or afternoon?
- Waiting time. What might the office staff expect if the wait time exceeds your child's ability to manage it?
- Your child's sensitivity to lighting, sound or touch. For example, if you know your child cannot manage with bright lights, ask the provider to dim them.

Don't feel like you have to come up with all of the ideas yourself. Ask the staff what options or suggestions they may have if things get tough.

4. Develop a care notebook to keep track of information about your child and show it to your doctor:

- Invite your doctor to brainstorm ways that the two of you should use it together.
- Along with a written notebook, find out from your physician if your child has an Electronic Health Record and find out how it works.
- Find out from your doctor what the plan is in the event that your child needs to go to the emergency room. How will the emergency room physicians know the details of your child's special needs? The care plan also may include information for emergency room (ER) staff in case your child needs emergency care. ER staff will need to know the most likely health issues that would require emergency care, your doctor's recommended treatment, how best to communicate with your child, and any special issues such as your child's sensitivities to light, sound or touch.

5. Prepare your *child*:

- Construct a social story about visiting the doctor. (Carol Gray's social stories, www.thegraycenter.org/social-stories)
- Use a picture schedule. (www.handsinautism.org)
- Visit the office before the appointment so he or she will not be surprised or anxious.
- Role play parts of the exam such as using the stethoscope and looking in the mouth.
- Reward your child generously for a successful visit, but never use a punishment for when the visit doesn't go well. (Example: If your child likes stickers of a certain kind, slip them to the doctor or staff so THEY have a reward you know your child will like. Or, stop somewhere on the way home like the park, or for ice cream as a reward)
- Read a story together about visiting the doctor.
- Don't talk too frequently about the upcoming visit.
- Refer to your child's doctor in a positive way when your child can hear you. Mention things like "Dr. Jones took good care of your dad when he was little." Or "I heard Dr. Jones likes to ride horses like you." Never say anything about the provider or the office that might make your child afraid.

6. Prepare *yourself*:

- Bring toys and visual supports from home as needed.
- Bring any adaptive equipment your child uses; for example, glasses or a communication device.
- Write down the questions you would like answered at that visit.
- Bring your care notebook, school information and reports from specialists.
- Make sure the office staff know how best to communicate with you and your child. For example, do you need an interpreter or does your child use augmentative communication.

7. Prepare the *health care office staff*:

- Remind the receptionist your child has an ASD.
- Check to see if they know and have addressed your/your child's special needs for the appointment.

During the Visit:

8. Mention any concerns you have about safety, such as:

- Running away or night time wandering.
- Inability to follow your instructions like “come here,” or “stop.”
- Refusal to ride in car safely.
- Aggression to siblings, parents, pets or others.
- Self-injurious behavior such as skin picking, head banging, etc.
- Attraction to unsafe activities or places such as swimming pools, fences, or animals.
- Attraction to unsafe people such as bullies or “friends” who might victimize.

9. Remember to ask about “regular” health issues such as nutrition and exercise.

Brainstorm activities that might be good for your child that typical children participate in such as swimming, gymnastics, ballet lessons, etc. Your physician can possibly write a letter of support for those activities if for some reason you meet resistance enrolling your child.

10. Mention any concerns you may have about your child’s mental or emotional health.

Children and youth with ASD, like other children, may experience depression, anxiety, or symptoms that are frightening to you, such as “hearing voices,” or experimenting with tobacco, drugs, or alcohol.

11. Talk with your provider about what you are reading on the internet.

- If you find something on the web you feel is relevant, bring in a copy for your doctor to look over. Keep an open mind about what is on the web, but always be cautious.
- Ask your provider to recommend websites he or she finds helpful.

Find more tips to help make sure your office visit is successful:

- <http://www.ohsu.edu/xd/outreach/occyshn/programs-projects/upload/TipsForSuccessfulHealthcareVisitForCYSHCNandFamilies.pdf>
- family toolkit at www.handsinautism.org

Helpful community services:

- supplemental security income (SSI) from the Social Security Administration (<http://www.ssa.gov/applyfordisability/child.htm>),
- Developmental Disabilities services (<http://www.oregon.gov/DHS/Pages/ddeligibility/home.aspx>),
- medical transportation for children on the Oregon Health Plan (<http://www.dhs.state.or.us/policy/healthplan/guides/medtrans/main.html>),
- and adaptive recreational programs (<http://www.eugene-or.gov/index.aspx?NID=134> and <http://www.portlandonline.com/parks/index.cfm?c=39830>).