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Why You Need to Worry About Incapacity Planning

Death is the elephant in the room when we talk about estate planning. We often use phrases like pass away and pass on to make our meetings feel more comfortable and avoid being overly macabre, but the not-so-subtle subtext of an estate plan is death's inevitability. If death is the elephant in the room in estate planning discussions—the obvious issue nobody names out loud—then incapacity is what is obscured behind the elephant, sometimes so obscured that you do not even know it is there.

Incapacity can happen at any age and can have many causes. An estate plan that addresses only what happens to your assets (such as your money, property, life insurance policies, and retirement accounts) after death—and does not address who can make decisions about your personal affairs if you become temporarily or permanently incapacitated—is fundamentally flawed.

What It Means to Be Incapacitated

Incapacity means that you lack the ability to handle your affairs due to illness, injury, cognitive decline, or some other cause. You are, to take the literal meaning of the word, in a state of being incapable. Legally, incapacity means something similar to incompetency. In the context of estate planning, incapacity refers to an impairment that renders you unable to make or communicate important decisions or to manage your affairs, including financial and healthcare matters.

Although often conflated with disability, incapacity and disability are technically not the same. A disabled person can be incapacitated, but disability does not necessarily involve incapacity. Someone who is in a serious car crash, for example, may have injuries that affect their mobility but not their cognition and communication. They may not be able to get around without assistance, but they can still make important decisions about their financial, property, legal, and healthcare affairs.

Incapacity and Your Estate Plan

When you become incapacitated, somebody else must step in and handle your affairs for you. Your bills and taxes still need to be paid, your investments must be managed, and healthcare must be provided, especially if you have suffered a medical emergency that renders you incapacitated and requires immediate treatment. If you want to take a proactive approach to incapacity planning, then you should create an estate plan in which you name and appoint your trusted decision-makers to act on your behalf when you are incapacitated using documents such as financial and medical powers of attorney and a living trust.

Without an estate plan that names financial and medical decision-makers for you in the event of your permanent or temporary incapacity, these choices could be left up to the court.

States have laws that provide guidelines for determining incapacity when the court must appoint a guardian or conservator (the term used may vary by state) for an incapacitated person. These legal definitions typically include medical, functional, and cognitive components.

However, you are not bound by state law standards when specifying in your estate plan how to determine when you are incapacitated—and when decision-making authority should be transferred to another person. Typically, loved ones, physicians, or a combination of the two can make the determination, but you could choose to specify in your estate plan that a disability panel or—in rare cases—court oversight should be involved if you prefer.

You may wish to remain in charge of your affairs as long as possible, or have concerns about others making decisions for you, and prefer a conservative standard. If you are highly confident in your chosen decision-makers (e.g., it is your spouse of 40 years), you may be comfortable with a less rigorous process.

The goal of an estate plan should be to strike the right balance between convenience, objectivity, and timeliness. In addition, you can create provisions in your estate plan to compensate those you name to act on your behalf while you are incapacitated.

The people you name to make decisions for you may not expect to be paid. But reimbursing them for expenses they pay while managing your affairs, such as legal fees and accounting costs, and compensating them for time spent not working can help ensure that all of the necessary legwork (and paperwork) is performed during your incapacity.

Incapacity Is an Ever-Present Risk

The following statistics should be a sobering reminder that incapacity is a very real threat to you, your family, and your legacy that can strike at any time and any age:

- One in four 20-year-olds will become disabled before retirement.¹ A disability does not always lead to functional incapacity, but it often does.
- There is an approximately 70 percent chance that an adult age 65 and older will need long-term care in their remaining years.²
- One in nine adults age 65 and older has Alzheimer's disease, the leading cause of dementia and a common cause of incapacity.³
- Around 13 percent of all adults and 66 percent of adults age 70 and older are living with a cognitive disability such as dementia, autism, or traumatic brain injury that may render them unable to make an emergency medical decision.⁴
- As we live longer, our chances of becoming incapacitated rise. Fewer than 10 percent of Alzheimer's cases occur before age 65.⁵ At age 85, the risk increases to one in three.⁶
- Incapacity can be permanent (e.g., due to dementia or a stroke) or temporary (e.g., because someone is unconscious or under anesthesia).
- Many different conditions can result in incapacity, such as substance abuse disorder, mental illness, post-surgical complications, and grief and bereavement.

Plan for Incapacity to Avoid Estate Planning Gaps

Like death, incapacity looms large, especially as you get older. Acknowledging the very real risk of incapacity is the first step in addressing it. The next step is meeting with an attorney and taking action to build incapacity contingencies into your estate plan.

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- 1) Fact Sheet: Social Security, Soc. Sec. Admin., <https://www.ssa.gov/news/press/factsheets/basicfact-alt.pdf> (last visited Dec. 18, 2024).
 - 2) How Much Care Will You Need?, LongTermCare.gov (Feb. 18, 2020), <https://acl.gov/ltc/basic-needs/how-muchcare-will-you-need>.
 - 3) Michelle M. Mielke et al., Considerations for widespread implementation of blood-based biomarkers of Alzheimer's disease, 20 *Alzheimers Dement.* 8209 (2024), <https://pmc.ncbi.nlm.nih.gov/articles/PMC11567842>.
 - 4) Joanne Tompkins, Seize the Data: An Analysis of Guardianship Annual Reports, *J. of Aging & Soc. Pol'y*, May 5, 2024, at 1, <https://www.tandfonline.com/doi/full/10.1080/08959420.2024.2349494#abstract>.
 - 5) Thinking About Your Risk for Alzheimer's Disease? Five Questions to Consider, NIH: Nat'l Inst. on Aging (Oct. 25, 2023), <https://www.nia.nih.gov/health/alzheimers-causes-and-risk-factors/thinking-about-your-risk-alzheimersdisease-five>.
 - 6) *Id.*