

Estate Planning Considerations for Caregivers

Navigating Planning for Yourself and Those in Your Care

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Today's Roadmap

1. Who Are Caregivers?

Defining the caregiver landscape

2. The Dual Planning Challenge

Planning for yourself AND your care recipient

3. Foundational Documents

HCP • Living Will • POA • Last Will

4. Trusts & Advanced Planning

Revocable, irrevocable & special needs trusts

5. Special Needs & Disabled Children

Preserving benefits, ABLE accounts

6. Public Benefits & Medicaid

Home care, long-term care & spend-down

7. Guardianship

Article 17-A & Article 81

8. Putting It All Together

Action steps & key takeaways



Who Are Caregivers?

Who Are Caregivers?

53M+

Americans provide
unpaid care

61%

of caregivers are
women

\$7,200

avg. out-of-pocket
costs per year

Informal / unpaid caregivers: family members, spouses, adult children, friends

Formal caregivers: home health aides, nursing staff, professional managers

Legal caregivers: court-appointed guardians, trustees, agents under power of attorney

They care for: aging parents, spouses with illness/disability, children with special needs, and others



The Dual Planning Challenge

Why Caregivers Face Unique Complexity

You must plan for TWO lives — often simultaneously, often under pressure

PLANNING FOR YOURSELF

- Your own incapacity documents
- Your own retirement & finances
- Your own healthcare wishes
- Your will & beneficiary designations
- Who will care for YOU if you are incapacitated?

PLANNING FOR YOUR CARE RECIPIENT

- Their healthcare decision-making
- Their financial management
- Preserving their public benefits
- Long-term care & housing
- What happens when YOU are no longer the caregiver?

When Circumstances Change

Estate plans must be living documents — not set-and-forget

1. Caregiver becomes incapacitated or dies
2. Care recipient's condition worsens significantly
3. Care recipient enters a nursing home or memory care facility
4. Family dynamics change (divorce, estrangement, new dependents)
5. Financial circumstances change (inheritance, spend-down, benefits changes)
6. Change in applicable law (Medicaid rules, tax law, benefits thresholds)
7. Care recipient regains capacity (rare but legally significant)

 **Review your plan at every major life event — do not wait.**



Foundational Legal Documents

Health Care Proxy (HCP)

What it is

A legal document appointing an agent to make healthcare decisions when you lack capacity.

For the Caregiver

Who will make YOUR medical decisions if you are in an accident or become ill? Your care recipient cannot serve as your agent.

Key rule

Agent's authority activates only upon physician's determination of incapacity.

For the Care Recipient

If competent, they can execute their own HCP naming you or another trusted person.

If already incapacitated

A court proceeding (Article 81 guardianship) may be necessary to authorize healthcare decisions.

Caregiver tip

Keep a copy with the care recipient's hospital bag and upload to any digital health record system.

Living Will / Advance Directive

What it is: Written instruction documenting a person's wishes regarding end-of-life medical treatment.

Common directives include: CPR preferences, mechanical ventilation, artificial nutrition, dialysis, and hospice care.

MOLST (Medical Orders for Life-Sustaining Treatment): A physician-signed order (not merely a directive) used in clinical settings — carries immediate legal effect.

For caregivers: Discuss your own end-of-life wishes with your agent NOW, before a crisis. Also ensure your care recipient's wishes are documented — reduces burden on you as decision-maker.

Conflict caution: If the care recipient's wishes are undocumented, you may face family conflict or hospital ethics committee review.

Power of Attorney (POA)

What it does

Authorizes an agent ("attorney-in-fact") to manage financial and legal matters on behalf of the principal.

Durable vs. Springing

Durable: effective immediately; continues during incapacity.

Springing: activates only upon incapacity (rarely recommended — can delay access).

2021 Reforms

Mandatory acceptance by banks; expanded agent powers; statutory form updated.

Caregiver's Own POA

Who manages YOUR finances if you are incapacitated? Especially critical if your income funds the care recipient's housing.

POA for Care Recipient

If the care recipient still has capacity, execute now. Do not wait — capacity can disappear overnight.

Warning

Without a valid POA, the only option may be court-ordered guardianship (Article 81) — expensive and slow.

Last Will and Testament

Core function: Directs distribution of probate assets; names executor; nominates guardian for minor children.

Caregiver's own Will — key questions:

- Who inherits your estate if you die before your care recipient?
- Have you left assets directly to a disabled person (which may disqualify them from Medicaid/SSI)?
- Is your care recipient named as a beneficiary or executor — is that appropriate?
- **Care recipient's Will:**
- Does the care recipient have capacity to execute a Will?
- Testamentary capacity ≠ full legal competence (lower standard under EPTL § 3-1.1).
- Consider undue influence protections — caregivers are vulnerable to allegations.



Trusts & Advanced Planning

Trust Planning for Caregivers

Revocable Living Trust

Created during life; grantor retains control; avoids probate. Successor trustee steps in at incapacity or death. Ideal for caregivers to ensure seamless management.

Irrevocable Trust

Assets removed from estate; Medicaid asset protection after look-back period (5 years). Grantor gives up control — careful drafting required.

Medicaid Asset Protection Trust (MAPT)

Transfers assets outside the countable estate; must be irrevocable; subject to 5-year look-back.

Testamentary Trust

Created by Will; takes effect at death. Useful to control distribution to a disabled beneficiary without outright gift.

Pooled Income Trust

Managed by a non-profit; allows individuals over 65 to shelter excess income while qualifying for Medicaid home care. Authorized under 42 U.S.C. § 1396p(d)(4)(C).

Caregiver reminder

A trust is a planning tool, not a Medicaid magic wand. Timing, structure, and benefit rules matter.



Special Needs Planning & Disabled Children

Special Needs Trusts (SNT)

Purpose: Supplement — not replace — government benefits (SSI, Medicaid, OPWDD services) for a beneficiary with disabilities.

First-Party (Self-Settled) SNT:

- Funded with the beneficiary's own assets (e.g., personal injury settlement, inheritance received outright).
- Must be established by parent, grandparent, guardian, or court; payback provision required for Medicaid.
- **Third-Party SNT:**
- Funded with assets of parents, grandparents, or others — NOT the beneficiary's own funds.
- No Medicaid payback required. Ideal vehicle for a caregiver's estate plan.
- **Critical caregiver mistake to avoid:** Leaving assets directly to a disabled child in your Will destroys their eligibility for SSI and Medicaid. Always leave through an SNT.

ABLE Accounts & Letter of Intent

ABLE Accounts

Tax-advantaged savings for individuals disabled before age 26.

- Annual contribution limit: \$18,000 (2024).
- First \$100,000 excluded from SSI resource limit.
- Distributions for qualified disability expenses are tax-free.
- Can be used alongside an SNT — not either/or.

Letter of Intent

Not a legal document — a love letter to future caregivers.

- Medical history, diagnoses, medications.
- Daily routines, likes/dislikes, behavioral triggers.
- Living arrangements and social connections.
- Financial accounts and benefit numbers.
- Future wishes and values.



Public Benefits, Home Care & Medicaid

Key Public Benefits for Care Recipients

SSI (Supplemental Security Income): Federal income for disabled/elderly with limited resources. Resource limit: \$2,000 individual. Requires careful asset planning.

Medicaid: Health coverage for low-income individuals; primary payer for long-term care services.

I: \$1,836 A: \$33,038 (1 person)

I: \$2,489 A: 44,796 (2 people)

OPWDD (Office for People With Developmental Disabilities): Funding for residential, day program, and support services for individuals with developmental disabilities.

Medicare: Federal health insurance for 65+ or disabled (with qualifying work history). Does NOT cover long-term custodial care beyond 100 days.

Veterans Benefits: Aid & Attendance pension for wartime veterans who require assistance with daily activities. Often overlooked.

Medicaid: Home Care & Long-Term Care

Community Medicaid (Home Care)

Provides home health aides, personal care, CDPAP, adult day services in the community.

No look-back period for community Medicaid (as of 2024 — watch for 30-month lookback phased implementation).

Income over the limit → Pooled Income Trust.

CDPAP: Consumer Directed Personal Assistance — care recipient directs their own care; a family member may be paid.

Institutional Medicaid (Nursing Home)

- 5-year (60-month) look-back period.
- Transfers within look-back = penalty period of ineligibility.
- Community Spouse Resource Allowance (CSRA): non-institutionalized spouse may retain approximately \$154,140 (2024).
- Minimum Monthly Maintenance Needs Allowance (MMMNA) for community spouse.
- **Estate recovery: State may seek reimbursement from estate after death.**



Guardianship: Article 17-A & Article 81

Guardianship: Two Pathways

When voluntary planning documents are insufficient, courts may appoint a guardian

Article 17-A

(Surrogate's Court Procedure Act § 1750 et seq.)

- For individuals with intellectual or developmental disabilities (IDD).
- Plenary (full) guardianship — all decision-making authority granted.
- Typically filed by parents of a child approaching age 18.
- Less burdensome process; limited court oversight after appointment.
- Criticized for lack of individualized assessment of functional limitations.

Article 81

(Mental Hygiene Law § 81.01 et seq.)

- For adults who lack capacity due to illness, age, or injury.
- "Least restrictive" standard — court tailors powers to individual needs.
- Separate guardian of the person and guardian of property possible.
- Ongoing court reporting; annual accountings required.
- Preferred for acquired incapacity; more protective of civil rights.

The Caregiver as Guardian: Key Considerations

Succession planning for guardianship: Who serves as guardian when you can no longer do so? Nominate a successor in your petition and estate plan.

Financial accountability: Guardian of property must file an initial inventory and annual accountings with the court. Commingling of funds is a common — and serious — error.

Bond requirements: Courts may require a surety bond to protect the incapacitated person's assets.

Intersection with Medicaid: Guardian may need court approval before entering a Medicaid spend-down plan or executing a Medicaid application.

Planning alternative: If the individual still has capacity, execute an HCP, POA, and Trust NOW — guardianship is the option of last resort.



Storing Important Information

Safeguarding Important Documents

- **Fireproof and Waterproof Home Safe**
 - **Home Filing System**
 - **Emergency Grab and Go Binder**
 - **Digital Storage**
 - **Password Manager**
 - **External Hard Drives or Encrypted USB**
 - **Secure Medical and Financial Portals**
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- **Avoid: Safe Deposit Box at the Bank**



Putting It All Together

The Caregiver's Estate Planning Checklist

For Yourself

- Health Care Proxy executed
- Living Will / advance directive
- Durable Power of Attorney
- Updated Last Will & Testament
- Revocable Living Trust (if applicable)
- Beneficiary designations reviewed
- Life insurance adequate if you predecease

For Your Care Recipient

- HCP & Living Will (if capacity exists)
- POA in place (do not wait)
- Will reviewed — no outright gifts to disabled beneficiary
- Special Needs Trust established or named in Will
- ABLE account opened (if eligible)
- Medicaid planning reviewed with elder law attorney
- Guardianship plan / successor named

Key Takeaways

01

Plan early — it takes time.
Capacity can be lost without warning. Execute documents while everyone still can.

02

Plan for BOTH lives — your own incapacity plan is as critical as the care recipient's.

03

Keep important information safe.

04

Medicaid planning is complex and time-sensitive. The 5-year look-back is real.

05

Guardianship is the option of last resort — voluntary documents are always preferable.

06

Review and update your plan at every major life change. This is not a one-time task.

Questions & Discussion

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