



A Guide for Medical Professionals: How to help a Patient with Autism Navigate a Healthcare Appointment Successfully

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Common Communication Challenges ASD patients Face when Navigating the Healthcare System:	What it May Look Like	How You Can Help
<p>Challenge 1: Difficulty grasping the main idea, making inferences, recognizing context & processing information</p>	<ul style="list-style-type: none"> ○ Patient may under-report or over-report symptoms <i>Example:</i> Patient may report their entire medical history during a COVID-19 check because they are unsure what details are important to report. ○ Patient may report irrelevant information for given context and/or patient may be unsure which medical provider to tell what information <i>Example:</i> Patient reports information to Physical Therapist that is more appropriate to tell an OB/GYN ○ Patient may have difficulty understanding the main idea of what you are trying to relay <i>Example:</i> Patient may not follow with recommendations or next steps because they are unable to organize all of the information that was shared during the appointment into a step by step plan ○ Patient may have difficulty processing all of the information you are giving them <i>Example:</i> Patient may yell at you or stare blankly because they are overwhelmed with the amount of information being presented. 	<ul style="list-style-type: none"> ● Ask specific questions related to the symptoms you need to know ● Limit verbal directions and explanations to the very important details ● Speak slowly ● Give lots of time to process what you say and respond to your questions ● Write down the main points of what you want your patient to know or do after the appointment. ● Ask patient to report back the important information shared and/or next steps that they need to take to ensure they understand your main points. ● Clearly define what new symptoms, side effects, etc. you need the patient to communicate to you after the appointment. ● Encourage patient to use alternative forms of communication (e.g., writing or



	<ul style="list-style-type: none"> ○ Patient may be very literal or define language/concepts more concretely. <i>Example:</i> You ask a patient, “How are you doing?” and patient answers, “OK” because they literally feel okay in that moment (even though they might be struggling with a health-related issue on and off prior to the appointment.) 	<p>texting) during the visit if they are struggling to give information verbally</p> <ul style="list-style-type: none"> ● Encourage communication after the appointment via the portal/email
<p>Challenge 2: Difficulty seeking clarification</p>	<ul style="list-style-type: none"> ○ Patient may have difficulty starting conversation when overwhelmed with processing lots of information. <i>Example:</i> Patient may look like they understand and/or say that they understand, but they don’t. ○ Patient may not realize they need clarification until they have time to process the appointment after the fact. <i>Example:</i> Patient is working hard at processing all of the information in the shared in the appointment and don’t realize that they need additional information until after the appointment. 	<ul style="list-style-type: none"> ● Speak slowly to give lots of time to process questions or instructions ● Limit extra verbal details ● Write down the main points of what you want your patient to know or do after the appointment. ● Ask patient to report back the important information shared and/or next steps that they need to take to ensure they understand your main points. ● Encourage communication after the appointment via email/portal.
<p>Challenge 3: Difficulty using verbal/nonverbal communication and/or uses ‘atypical’ body mannerisms to help them regulate</p>	<ul style="list-style-type: none"> ○ Patient may not use eye contact or other ‘typical’ nonverbal communication skills that traditionally demonstrate listening. <i>Example:</i> Patient needs to look away in order to process what you have to say (they can’t look at you and listen to you at the same time). ○ Patient may have ‘atypical’ mannerisms such as flapping, fidgeting, sitting/rocking in chair, pacing, etc. <i>Example:</i> Patient is using these mannerisms to help them regulate and participate in the appointment with you. 	<ul style="list-style-type: none"> ● Don’t assume the person is not listening, that they are angry/anxious, they don’t like you, etc. based on their body language. ● Allow patient to use regulation strategies such as pacing, rocking, etc. to help them participate during the appointment.



Common Sensory Challenges ASD patients Face when Navigating the Healthcare System:	What it May Look Like	How You Can Help
<p>Challenge 1: Patient may be over- or under-responsive to the sensory aspects of a medical appointment.</p>	<ul style="list-style-type: none"> ○ Patient may resist or refuse routine medical procedures/aspects of an exam because it is painful <i>Example:</i> Patient grows agitated at the sight of a blood pressure cuff because the feel of it is painful to their system) ○ Patient may have difficulty attending to what you are saying because they are bothered by sensations in the environment. <i>Example:</i> Patient may not answer your questions because they are so painfully overwhelmed by the fluorescent lights in the exam room. ○ Patient may appear detached or upset <i>Example:</i> Patient may be yelling when you enter the exam room because they are completely dysregulated and exhausted from the effort they expended to attempt to regulate amongst all of the sensory stimuli in the waiting room (overwhelmed by all of the other patients talking, the hum of the fluorescent lights, etc) ○ Patient might appear to not hear what you say even though you know their hearing is okay <i>Example:</i> Patient might be under-responsive to sound and not notice that their name is being called. 	<ul style="list-style-type: none"> ● Provide a quiet waiting space for the patient ● Examine the environment and limit any extraneous sensory stimulation while the patient is in your office (e.g., turn off overhead lights and use lamps/natural light; reduce any noise in hallways/nearby exam rooms, etc.) ● Make the sensory aspects of your exam as predictable as possible (e.g. tell the person what you are going to do...or even better write the steps down for them!). ● Give the person a signal that they can use to stop anything during the exam if it becomes too overwhelming ● Invite and/or encourage the patient to use sensory regulation strategies during your appointment (e.g., noise cancelling headphones, sunglasses, fidgets, etc.) ● For more information on how to support the sensory needs of your patient, please see handout: Sensory Stimuli That Can Be A Challenge for a Person with Autism
<p>Challenge 2: Difficulty with interoception and</p>	<ul style="list-style-type: none"> ● Patient has an unclear inner sensory experience 	<ul style="list-style-type: none"> ● Validate their health concerns. Even if they are unable to describe them, it



identifying/understanding their internal body sensations	<p><i>Example:</i> Patient reports feeling ‘off’ but can’t tell you where the feeling is coming from or what the quality of the feeling is</p> <ul style="list-style-type: none"> ● Patient does not notice internal body sensations until they are very severe <i>Example:</i> Patient has a severe injury or illness and did not seek medical care in a timely manner ● Patient is over-responsive to their internal sensations <i>Example:</i> Patient schedules frequent visits and has many medically unexplained symptoms ● Patient completely misses internal sensations that serve as important clues to their health and emotional experience <i>Example:</i> Patient is unaware of a critical physical or mental health issue that they may be experiencing 	<p>doesn’t mean that they are not sick/injured</p> <ul style="list-style-type: none"> ● Ask concrete questions related to changes in their habits or routines (rather than symptoms) such as have you noticed a change in your sleep or eating habits ● Extra testing may be needed if patient is unable to identify/describe symptoms ● Be aware that the patient may not feel pain in the traditional manner
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Additional Challenges ASD Patients face when Navigating the Healthcare System	What it May Look Like	How You Can Help
Challenge 1: Difficulty with changes in routine	<ul style="list-style-type: none"> ○ Patient may appear anxious, overwhelmed, frustrated, and/or non-compliant with your recommendations. <i>Example:</i> Patient failed to pick up their new prescription at the pharmacy because they are unsure of how to navigate the new routine. <i>Example:</i> Patient is irritable, short or shut down during appointment because the environment and appointment process is new and they are unable to predict what is going to happen during the appointment. 	<ul style="list-style-type: none"> ● Allow patient to see same provider each appointment ● If possible, follow the same routine each appointment ● If you see the patient on a repeating schedule, set the appointments at the same day/time ● Give a written notice regarding any changes as far in advance as possible



	<p><i>Example:</i> Despite the patient being a long-term patient, small changes such as rearrangements in the waiting room set-up or seeing a new provider can be very disorienting.</p> <p><i>Example:</i> Patient may refuse to eat, use the bathroom or participate in medical testing because their routine is disrupted and they unsure of the new routine.</p>	<ul style="list-style-type: none"> ● Give a written bulleted list of next steps in the order you need the patient to follow (e.g., steps to follow to pick up prescription at pharmacy). ● Provide a visual schedule
<p>Challenge 2: Difficulty with the unknown</p>	<ul style="list-style-type: none"> ○ Patient may appear anxious, overwhelmed, frustrated, and/or non-compliant with your recommendations. <p><i>Example:</i> Patient refuses to cooperate with a medical procedure because it is new and unpredictable.</p> <p><i>Example:</i> Patient yells or becomes violent with staff because they are unsure what is about to happen.</p> <p><i>Example:</i> Patient asks a lot of questions and may seem as if they are trying to challenge your expertise (why do I need to do that?), but they are trying to make sense of the unknown.</p>	<ul style="list-style-type: none"> ● Explain new symptoms to the patient and/or progression of an illness including the whys behind (e.g., why might the person feel tired) ● Explain to the patient what they might expect when taking a new medication/treatment ● Give a written bulleted list of next steps in the order you need the patient to follow (e.g., steps to follow to pick up prescription at pharmacy). ● Be patient