

LEGAL CARE FOR LIVING WITH ALS

PRESENTED BY:

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ITEMS TO BE DISCUSSED

- Health Care Decision-Making and Management
- Financial Decision-Making and Management
- Care Planning
- Long-Term Care Costs

SURROGATE DECISION-MAKING

Who has the authority to make health care and financial decisions?

1. The patient if not incapacitated – legal presumption of capacity;
2. An agent under Power of Attorney;
3. A surrogate under the HCSA;
4. A court-appointed guardian.

POWER OF ATTORNEY FOR HEALTHCARE



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POWER OF ATTORNEY FOR HEALTH CARE

- ◆ The Power of Attorney for Health Care allows an individual, referred to as the “principal” in the document, to designate another person, known as the “agent,” to act for the principal as described in the document to make health care decisions for the principal.
- ◆ The agent stands in the shoes of the principal and is then legally authorized to act, including acting to withhold or withdraw life support, as well as any other type of health care decision, including placement.

POWER OF ATTORNEY FOR HEALTH CARE

- ◆ Requires “legal capacity” to execute
- ◆ May be customized to the values of the principal:
 - ◆ Organ donation
 - ◆ Autopsy
 - ◆ Medical Treatment
 - ◆ Life Sustaining Treatment
 - ◆ Consultation with Children
- ◆ Can be effective immediately or “spring” into action upon occurrence of incapacity
- ◆ Termination Date

POWER OF ATTORNEY FOR HEALTH CARE

- ◆ Revocable (even without capacity) and amendable (with capacity)
- ◆ May name only one person to act at a time
- ◆ Successor Agents
- ◆ Statutory form states that signing new power revokes old powers
- ◆ Agent to use substituted judgment in making decisions if known, otherwise to act in best interests
- ◆ Although agent has no duty to act, if agent does act, must be with due care for principal

HEALTH CARE SURROGATE ACT



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HEALTH CARE SURROGATE ACT

Routine medical decisions:

When a person lacks “decisional capacity” and has no Power of Attorney for Health Care, persons, in order of hierarchy, may make routine medical decisions.

Decisions to refuse or discontinue life support:

When a person both lacks “decisional capacity” and has a “qualifying condition” and has no Power of Attorney for Health Care, persons, in order of hierarchy, may make decisions to refuse or discontinue life support.

HEALTH CARE SURROGATE ACT

1. The patient's guardian of the person;
2. The patient's spouse;
3. Any adult son or daughter of the patient;
4. Either parent of the patient;
5. Any adult brother or sister of the patient;
6. Any adult grandchild of the patient;
7. A close friend of the patient;
8. The patient's guardian of the estate.

POWER OF ATTORNEY FOR PROPERTY



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POWER OF ATTORNEY FOR PROPERTY

- ◆ Requires “legal capacity” to execute
- ◆ Cannot name co-agents
- ◆ Can be customized to the situation
- ◆ Can be effective immediately or “spring” into action upon occurrence of incapacity
- ◆ Revocable and amendable (with capacity)
- ◆ Agent can delegate authority to others
- ◆ Agent is entitled to reasonable compensation

POWER OF ATTORNEY FOR PROPERTY

- ◆ Executing new Power of Attorney for Property revokes old Powers unless customized
- ◆ Agent must act in accordance with principal's known expectations, otherwise in principal's best interests
- ◆ Powers of agent defined in statute unless modified in document – very broad
- ◆ Agent must keep record of receipts, disbursements, and other significant actions.

POWER OF ATTORNEY FOR PROPERTY

- ◆ Duty to Account
- ◆ Agent must provide, upon request, a copy of receipts, disbursements, significant actions to principal or fiduciary on behalf of principal, Adult Protective Services agency, ombudsman, public guardian or court
- ◆ Standard of Actions
- ◆ Agent must be act in “good faith” using “due care, competence and diligence” in acting for principal
- ◆ Gifting
- ◆ No authority to gift unless power is added to the document

JOINT TENANCY



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JOINT TENANCY

A form of joint ownership whereby each owner owns one hundred percent of the property; at the death of one of the joint owners, the surviving owners own the entire property.

Advantages

1. No cost to set up.
2. Effective way to avoid probate.
3. Effective way to arrange estate so that others will be able to manage during incapacity.

JOINT TENANCY

Disadvantages

1. Risky, joint tenancy has an ownership interest in the property and the property is available to the creditors of the joint tenant, as well as may become subject to the marital disputes, disabilities, and other problems of the joint tenant.
2. Does not allow for contingent beneficiaries if the joint tenant predeceases.
3. Surviving joint tenant is entitled to the entire property at death of a joint tenant - where there are several persons who are the beneficiaries of the owner's estate, difficult to name all as joint tenants, and more risky.
4. For Medicaid purposes, Medicaid applicant presumed to be 100% owner of all personal joint property.

TRUSTS



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DEFINITION

What is a trust?

- A legal arrangement through which one person or an institution holds legal title to property for another person. The rules/instructions under which the trustee operates are set out in the trust instrument.

Types of Trusts:

- Revocable and Irrevocable

REVOCABLE TRUSTS

Revocable Trusts

Gives the donor complete control over the trust, can take back the funds he or she put in the trust or change the trust's terms.

Used For:

- 1. Asset Management:** Allows the trustee to administer and invest the trust property for the benefit of one or more beneficiaries of the trust.

- 2. Probate Avoidance:** at the death of the person who created the trust, the trust property passes to whomever is named in the trust. It does not come under the jurisdiction of the probate court and its distribution need not be helped up by the probate process. However, the property of a revocable trust will be included in the donor's estate for tax purposes.

REVOCABLE TRUSTS

3. Tax Planning: While the assets of a revocable trustee will be included in the donor's taxable estate, the trust can be drafted so that the assets will not be included in the estates of the beneficiaries, thus avoiding taxes when they die.

4. Disability Planning: Wills only provide for death. Trusts can help a person have a plan in place in the event of their own illness.

Important to Know:

Assets must be transferred to the trust and held in the trust, which requires lifetime administration.

REVOCABLE TRUSTS

Disadvantages:

1. More expensive to create - legal fees.
2. Assets must be transferred to the trust – time consuming effort.
3. Assets must be held in the trust – requires lifetime administration.
4. Trustee has authority over Trust assets and is limited by the terms of the trust document.

Duties of the Trustee

1. Prudently invest and administer trust assets.
2. Loyalty to trust beneficiaries: no self-dealing.
3. Accounting to trust beneficiaries.
4. Compliance with the terms of the trust document.

IRREVOCABLE TRUST

Cannot be changed or amended by the donor.

Any property placed into the trust may only be distributed by the trustee as provided for in the trust document itself.

For instance, the donor may set up a trust under which he or she will receive income earned on the trust property, but the trust bars access to the trust principal.

TESTAMENTARY TRUSTS

- A trust created by a will.
- No power or effect until the will of the donor is probated.
- Although this trust will not avoid the need for probate and becomes a public document as it is a part of the will, it can be useful in accomplishing other estate planning goals. For example, this trust can be used to provide funds for a surviving spouse who would be protected if they required Medicaid-covered facility care, an option that is not available through the use of a revocable trust.

SPECIAL NEEDS TRUSTS

- Established by the Omnibus Reconciliation Act of 1993. Often called OBRA Trusts.
- Irrevocable
- Can be used to assist a person who is, or may become, eligible for SSI or Medicaid.

- **Two Types:**
 - (D)(4)(A)- for people under 65 years old & disabled
 - (D) (4)(C)-for people over 65 years old

(D)(4)(A)- FOR PEOPLE UNDER AGE 65

- Irrevocable
- In the past, the trust needed to be established by parent, grandparent, court or guardian. However, the Special Needs Trust Fairness Act, which recently became law, allows individuals who have a disability to create their own trust.
- If proceeds of trust are from personal injury action, a lien from Medicaid must be paid off before transferring the proceeds to the trust.
- Trustee can be an individual or corporate trustee.

(D)(4)(C) – FOR PEOPLE OVER AGE 65

- Irrevocable
- Established by parent, grandparent, court or guardian or the beneficiary him or herself
- Referred to as ‘pooled trust’ as assets are pooled together with assets of other people for investment purposes
- Administered by a non-profit organization partnered with a corporate trustee.
- The SMART Act (effective July 1, 2012) restricts the use of this type of trust as a transfer into the trust is considered a ‘transfer of asset for less than fair market value’ which results in period of Medicaid ineligibility.

WHAT CAN THE FUNDS BE USED FOR?

- Funds are to be used only for the beneficiary but are NOT distributed to the beneficiary.
- Used for items Medicaid and SSI do not pay for.
Examples: clothing, companion care, taxes, debt, furniture, transportation, accessibility devices, education, eyeglasses, dental care, etc.

WHAT HAPPENS TO THE FUNDS WHEN THE BENEFICIARY DIES ?

- Any state which paid out Medicaid benefits on behalf of beneficiary is paid back before any other payment except taxes and reasonable expenses of administration.
- If there is any money left over, funds may be distributed to other beneficiaries
- Some pooled trusts require that a portion of the remaining funds be kept by the non-profit trustee.

CARE COSTS



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PLAN FOR LONG-TERM CARE

If you needed assistance with Activities of Daily Living, how would you access that assistance?

- ◆ Driving
- ◆ Meal Preparation
- ◆ Bathing
- ◆ Toileting
- ◆ Dressing
- ◆ Transferring from bed to chair, etc.

How would you pay for it ?

PLANNING FOR LONG-TERM CARE COSTS

The cost of long term care-meaning either in-home care or in a care community for individuals requiring assistance with activities of daily living- is largely an uninsured healthcare cost for most individuals.

Planning for possible exposure to these costs is necessary for effective retirement planning.

Medicare Coverage

Covers up to 100 days of skilled nursing care provided in a Medicare certified nursing facility following an in-patient hospitalization of at least 3 Midnights. Medicare pays the full cost of the first 20 days. There is a coinsurance payment of \$164.50 (for 2017) per day for days 21 through 100 which many Medicare supplemental policies cover.

Medicare provides home care to those individuals needing intermittent skilled care, usually post hospitalization only, although long term part time skilled home care services are covered. Skilled care does not include custodial care, which is the type of long- term care most individuals require.

LONG-TERM CARE INSURANCE

Long Term Care Insurance is the only health insurance that pays for custodial long term care, either at home, or in a care community.

MEDICAID

- ◆ Federal – State Program
- ◆ Federal Law and Monitoring
- ◆ State Law – Regulations and Policy
- ◆ State “Medicaid Agency” – Illinois Department of Healthcare and Family Services
- ◆ State Eligibility Determinations – Illinois Department of Human Services

MEDICAID

- Nursing Homes
- Supportive Living- “Waivered”
- Community care program (over 60) – “Waivered”
- In-Home services (under 60) – “Waivered”

MEDICAID

- Residency and Citizenship
- Categorical eligibility
- Need

RESIDENCY

- ◆ Only residents of Illinois are eligible for Illinois Medicaid.
 - ◆ Voluntarily living in Illinois
 - ◆ No durational requirement
 - ◆ Intention to remain in Illinois
 - ◆ If an individual maintains a home in another state, Illinois residency may not be established.

CITIZENSHIP

- ◆ Only U.S. Citizens or lawful aliens are eligible for Medicaid.
 - ◆ Lawfully admitted for permanent residency; or
 - ◆ Permanently residing in the United States under color of law
 - ◆ Documentation of U.S. Citizenship and identity is required of all applicants except for Medicare, SSI, and RSDI recipients.

MEDICAID ELIGIBILITY ASSET LIMITATIONS

- ◆ Exempt assets:
 - ◆ \$2000 asset disregard
 - ◆ Homestead Property if: intend to return; occupied by spouse; siblings; minor or disabled child. **Equity must be less than \$536,000 or not exempt unless occupied by spouse, dependent siblings, minor or disabled child.**
 - ◆ Personal Effects or Household Goods
 - ◆ Motor Vehicle necessary for medical transportation, modified for handicap, transferred to community spouse, or worth less than \$4500
 - ◆ Life Insurance
 - ◆ Burial Funds
 - ◆ Burial Space and Merchandise

EXEMPT HOMESTEAD

- ◆ Property in which a person has an ownership interest and serves as the person's place of residence (includes adjoining land and buildings)
- ◆ Exemption requires either intent to return or occupancy by spouse, child under age 21, disabled child, caregiver child who resided with and provided care to applicant
- ◆ Unless occupied by one of the above, equity limited to \$536,000 as determined by appraisal no more than 6 months old, assessor's current estimate, or other reliable or verifiable indication of fair market value.

PERSONAL PROPERTY

- ◆ Personal effects and household goods are exempt to the extent they are exempt under federal law (>\$2000 according to policy manual)
- ◆ Items acquired or held for their value or as an investment are excluded
- ◆ Examples of excluded items are: gems, jewelry not worn or held for family significance, or collectibles

JOINT ASSETS

- ◆ Joint accounts and personal property
 - ◆ Presumption is 100% belongs to applicant
- ◆ Joint real estate
 - ◆ Applicant's proportionate share of the equity value of the property is an available asset, unless property is exempt or client verifies that the property is not accessible.
- ◆ Life estate
 - ◆ Life estate may be subject to lien
 - ◆ Change: funds used to purchase life estate will be considered to be non-allowable transfer of assets unless the purchaser resides in the home for a period of at least one year after date of purchase

BURIAL FUNDS

- ◆ Up to \$1,500 in a revocable burial fund contract;
- ◆ Funds in a irrevocable prepaid burial contract up to \$6,264 (2017), including both goods and services but not including burial spaces; or
- ◆ A prepaid burial contract funded by an irrevocable assignment of a person's life insurance policy to a trust which includes a statement that upon the death of the person the State will receive all amounts remaining in the trust. Must be acknowledged by insurance company.

INCOME ELIGIBILITY

- ◆ To qualify for Medicaid coverage, the nursing home or supportive living resident's countable monthly income must be less than the nursing home's monthly private pay rate.
 - ◆ Different income rules apply to the Community Care Program
- ◆ Income in the community spouse's name is not considered available to the nursing home spouse from the first full month in which the nursing home spouse is institutionalized.
- ◆ "Name on the instrument" rule

COMMUNITY SPOUSE ASSETS

- ◆ All assets of the institutionalized spouse and community spouse count as available in determining eligibility.
- ◆ Community Spouse Asset Allowance – the standard allowance is \$109,560. All other nonexempt assets considered available to pay for case.
- ◆ Court Orders – the State must allow assets awarded to the community spouse by court order

COMMUNITY SPOUSE ASSET ALLOWANCE

Increased Asset Allowance by Appeal Hearing

- ◆ Based upon community spouse's separate income;
- ◆ Increase in Asset Allowance measured by the cost of an actuarially sound single premium life annuity that, when added to the combined income of the institutionalized spouse and community spouse will be sufficient to raise the CS's total income, including the income of the nursing home spouse, to the standard (\$2,739).

TRANSFER OF ASSETS RULES

- ◆ For applications filed on or after 1/1/2012, a 60-month “look back”
- ◆ New rules applicable to all transfers occurring on or after January 1, 2007, except hardship exceptions apply
- ◆ Penalty period calculated for each month in which nonallowable transfer occurred by dividing amount transferred by average cost of nursing home care
- ◆ Penalty period measured in months and partial months/days

MEDICAID RULES AND PAYMENTS TO FAMILY CAREGIVERS

- ◆ Personal Care Contracts must be established prior to the receipt of services;
- ◆ Services must be clearly identified and reimbursed consistent with the prevailing cost in the service area;
- ◆ Contemporaneous receipts, logs or other credible documentation showing actual delivery of services;
- ◆ Presumption that services provided by friends or family are “gratis” unless there is contemporaneous written agreement.

MEDICAID TREATMENT OF TRUSTS

- ◆ Self Settled (or by spouse) Revocable Trusts - commonly known as “Living Trusts”
 - ◆ Count as an asset
- ◆ Self Settled (or by spouse) Irrevocable Trusts
 - ◆ Whatever amounts that the trustee may use for the benefit of the Medicaid applicant is presumed available; it can use any principal, all available
- ◆ Third -Party Trusts
 - ◆ Do not count if “discretionary”; count if can be used for support, health and maintenance
- ◆ OBRA Payback Trusts
 - ◆ Do not count if meet all requirements

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Janna Dutton and Kathryn Casey have been named two of the “Top 10 Elder Law Attorneys in Illinois”, by the Leading Lawyers Network. Helen Mesoloras was the President of the National Academy of Elder Law Attorneys, Illinois Chapter in 2017.

Both Janna Dutton and Kathryn Casey are Certified Elder Law Attorneys (CELA). The Certified Elder Law Attorney is the only American Bar Association approved designation for elder law.

ABOUT OUR FIRM

At Dutton Casey & Mesoloras, P.C., we provide comprehensive and personally tailored elder law, estate planning, guardianship, and probate services. Through our expertise of over 125 years of combined legal experience, personal attention, and commitment to service, we assist our clients in achieving their goals and finding peace of mind. Our clients can depend on our team for the knowledge, advice, and support they require to resolve their legal needs.

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OUR TEAM

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PRACTICE AREAS

ELDER LAW

- ◆ Medicaid Planning and Applications
- ◆ Litigation for Vulnerable Adults Against Abuse, Neglect, and Financial Exploitation
- ◆ Care Navigation and Advocacy
- ◆ Senior Housing Contracts, Admissions and Discharges
- ◆ Real Estate

ESTATE PLANNING

- ◆ Estate Planning (wills, trusts, powers of attorney)
- ◆ Long-Term Care Planning (for those living with dementia and other chronic medical conditions)
- ◆ Special Needs Planning

GUARDIANSHIP

- ◆ Guardianship and Contested Guardianship
- ◆ Financial Exploitation Litigation

PROBATE

- ◆ Probate and Trust Administration
- ◆ Will and Trust Litigation