



## Office of Developmental Primary Care

Improving outcomes for people with developmental disabilities

# What I Wish My Doctor Knew About Me as a Person on the Autism Spectrum (Aspie)

### Medical Alert

- I'm sick. No small talk please.
- Face me, and talk directly to me
- Speak in a clear, direct way. I'm literal.
- Can I be in a quiet, dim room?
- Give it to me straight. Spare me the bull.
- Your perkiness isn't helping.
- I'm unique, not a child.

### Common Challenges Include:

- Overstimulation from travel, lights, sounds, unfamiliar people and feeling poorly.
- Sensory problems with identifying and reporting symptoms.
- Difficulty with communication with health care providers.

### Don't make small talk

Conversations take a lot of concentration – like talking in a non-native language. They don't put me at ease. Save talking for getting a history and negotiating a plan. Minimize distractions. Work silently when not interviewing me. Don't make jokes or use sarcasm, unless you clearly identify it.

### Talk Directly To Me

It helps if I can see your lips. If you don't look at me, I may not be able to tell if you're talking to me or to someone else. My expressions and body language aren't typical, but they are expressive. For example, it's OK to ask, "You tilted your head. What did that mean?" Three-way conversations are difficult. Until the conversation between us is complete, ask other people to be quiet. Allow silent pauses. They give me time to think. If I need more time, consider leaving the room and returning. Talk directly to me, but if I come with a Health Advocate listen carefully to them. Even if very verbal, many Aspies find it easier to communicate in writing. Offer options.

## Make Your Intentions Clear

I tend to interpret language very literally. I often have difficulty inferring the purpose of questions. Explain why you are asking, and share your reasoning. Be open to the possibility that your assessment might be wrong. Give me an opportunity to question it. Try to be as detailed, clear and unambiguous as possible. Check for understanding. Because many Aspie's are articulate and have good vocabularies, it may not be obvious that there is a communication barrier. For example, there are many interpretations of the sentence, "Take your medicine with meals." It is ambiguous how often to take the medication, what to do for snacks and what to do if meals are skipped or added.

## Can I Be In A Quiet, Dim Room?

Many Aspies have difficulty filtering sights and sounds or have specific sensitivities to smells, tastes or touch. Alarms and motor hums, strong visual contrasts such as bright lights and touch for physical exam can be painful or disorienting. Some of these can be very peculiar such as emotional responses to colors or sensitivity to the buzz and flicker of fluorescent lights. Sensitivities can range from mildly annoying to painfully intense. Warn and ask patients before touching them. Ask about how to accommodate individual sensory needs. Also, sensory issues can make it difficult for Aspies to identify and report symptoms.

## No Bull

Ask. Don't pretend to know or understand more than you do. Every Aspie is unique. Invite questions and suggestions. Learn more. If you need consultation, contact the Office of Developmental Primary Care in the UCSF Department of Family and Community Medicine.

## Your Perkieness is Not Helping

To communicate, most people rely heavily on body language, voice tone and facial expressions. Aspies often have difficulty interpreting these forms of communication. If the honest answer to, "And how are we today?" is "I feel like crap" then to an Aspie, the comment can just emphasize that you feel good and I don't. It can come across as not being concerned. From an Aspie's perspective, cheeriness is at odds with the hope that the professional is concerned about us, and gives the impression that the person making the comment is happy about our distress. Also, the atypical body language of Aspies can be misinterpreted as lack of attention, disrespect or malingering. Some Aspies may avoid eye contact, speak in monotone, or have a meltdown when over-stimulated or frustrated. Alternatively, some may become calmly analytical when in extreme pain or distress. Rely more on literal interpretations of verbal or written communication. For example, if we tell you that we are in extreme pain, believe us even if we don't jerk and wince.

## I'm Unique, Not A Child

Use your normal adult voice at a normal volume and rate. Language needs to be unambiguous, but not necessarily simple. It is not necessary to avoid technical language as long as it is defined. In fact, technical language can be helpful because it is precise. Open-ended questions can be difficult because there are so many possible answers. Pain scales are particularly difficult. Instead, ask specific questions such as, "Compared to this morning, over the past hour, is your pain the same, better or worse?" or "Do you want more or stronger pain medication?" Before treating, make sure I understand options and give my consent.

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