



PARENT MEDICAL GUIDE

Recognizing and documenting medical symptoms in autistic children

Autism Infectious Disease Alliance

aidaalliance.org

SECTION 1: PURPOSE OF THIS GUIDE

Although autism is currently defined by differences in social communication and behavior, autistic individuals commonly experience medical symptoms and conditions throughout the body.

This guide is designed to help you:

1. Learn about the types of medical symptoms and conditions commonly found in autism.
2. Identify symptoms, changes, and patterns in your child that may warrant further medical evaluation.
3. Look beyond behavior to consider whether pain, illness, inflammation, immune dysfunction, or another medical condition could be contributing to what you are seeing.
4. Consider the whole picture, including symptoms across multiple body systems, changes from your child's baseline, family medical history, and relevant exposures.
5. Prepare for an informed discussion with your child's healthcare provider about what you are seeing and what may warrant further investigation.

A diagnosis of autism should never end the search for medical explanations for new, worsening, or unexplained symptoms. Medical symptoms should be investigated and treated, not dismissed as "just autism."

SECTION 2: WHAT AM I SEEING IN MY CHILD?

Check any symptoms your child currently experiences or has experienced in the past. Use the space beside each symptom to briefly describe what you have observed. We will ask separately about symptoms that are new, worsening, or represent a change from your child's usual baseline.

Neuropsychiatric & Cognitive

- ☐ OCD or compulsive behaviors, repetitive thoughts, rituals, checking, washing, asking, or actions the child feels driven to do _____
- ☐ Severe anxiety or panic _____
- ☐ Irritability, aggression, or rage _____
- ☐ Rapid or extreme changes in mood or emotions _____
- ☐ Inappropriate laughing or crying, emotional expression that does not fit the situation _____
- ☐ New fears or separation anxiety _____

- ☐ Tics, sudden repeated movements or sounds such as blinking, head movements, throat clearing, or vocal sounds _____
- ☐ Brain fog, difficulty thinking clearly, processing information, remembering, or concentrating _____
- ☐ Loss of attention or concentration _____
- ☐ Decline in school or learning abilities _____
- ☐ Developmental regression, loss of previously acquired language, social, motor, toileting, or self care skills _____
- ☐ Changes in speech or communication _____
- ☐ Social withdrawal or loss of social engagement _____

Neurologic & Sensory

- ☐ Headaches or migraines _____
- ☐ Dizziness or balance problems _____
- ☐ New coordination or walking problems _____
- ☐ Tremors or unusual movements _____
- ☐ Seizures or seizure-like episodes _____
- ☐ Numbness, tingling, burning, pins and needles, or unexplained nerve pain _____
- ☐ Increased sensitivity to light, sound, touch, smell, or temperature _____
- ☐ Changes in vision or hearing _____

Sleep & Energy

- ☐ Difficulty falling asleep _____
- ☐ Frequent waking _____
- ☐ Restless or disrupted sleep _____
- ☐ Sleeping much more than usual _____
- ☐ Severe fatigue or reduced stamina _____
- ☐ Significant change in activity level _____

Gastrointestinal & Feeding

- ☐ Abdominal pain _____
- ☐ Constipation _____
- ☐ Diarrhea or loose stools _____
- ☐ Reflux _____
- ☐ Nausea or vomiting _____
- ☐ Bloating _____
- ☐ New or worsening food restriction _____
- ☐ Loss of appetite _____
- ☐ Difficulty chewing or swallowing _____
- ☐ Unexplained weight loss or poor weight gain _____

Pain, Joints & Connective Tissue

- ☐ Joint pain _____
- ☐ Muscle pain _____
- ☐ Bone pain _____
- ☐ Nerve pain _____
- ☐ Neck or back pain _____
- ☐ Foot, heel, or sole pain _____
- ☐ Joint hypermobility, joints that move farther than expected or being unusually flexible _____
- ☐ Frequent sprains, injuries, or joint instability _____

Dizziness, Heart Rate & Temperature Regulation

- ☐ Racing or pounding heartbeat _____
- ☐ Dizziness when standing, feeling lightheaded, weak, faint, or having a racing heart after standing

- ☐ Fainting or near fainting _____
- ☐ Unusual sweating _____
- ☐ Temperature dysregulation, becoming unusually hot or cold or having difficulty tolerating heat or cold

- ☐ Cold hands or feet _____
- ☐ Air hunger, feeling unable to get a satisfying breath or repeatedly needing to take deep breaths

- ☐ Unusual exercise intolerance _____

Skin, Allergy & Immune

- ☐ Unexplained rashes _____
- ☐ Unusual linear skin marks, unexplained red, pink, purple, or discolored lines or streaks that may resemble stretch marks

- ☐ Flushing _____
- ☐ Hives or itching _____
- ☐ Swollen lymph nodes _____
- ☐ Frequent or unusual infections _____
- ☐ Persistent fevers or unexplained temperature changes _____
- ☐ New or worsening allergic reactions _____

Urinary

- ☐ New urinary frequency _____
- ☐ Urinary urgency _____
- ☐ New bedwetting after previously being dry _____
- ☐ Daytime accidents _____
- ☐ Pain or difficulty urinating _____

Changes From Baseline

The three changes that concern me most are:

1. _____
2. _____
3. _____

These changes began around: _____

What was happening around that time?

☐ Infection or illness ☐ Medication change ☐ Vaccination ☐ Significant stress ☐ Environmental exposure ☐ Tick, flea, or animal exposure ☐ Other: _____

COULD MCAS BE CONTRIBUTING?

Does your child experience several of these symptoms?

Sensory sensitivities • brain fog or difficulty concentrating • irritability or anxiety • headaches or migraines • dizziness • GI problems, including abdominal pain, nausea, reflux, diarrhea or constipation • food reactions or intolerances • rashes, flushing, hives or itching • temperature intolerance • sleep problems • fatigue • racing heart or palpitations • urinary frequency or urgency • hEDS or joint hypermobility • POTS or symptoms when standing

If so, Mast Cell Activation Syndrome, MCAS, is an important condition to discuss with your child's doctor.

What is MCAS?

Mast cells are immune cells found throughout the body. They release substances such as histamine and other chemical mediators as part of the body's immune response.

In Mast Cell Activation Syndrome, MCAS, mast cells release these mediators inappropriately or excessively. Because mast cells are found throughout the body, MCAS can cause symptoms involving many different systems, including the brain and nervous system, gastrointestinal tract, skin, cardiovascular and autonomic systems, and respiratory system.

This is one reason symptoms that may appear unrelated, such as sensory sensitivities, GI problems, rashes, dizziness, brain fog, and irritability, may be important to consider together.

Having these symptoms does not mean your child has MCAS. They are a reason to discuss MCAS with a knowledgeable healthcare provider and determine whether further evaluation is appropriate.

SECTION 3: LOOKING BEYOND BEHAVIOR

Behavior Can Be Communication

For some autistic individuals, pain, discomfort, dizziness, nausea, fatigue, anxiety, or other physical symptoms can be difficult to recognize or communicate.

A new behavior, or a significant change in an existing behavior, may be one of the first signs that something is medically wrong.

Instead of asking only, "How do we stop this behavior?" also ask, "What could my child be experiencing that is causing this behavior?"

What Could the Behavior Be Telling You?

Head banging, self injury, hitting, biting, aggression, rage, or sudden irritability

Consider: Pain or physical discomfort, headache or migraine, ear or dental pain, GI discomfort, illness or infection, sleep disruption, anxiety, neuropsychiatric symptoms, or frustration from difficulty communicating pain, needs, or what the person is experiencing.

Refusing to walk, exercise, leave the house, or participate in activities

Consider: Pain or physical discomfort, fatigue, dizziness, headache, joint or muscle pain, foot or sole pain, exercise intolerance, shortness of breath, illness, anxiety, or difficulty communicating what feels wrong.

Food refusal or suddenly restricting foods

Consider: Abdominal pain, nausea, reflux, constipation, swallowing difficulty, dental pain, food reactions, sensory changes, ARFID, OCD or fear based compulsions.

Removing clothes, refusing certain clothing, scratching, or appearing unusually uncomfortable in clothing

Consider: Itching, rashes, hives, skin pain, flushing, temperature dysregulation, sensory discomfort, allergic or mast cell related symptoms, including possible MCAS.

Covering the ears or suddenly becoming much more sensitive to sound

Consider: Ear pain, headache or migraine, tinnitus, sensory changes, or mast cell related symptoms.

Becoming unusually hot or cold, removing clothes because of temperature, seeking cold or heat

Consider: Temperature dysregulation, autonomic dysfunction, illness or fever, or mast cell related symptoms.

Running around excessively, unusually high energy, frequent laughing or silliness, periods of behavior that seem unusually "amped up"

Consider: Sleep disruption, anxiety, ADHD symptoms, medication effects, neuropsychiatric changes, mood dysregulation or manic symptoms.

Refusing to shower, change clothes, wash, or complete other hygiene activities

Consider: OCD, contamination or germ fears, anxiety, sensory discomfort, pain, fatigue, executive functioning difficulties.

Sudden screaming, crying, prolonged distress, or episodes of being inconsolable, particularly when your child cannot explain what is wrong

Consider: Pain or physical discomfort, headache or migraine, ear or dental pain, abdominal or GI pain, urinary symptoms, illness or infection, anxiety, sensory distress, sleep disruption, or frustration from being unable to communicate what they are experiencing.

Becoming sluggish, withdrawn, unusually quiet, spending much more time alone or in bed, losing interest in favorite activities, or engaging much less with family and others

Consider: Anxiety or depression, fatigue, pain, sleep problems, illness, brain fog, medication effects, or other medical or neuropsychiatric changes.

Loss of skills or regression

Requires medical evaluation. Consider neurologic, immune, inflammatory, infectious, metabolic, sleep related, or other medical contributors. Neuroinflammation may not be visible on routine structural imaging such as MRI or CT, so normal imaging does not by itself exclude an inflammatory process.

Nonspeaking or difficulty getting words out despite appearing to know what they want to say, clumsiness, difficulty initiating movements, or difficulty performing purposeful movements

Consider: Apraxia or motor planning difficulties, including more generalized motor impairment. Also consider neurologic symptoms such as numbness, weakness, coordination problems, or other motor dysfunction.

Toe walking, suddenly avoiding putting the whole foot down, or walking differently

Consider: Sensory or motor differences, tight muscles or tendons, orthopedic issues, pain, including possible nerve pain or pain in the feet or soles.

A Behavior Should Not End the Medical Investigation

Behavior is something we observe. It does not tell us why it is happening.

When behavior changes, particularly when it changes suddenly, becomes severe, occurs with regression, or appears alongside other physical or neuropsychiatric symptoms, consider whether there could be an underlying medical explanation.

Medical symptoms deserve medical investigation, even when a child cannot describe what hurts or feels different.

SECTION 4: LOOK AT THE WHOLE FAMILY

Your Family's Health History May Provide Important Clues

When looking for possible underlying medical conditions in an autistic child, it can be helpful to look beyond the child. This information may be particularly useful when working with a functional, integrative, or other clinician taking a broader medical history.

Check anything that has occurred in parents, siblings, grandparents, aunts, uncles, or other close relatives. Write who experienced it on the line.

Autoimmune, Immune & Inflammatory Conditions

- ☐ Autoimmune thyroid disease _____
- ☐ Rheumatoid arthritis _____
- ☐ Lupus _____
- ☐ Multiple sclerosis _____
- ☐ Type 1 diabetes _____
- ☐ Inflammatory bowel disease _____
- ☐ Celiac disease _____
- ☐ Psoriasis or other autoimmune disease _____
- ☐ ME/CFS or chronic unexplained fatigue _____
- ☐ Long COVID _____
- ☐ Frequent or unusual infections _____
- ☐ Mast cell activation syndrome, MCAS _____
- ☐ Fibromyalgia _____
- ☐ Other immune or inflammatory condition _____

Neurologic, Neuropsychiatric & Learning

- ☐ Anxiety or panic attacks _____
- ☐ Depression _____
- ☐ OCD or significant compulsive behaviors _____

- ☐ ADHD or significant attention problems _____
- ☐ Brain fog or cognitive problems _____
- ☐ Learning challenges _____
- ☐ Dyslexia or dysgraphia _____
- ☐ Tics _____
- ☐ Severe irritability or rage _____
- ☐ Bipolar disorder or manic episodes _____
- ☐ Psychosis _____
- ☐ Seizures or epilepsy _____
- ☐ Migraines or frequent headaches _____
- ☐ PANS or PANDAS _____
- ☐ Autism or developmental differences _____
- ☐ Suicidal thoughts or behavior _____
- ☐ Substance use problems _____

Autonomic, Connective Tissue, Pain & Cardiac

- ☐ POTS or significant dizziness when standing _____
- ☐ Fainting or near fainting _____
- ☐ Ehlers-Danlos syndrome or significant joint hypermobility _____
- ☐ Chronic joint pain _____
- ☐ Chronic muscle pain _____
- ☐ Chronic bone pain _____
- ☐ Nerve pain, numbness, tingling, or burning _____
- ☐ Foot, heel, or sole pain _____
- ☐ Heart rhythm problems or arrhythmias _____
- ☐ Heart valve disease _____
- ☐ Myocarditis or pericarditis _____
- ☐ Endocarditis _____
- ☐ Other unexplained cardiac problems _____

Gastrointestinal & Other Medical Problems

- ☐ IBS or chronic GI problems _____
- ☐ Chronic constipation or diarrhea _____
- ☐ Significant food intolerances or sensitivities _____
- ☐ Unexplained nausea or abdominal pain _____
- ☐ Metastatic cancer _____
- ☐ Other cancer _____

Pregnancy, Fertility & Family History

- ☐ Recurrent miscarriages _____
- ☐ Stillbirth _____

- ☐ Fertility problems _____
- ☐ Pregnancy complications _____
- ☐ More than one child with significant developmental, neuropsychiatric, immune, or medical problems

Infection, Animal & Vector Exposure

- ☐ Lyme disease _____
- ☐ Bartonella or cat scratch disease _____
- ☐ Babesiosis _____
- ☐ Other tick-borne infection _____
- ☐ Tick exposure _____
- ☐ Flea exposure _____
- ☐ Cat bite, scratch, or lick on broken skin _____
- ☐ Dog bite, scratch, or lick on broken skin _____
- ☐ Exposure to stray or feral cats _____
- ☐ Unexplained red or purple linear skin marks resembling stretch marks _____
- ☐ Long COVID or significant illness following COVID-19 _____
- ☐ Other chronic or difficult-to-explain illness _____

What patterns stand out in your family?

SECTION 5: EXPOSURE & MEDICAL HISTORY

Sometimes the Timeline Provides Important Clues

Think about your child's health history from pregnancy through today. Consider illnesses, exposures, treatments, and other events that occurred before a major change in health, behavior, development, or functioning.

You do not need to know whether an event was related. The goal is simply to identify patterns and timing that may be useful to discuss with your child's doctor.

Pregnancy & Birth

- ☐ Significant illness or infection during pregnancy _____
- ☐ Fever during pregnancy _____

- ☐ Significant complications during pregnancy _____
- ☐ Premature birth _____
- ☐ Complications during delivery _____
- ☐ NICU stay _____
- ☐ Other concerns during pregnancy or birth _____

Infections & Illnesses

- ☐ Ear infections _____
- ☐ Strep infection _____
- ☐ Frequent or recurrent strep _____
- ☐ Flu or significant viral illness _____
- ☐ COVID-19 _____
- ☐ Mycoplasma infection or pneumonia _____
- ☐ Mononucleosis or Epstein-Barr virus, EBV _____
- ☐ Frequent or unusual infections _____
- ☐ Significant illness followed by a change in behavior, mood, cognition, or functioning _____
- ☐ Other significant infection or illness _____

Tick, Flea & Animal Exposure

- ☐ Tick bite or tick exposure _____
- ☐ Flea exposure or flea infestation _____
- ☐ Cats in the home _____
- ☐ Dogs in the home _____
- ☐ Cat bite _____
- ☐ Cat scratch _____
- ☐ Cat licking broken skin or an open wound _____
- ☐ Dog bite, scratch, or licking broken skin _____
- ☐ Exposure to stray or feral cats _____
- ☐ Unexplained rash following an animal, flea, or tick exposure _____

Home & Environmental Exposures

- ☐ Known or suspected mold exposure _____
- ☐ Water damage in the home, school, or another frequently used building _____
- ☐ Symptoms that improve when away from a particular environment _____
- ☐ Other environmental exposure _____

Treatments & Changes Worth Remembering

- ☐ Significant improvement or worsening while taking an antibiotic _____
- ☐ Significant improvement or worsening while taking an antiviral _____

- ☐ Significant change with an antihistamine _____
- ☐ Significant change with a steroid or other anti-inflammatory medication _____
- ☐ Significant change after starting or stopping another medication _____
- ☐ Other treatment associated with a noticeable change _____

Changes Following an Immune Challenge

Did you notice a significant change in your child's health, behavior, development, or neuropsychiatric symptoms following:

- ☐ Infection or illness _____
- ☐ Vaccination _____
- ☐ Significant allergic or inflammatory reaction _____
- ☐ Mold or environmental exposure _____
- ☐ Other event _____

What changed?

How soon afterward did you notice the change?

Did your child return to their previous baseline?

- ☐ Yes ☐ No ☐ Partially ☐ Unsure

SECTION 6: SCREENING FOR PANS AND NEUROINFLAMMATION

PANS, Pediatric Acute Onset Neuropsychiatric Syndrome, is currently defined by the abrupt onset of OCD or severely restricted eating, together with other acute neuropsychiatric symptoms.

Many symptoms associated with PANS are also commonly reported in autistic children. This overlap can make changes difficult to recognize, particularly when a symptom has been present for a long time.

Does your child experience several of these symptoms?

- ☐ OCD or compulsive behaviors
- ☐ Restrictive eating, ARFID, or significant food restriction
- ☐ Anxiety or panic attacks
- ☐ Separation anxiety or new fears
- ☐ Irritability, aggression, or rage
- ☐ Rapid or extreme mood changes

- ☐ Depression or withdrawal
- ☐ Tics or unusual movements
- ☐ ADHD symptoms or difficulty concentrating
- ☐ Brain fog or cognitive changes
- ☐ Decline in school performance
- ☐ Changes in handwriting or dysgraphia
- ☐ Developmental or behavioral regression
- ☐ Sensory sensitivities
- ☐ Sleep disturbances
- ☐ Urinary frequency, urgency, or bedwetting
- ☐ Hallucinations, psychosis, or other significant neuropsychiatric changes
- ☐ Suicidal thoughts or self harm

If your child experiences multiple PANS associated symptoms, particularly if they appeared suddenly, worsened dramatically, or flare with illness, talk with your child's doctor about whether screening for PANS, immune dysfunction, inflammation, or neuroinflammatory markers may be appropriate.

Tests to Discuss With Your Doctor

Infections and Potential Triggers

- ☐ Rapid Strep A test
- ☐ Throat culture
- ☐ Perianal strep culture, if indicated
- ☐ ASO titer
- ☐ Anti-DNase B titer
- ☐ Streptozyme
- ☐ Mycoplasma pneumoniae IgG and IgM
- ☐ Epstein-Barr virus, EBV, panel
- ☐ Coxsackie A and B titers
- ☐ HHV-6
- ☐ HSV-1 and HSV-2 antibodies
- ☐ CMV antibodies
- ☐ Influenza A and B
- ☐ COVID-19 testing, when clinically appropriate

Immune and Autoimmune Screening

- ☐ Quantitative IgG, IgA, IgM and IgE
- ☐ IgG subclasses 1 through 4
- ☐ Pneumococcal serotype antibodies
- ☐ ANA
- ☐ GAD-65 antibodies
- ☐ Cunningham Panel, when clinically appropriate

Inflammation and General Medical Screening

- ☐ CBC with differential
- ☐ Comprehensive metabolic panel, CMP
- ☐ C-reactive protein, CRP
- ☐ Erythrocyte sedimentation rate, ESR
- ☐ Ferritin
- ☐ Vitamin B12
- ☐ Vitamin D
- ☐ Thyroid panel
- ☐ Celiac panel
- ☐ Urinalysis
- ☐ Cytokine panel, including IL-6, TNF-alpha, IL-10, IL-17 and IFN-gamma, when clinically appropriate

There is no single laboratory test that diagnoses PANS or neuroinflammation. Testing is used alongside your child's symptoms, medical history, physical examination, and clinical course to look for evidence of infection, inflammation, immune dysfunction, or other conditions that may be contributing to the symptoms.

SECTION 7: PREPARING TO TALK WITH YOUR DOCTOR

Bring the Whole Picture

Your child may have symptoms involving several different body systems. Looking at these symptoms together, along with changes from baseline, family history, infections, and exposures, may reveal patterns that are difficult to recognize when each symptom is considered separately.

Bring this completed guide to your child's appointment.

Before Your Appointment

Identify the three concerns you most want your doctor to understand:

1. _____
2. _____
3. _____

Changes From Baseline

Has your child experienced a significant change or loss of function?

☐ Yes ☐ No ☐ Unsure

What changed?

When did it begin?

Was the change: ☐ Sudden ☐ Gradual ☐ Episodic ☐ Unsure

Did your child ever return to their previous baseline?

☐ Yes ☐ No ☐ Partially ☐ Unsure

Questions You May Want to Ask

| Could an underlying medical condition be contributing to these symptoms?

| Could pain or physical discomfort be contributing to the behaviors I am seeing?

| Could immune dysfunction, inflammation, or infection be contributing?

| Could mast cell activation syndrome, MCAS, or mast cell dysfunction be contributing to my child's symptoms?

| Do the symptoms across different body systems suggest a pattern that should be investigated?

| Does our family medical history change what we should consider?

| Could PANS or another immune-mediated neuropsychiatric condition be relevant?

| Are there medical conditions commonly associated with autism that we should evaluate?

| Would referral to a specialist or a functional or integrative physician be appropriate?

Information to Bring

- ☐ This completed guide
- ☐ A timeline of major changes or regression
- ☐ Current medications and supplements
- ☐ Previous diagnoses
- ☐ Recent laboratory results
- ☐ Imaging or other test results
- ☐ Relevant medical records

- ☐ Photos of unusual rashes or skin changes
- ☐ Videos of movements, tics, episodes, gait changes, or behaviors that may be difficult to demonstrate during an appointment
- ☐ Family medical history

Remember

Medical symptoms deserve medical investigation.

Autism may affect how a person communicates pain, discomfort, or changes in how their body feels. It should not be used as the explanation for every medical or behavioral symptom an autistic person experiences.

SECTION 8: RESOURCES & APPOINTMENT NOTES

Resources

Autism Infection Associated Disease Alliance, AIDA
aidaalliance.org

AIDA Physician Guide

Cerewell

Child's name: _____

Date: _____

Questions for my child's doctor:

Appointment notes:

LEARN MORE

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For additional background and research discussion, see A Blind Spot on Autism: Rethinking What Could Be Driving the Autism Pandemic.