

OASIS · AT A GLANCE

Navigating Hospitals: Inpatient Stays When Your Autistic Adult Needs Surgery or Extended Care

Caregivers consistently describe an inpatient hospital stay as among the worst experiences of their entire caregiving life. Planning ahead is the one thing that reliably changes that.

BY JIM PALASTY · 11 MIN READ · THREE PHASES, EACH WITH A REAL PLAN

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PHASES OF A HOSPITAL STAY THIS GUIDE PREPARES YOU FOR

Pre-admission preparation, inpatient advocacy through every shift change, and post-surgical considerations. Each phase has its own specific risks and its own specific strategy.

How it works

THREE STEPS

STEP 1

Pre-admission preparation sets the tone

A medical passport, a pre-admission meeting with staff, and clear expectations established in advance change everything that follows.



STEP 2

Inpatient advocacy has to happen every shift

New nursing staff arrive without your family member's history unless someone actively hands it to them, again and again.



STEP 3

Caregiver presence is often medically necessary

For many nonverbal adults, a familiar person present isn't a comfort request. It's a genuine safety and communication necessity.

What to establish before or at admission

Medical passport	Given to every new nurse or provider, every shift
Presence expectations	In writing, especially for procedures and overnight stays
Communication plan	AAC device, communication card, or established signals
Consistent staff request	Ask explicitly, even if it can't always be guaranteed
Post-surgical pain plan	How pain will be assessed if self-report is limited

THE PASSPORT HANDED TO EVERY NEW NURSE

“Angela printed twelve copies of her son's one-page medical passport before his scheduled surgery, handing a fresh one to every new nurse at every shift change without exception. The consistency struck the charge nurse enough that she flagged it for the next shift proactively. What could have been a week of re-explaining his needs from scratch, over and over, became a stay where most staff already knew the basics before Angela said a word.

TWELVE COPIES OF ONE PAGE DID MORE THAN ANY SINGLE CONVERSATION COULD HAVE.

What matters, at a glance

Pre-admission preparation

A completed medical passport, a pre-admission meeting, and a clear plan for the first hours all reduce chaos before it starts.

Consistent nursing assignments

Requesting the same nurses across shifts, where possible, reduces how many times your family member's needs have to be re-explained.

Information gets lost at shift change

Without a proactive handoff plan, critical autism-specific information routinely fails to transfer between nursing shifts.

Caregiver presence is often medically necessary

For many nonverbal adults, having a familiar person present is directly relevant to safe, accurate care, not simply comforting.

Post-surgical considerations

Pain assessment, medication effects, and recovery environment all need autism-specific attention after a procedure.

Psychiatric hospitalization is different

Inpatient psychiatric admission carries its own specific risks and advocacy needs, distinct from a medical or surgical stay.

BRING THESE · CHECK AS YOU GO

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| ☐ Multiple printed copies of a one-page medical passport | ☐ A written record of presence and communication expectations |
| ☐ Contact information for hospital patient advocacy or family-centered care staff | ☐ A communication device or card, with backup power or a paper version |
| ☐ A plan for post-surgical pain assessment if self-report is limited | |

YOUR MOVE

When a hospital stay is coming, here is how to prepare and advocate

- 1 Complete and print multiple copies of a one-page medical passport.
- 2 Request a pre-admission meeting with nursing leadership and the attending.
- 3 Establish presence expectations in writing before the stay begins.
- 4 Hand a fresh medical passport copy to every new provider at every shift.
- 5 Request consistent nursing assignments explicitly, even if not guaranteed.
- 6 Plan specifically for post-surgical pain assessment and communication.

A hospital stay doesn't have to be the worst part of getting better. Preparation is what actually decides that.

HOSPITAL ADVOCACY RESOURCES

The Institute for Patient- and Family-Centered Care (ipfcc.org) provides guidance and advocacy tools for ensuring caregiver presence and family-centered practices during hospital stays.

Ask your hospital directly about a patient advocate or family-centered care coordinator, a role many hospitals have but rarely advertise.

Informational only. Not legal or medical advice. Verify current program rules before acting.

ABOUT THE AUTHOR



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