Legal Planning for Families Living with Huntington’s Disease
Sandra P. Gohn, Esq.
DLA Piper (US) LLP
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HDSA encourages all attendees to consult with their primary care provider, neurologist or other healthcare provider about any advice, exercise, medication, treatment, nutritional supplement or regimen that may have been mentioned as part of any presentation.
Presenter Disclosures

SANDRA P. GOHN

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose or list
Powers of Attorney

• Generally pertains to financial affairs, permits the attorney-in-fact to do anything the principal could do regarding finances
• “Durable power” required to be effective upon disability
• May be effective immediately or only upon disability
• Power should include back-up attorneys-in-fact, or a team
• May give the first attorney-in-fact (or the last one) the right to designate further successors
Powers of Attorney, continued

- Possible to name more than one person to serve at a time, or in sequence; also possible to provide that, where more than one is serving, they may act separately or must act together or, for example, two out of three must act
- Should provide that the designated person will be the guardian (at least of the property), if one is required
- Many states have statutory forms, which banks must accept; those forms may be otherwise unsatisfactory
Living Will

- Often combined into one document with the health care directive
- Living will
  - Signer’s statement to the world of his or her wishes
  - Many states or institutions have forms, but users can always modify to reflect personal wishes, religious beliefs, etc.
  - Generally directs withdrawal of medical care when the signer cannot communicate, is terminally ill, etc.
  - Generally overrides the wishes of the family, though physicians may be disinclined to withdraw treatment over family objections
- Reverse living wills also possible: take all possible medical steps
Health Care Directives

- Often combined with living will
- Only operative when the signer cannot express his or her own wishes and intentions
- Health care agent may make health care decisions, including care providers, withdrawal of treatment, etc.
- Many states or institutions have forms, but users can always modify to reflect personal wishes, religious beliefs, etc.
Health Care Directives, continued

• May provide for organ donation
• Possible to name more than one person to serve at a time, or in sequence; also possible to provide that, where more than one is serving, they may act separately or must act together or, for example, two out of three must act
• May give the first attorney-in-fact (or the last one) the right to designate further successors
Guardianships

• Always created by the state, though individuals may designate guardians for themselves under many circumstances
• Many durable powers of attorney contain provisions designating the attorney-in-fact as the person to be appointed guardian, if one is necessary
• Usually two types: Guardianship of the person
   Guardianship of property
Guardianship of the Person

- Standard is usually that the person lacks the ability to take care of himself or herself.
- Sample statute (Maryland):
  A guardian of the person shall be appointed if the court determines from clear and convincing evidence that a person lacks sufficient understanding or capacity to make or communicate responsible decisions concerning his person, including provisions for health care, food, clothing, or shelter, because of any mental disability, disease, habitual drunkenness, or addiction to drugs, and that no less restrictive form of intervention is available which is consistent with the person’s welfare and safety.
Guardianship of the Person, continued

- Requires certification by at least one physician
- State statutes generally provide a hierarchy of who has the right to be appointed, beginning with anyone appointed by the disabled person, then the spouse, parents, children
- Guardian has power over disabled person’s residence, medical care, basic personal property (clothes, vehicle, etc.), as well as the power to consent to withdrawal of care (often with court approval)
- Guardian must generally file an annual report with the court
Guardianship of the property

- Standard generally pertains to ability to manage property
- Sample statute (Maryland):
  The person is unable to manage his property and affairs effectively because of physical or mental disability, disease, habitual drunkenness, addiction to drugs, imprisonment, compulsory hospitalization, confinement, detention by a foreign power, or disappearance.
- May or may not be the same as the guardian of the person
- Generally only one guardian will be appointed at any time
Guardianship of the Property, continued

- State statutes generally provide a hierarchy of who has the right to be appointed, beginning with anyone appointed by the disabled person, then the spouse, parents, children
- Takes control of property of the disabled person
- Must report to court annually on all receipts, disbursements; is generally a highly-regulated relationship
ABLE Act of 2014

- Similar to section 529 account for college savings
- Tax-free savings accounts to be used for disability expenses
- Federal statute, but administered via state plans, like a college savings plan
- For individuals diagnosed with a disability before age 26
- Only one account per disabled person; gifts may not exceed $14,000/year
- If account total is less than $100,000, beneficiary remains eligible for SSI; if over $100,000, no longer SSI-eligible
ABLE Act of 2014, continued

- Account total cannot exceed state total for qualified tuition plans
- Withdrawals tax-free if used for disability expenses; otherwise subject to income tax + 10%
- Qualified disability expenses include housing, education, transportation, employment training, health care, financial management, legal fees, funeral costs, etc.
- Accounts are subject to state Medicaid reimbursement claims at death
- Link for ABLE Act discussion: [http://www.savingforcollege.com/529-able-accounts/]
Other Topics and Documents

• Divorce to preserve assets; effect on existing documents
• Clear record of assets, obligations, agreements
• Revocable Trust Agreement
• Last Will and Testament
• Ethical will
• Additional guidance for health care agent, other caregivers