

OASIS · AT A GLANCE

Aging caregivers and the double-aging reality

Both of you are aging. Only one of you has a plan. The Letter of Intent, the special needs trust, and the successor guardian conversation are the work you do this year, not the work you do after the fall.

BY JIM PALASTY · 14 MIN READ · LONG-TERM PLANNING

1 in 4

AGE 60+ CAREGIVERS

Of family caregivers for an adult with IDD in the US. Both bodies are aging. Only one has a documented plan.

How it works

THREE STEPS

STEP 1

Assess both bodies



STEP 2

Build the paper stack



STEP 3

Rehearse the transition

Documents to update every year on your birthday

Letter of intent	Who she is, what she needs. Updated yearly.
Special needs trust	Trustee, successor, assets titled correctly.
Guardianship / SDM	Successor on file with the court.
Will	Executor, guardianship provisions, beneficiaries.
Advance directive	Your medical wishes if you cannot speak.
HIPAA release	So your doctors can talk to the trustee.
Financial POA	For your accounts, not hers.
Care team roster	Every provider, every phone, every dose.

A STORY WE KNOW



Ruth is 74 and cares for her 46-year-old autistic son Peter. Last winter she fell in the driveway and lay there for forty minutes before a neighbor saw her. Peter was inside eating breakfast. Two hospitalizations and a hip later, Ruth wrote what she now calls the Peter book. Sixty pages. Every routine. Every trigger. Every pharmacy. Every doctor. She gave copies to her three siblings, the case manager, and the day program. She is the only Peter expert who exists. She wrote it down before the fall she has next.

THE BOOK YOU WRITE IS THE WILL YOU LEAVE

What matters, at a glance

Mobility

Caregivers over 60 report new falls, joint pain, and lift injuries. Every transfer she needed a decade ago is now a two-person job.

Health

Cardiac, cancer, dementia risk. Aging caregivers underuse their own healthcare because there is no one to cover the shift.

Caregiver incapacity

The scenario nobody wants to say out loud. Sudden hospitalization, a stroke, a fall. The plan for the next 72 hours has to exist before the 72 hours arrive.

Sibling readiness

Siblings are often the fallback plan. Not always the fallback plan they knew about. Have the conversation before you have the incident.

Residential wait

HCBS waiver residential placements have multi-year waiting lists in most states. Apply the day the diagnosis matures. Not the day you fall.

Six documents

Letter of intent. Will. Special needs trust. Guardianship succession. Advance directive. HIPAA release. Update annually.

BRING THESE · CHECK AS YOU GO

- | | |
|---|--|
| ☐ Letter of intent (current copy + one previous) | ☐ Special needs trust and funding letter |
| ☐ Will with guardianship provisions | ☐ Advance directive and HIPAA release |
| ☐ Guardianship or SDM order + succession | ☐ Financial power of attorney (yours) |
| ☐ Care team roster with 24-hour numbers | ☐ One-page emergency profile for your adult |

YOUR MOVE

When the plan has to become a document, here is how you write it

- 1 Block a Saturday afternoon this month. Nothing else on the calendar.
- 2 Draft the Letter of Intent by hand or dictate to your phone. Twenty pages if it takes twenty.
- 3 Schedule the special needs trust review with your attorney. Rules and tax code change more than you would think.
- 4 Meet with each sibling separately. Read them the letter. Ask what they need to know.
- 5 Introduce your successor guardian to the day program, the case manager, and the pharmacist. In person.
- 6 Update everything on your birthday. Every year. Until you cannot.

The fire safe is not a symbol. Buy the fire safe. Put it under the bed.

RESOURCES NAMED IN THIS POST

futureplanning.thearc.org · <https://futureplanning.thearc.org/>
 specialneedsalliance.org · <https://www.specialneedsalliance.org/>
 acl.gov/ADRC · <https://acl.gov/programs/aging-and-disability-networks/aging-and-disability-resource-centers>

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

ABOUT THE AUTHOR

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Jim Palasty

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