OASIS · AT A GLANCE

Pain Assessment in Nonverbal Autistic Adults: When Behavior IS the Symptom

A broken bone, a kidney stone, an abscessed tooth. None of them announce themselves with words in an adult who can't easily report pain verbally. They announce themselves as behavior, and too many providers stop looking once a behavior plan is on the table.

BY JIM PALASTY · 11 MIN READ · A FIVE-CATEGORY SCALE BUILT FOR EXACTLY THIS PROBLEM

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CATEGORIES IN THE FLACC PAIN OBSERVATION SCALE

Face, Legs, Activity, Cry, Consolability. Five observable categories built to score pain in people who can't self-report it, adapted from pediatric use for exactly this population.

How it works

THREE STEPS

STEP 1

Behavior changes, cause unclear

New self-injury, aggression, or withdrawal appears with no obvious trigger, and pain isn't the first thing anyone checks.

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STEP 2

Systematic assessment finds what guessing misses

Working through body systems methodically, rather than assuming a purely behavioral cause, surfaces physical explanations.

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STEP 3

Documentation makes providers listen

A specific, structured pain communication record moves a skeptical provider toward investigation faster than a general concern.

Behavioral indicators that warrant investigation

Self-injury or aggression	New onset or sudden increase, with no clear trigger
Food refusal or appetite change	Especially sudden or unexplained
Sleep disruption	New difficulty sleeping or frequent waking
Guarding or facial grimacing	Protecting a body area, or visible facial tension
Withdrawal from activities	Sudden disengagement from previously enjoyed activities

THE KIDNEY STONE BEHIND SIX WEEKS OF AGGRESSION

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Naomi's brother had six weeks of escalating aggression that three providers attributed to behavioral regression before anyone ordered imaging. Naomi insisted on a systematic body-systems review, working from a printed checklist she'd built herself after reading about pain assessment tools. A kidney stone showed up on the scan. The aggression resolved within a week of treatment, a symptom the whole time, never actually a behavior to be managed.

SIX WEEKS AND THREE PROVIDERS MISSED IT. ONE SISTER WITH A CHECKLIST DIDN'T.

What matters, at a glance

Behavioral indicators to watch

New or increased self-injury, sudden aggression, food refusal, sleep disruption, and guarding a body area all warrant investigation.

The FLACC scale

Face, Legs, Activity, Cry, and Consolability: five observable categories adapted for scoring pain without verbal self-report.

Providers often stop at 'behavioral'

A behavior plan gets proposed before a physical cause is ruled out more often than families are told is standard practice.

Work through body systems

Dental, GI, musculoskeletal, urological, ENT, skin, and neurological systems each deserve methodical review before assuming a purely behavioral cause.

The Non-Communicating Children's Pain Checklist

A second adapted tool, alongside FLACC, useful for structured pain observation in adults who can't self-report.

A pain communication card helps

A one-page summary of typical pain indicators speeds up how quickly a new provider takes a concern seriously.

BRING THESE · CHECK AS YOU GO

- [ ] A log of the behavioral change, with onset date and specifics
- [ ] A pain communication card summarizing typical indicators
- [ ] Advocacy language ready for a provider who dismisses the concern
- [ ] A completed FLACC scale observation, if applicable
- [ ] A body-systems checklist to guide a systematic medical review

YOUR MOVE

When behavior changes with no clear cause, here is how to investigate

1. Rule out pain before assuming a purely behavioral explanation.
2. Score observable indicators using the FLACC scale.
3. Work through body systems methodically: dental, GI, musculoskeletal, and beyond.
4. Bring a pain communication card to every relevant appointment.
5. Document the behavior change with dates, duration, and specifics.
6. Push for imaging or further workup if a provider dismisses the concern too quickly.

A behavior plan can't treat a kidney stone. Rule out pain first, systematically, before assuming behavior is the whole explanation.

PAIN ASSESSMENT RESOURCES

The FLACC scale and the Non-Communicating Children's Pain Checklist (NCCPC) are both adapted, validated tools for structured pain observation in individuals who cannot self-report verbally.

AASPIRE's autism-specific health research (aaspire.org) includes guidance on communicating physical symptoms and pain across the autism spectrum.

ABOUT THE AUTHOR

JP

Jim Palasty

Jim Palasty is the founder of OASIS for Autism and a single father of an adult autistic daughter in Michigan.