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GUARDIANSHIP

Elder Abuse and Guardianship: End of Life Decisions in the COVID-19 Era

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End of life planning empowers individuals to express their personal wishes about medical intervention during illness and the dying process. This decision-making is complicated and emotional work that involves reflecting on values, beliefs, and cultural traditions. Without advance planning documents, surrogate decision-makers, like a spouse, child, or close friend, are called upon to make these decisions when that individual is no longer able to do so.

When the court is involved, and a judge determines that an individual lacks capacity, this surrogate decision-making is formalized through the appointment of a guardian. Individuals who the court finds to lack capacity later in life frequently have a major neurocognitive disorder diagnosis as well as concomitant diseases. This confluence of factors means that court appointed guardians are often required to make deeply personal end of life decisions for a person who they may not be able to communicate with or have just met.

Surrogate decision-makers are being forced to grapple with end of life questions more frequently, suddenly and urgently due to the COVID-19 pandemic. The full impact of COVID-19 is not yet known, but it is clear that the virus is most severe in individuals 65 years and older, with this age group accounting for 80% of all COVID-19 deaths. (1) Initial data has also indicated that individuals with certain underlying health conditions – such as diabetes, heart disease, kidney disease, and COPD – are at increased risk of poor outcomes, and those with a dementia diagnosis may also be at greater risk for contracting COVID-19. (2) This pandemic puts additional pressure on end of life decisions and decision-makers due to the quick progression and the particularly invasive treatments for severe cases of COVID-19.

Impact of elder abuse

Older adults who have experienced physical, emotional, sexual, financial, and even spiritual abuse are often isolated from their family, friends, and community by their abuser. The abuser can

become their sole connection to the outside world. The family and friends who knew the older adult and could have described and attested to their value system are now gone, pushed out by the abuser. At the end of life, this isolation may prevent the involvement of loved ones to act or express end of life wishes of the older adult.

As a tactic of power and control, abusers will also often assert themselves as medical decision-makers, destroy pre-existing advance planning documents, or prevent the creation of new documents that carry out the wishes of the older adult. Without such documents, older adults are at higher risk of receiving unwanted medical intervention.

For older adults who have experienced abuse and have a court-appointed community guardian, that guardian may be the only person in their lives empowered and available to make end of life choices. However, guardians often refuse to make end of life decisions due to lack of clarity about their authority to facilitate such decisions, lack of understanding about the impact of medical interventions, or both. This refusal to engage can lead to tragic outcomes, including continued involvement of their abusers or painful, life-prolonging medical interventions, like cardiopulmonary resuscitation ("CPR") and intubation, at the end of life. These interventions rarely signal a return to independence, rather only prolong the experience of dying.

CPR is violent by nature, with compressions 100 times per minute and at least two inches deep. Often, CPR can cause major trauma, such as fractures to the rib, sternum, and spine, injury to the liver and spleen, damaged airways, internal bleeding, heart contusions, and pulmonary complications. If the older adult does happen to survive the CPR efforts, often they will have further neurological and functional impairments. In a study of patients over 80 years of age that received CPR after cardiac arrest, only 2% of the population survived long enough to leave the hospital; another study showed that only 20-40% of those that survived were able to leave the hospital without significant support. [3] With the increasing age of in-hospital patients and risk of serious cases of COVID-19 in this population, physicians are frequently confronted with the question of whether resuscitation is a medically appropriate and ethically acceptable treatment for an older patient.

The best outcome is always one in which the older adult's wishes are known and carried out. However, without the support of family and friends at end of life, no documentation indicating their wishes, and a guardian unwilling to act, medical providers are left without the ability to determine treatment approaches aligned with their patient's value system and older adults are at risk of undergoing invasive, painful, potentially unwanted procedures that are not in their best interest.

Case study

Ms. C was one such case. In 2017, Ms. C faced eviction from her longtime apartment in Harlem. When Adult Protective Services began to investigate her situation, they found that a stranger and his family had moved into her home, isolating, and financially exploiting her. Ms. C was scared and confused; she had a lengthy psychiatric history and was recently diagnosed with dementia. After a guardianship proceeding, Ms. C was appointed a community guardian who marshalled her assets and found her a safe placement at The Weinberg Center for Elder Justice at the Hebrew Home at Riverdale. Later, she was appointed a successor guardian in late 2019.

In April 2020, Ms. C contracted COVID-19 and spent ten days in the hospital. When she returned from the hospital, she had lost 30 pounds and her chronic kidney disease had progressed; her appetite was poor and despite encouragement and supplements, her weight continued to drop. Following regular protocol, the medical staff reached out to Ms. C's successor guardian to review advance planning documents due to her rapidly changing medical status and prognosis.

However, citing court closures and delays due to COVID-19, the successor guardian claimed that he was not formally commissioned, and therefore, lacked the power to make any healthcare decisions for Ms. C. Turning to the former guardian, the Weinberg Center was told that the community guardian's duties were discharged when the successor guardian was appointed, and therefore, they too, lacked the power to make any healthcare decisions. Meanwhile, Ms. C's COVID-19 was progressing and her health was rapidly declining. She was in urgent need of an informed healthcare decision-maker, but neither her original guardian nor the successor guardian would act. The Weinberg Center attorneys filed a motion to be heard before the court to get immediate relief, and a healthcare decision-maker in place.

Despite the New York Court system's closure due to COVID-19, the guardianship judge quickly responded and set up a remote video conference with the Weinberg Center, the former guardian, and the successor guardian. The judge issued a temporary commission and explicitly directed the successor guardian to consult with Ms. C's care team regarding her care and end of life considerations.

Ms. C's case exemplifies the importance of advance care planning and responsive surrogate decision-makers at end of life, distilled by the urgency of the COVID-19 pandemic. Empowered and responsive courts are essential to remedying these immediate, life-altering issues.

Recommendations

For individuals with the capacity to execute advance directives, the harm and confusion described above can be pre-empted. However, the ability, time, and access to legal forms is not an opportunity equally afforded, especially during the COVID-19 pandemic.

Attorneys can play a critical role to assisting and encouraging their clients to think about, express, and document their end of life wishes. Guardians should also ask these difficult questions and work to ascertain the value system and beliefs of the individuals for whom they are responsible.

In guardianship courts, end of life decision-making must be addressed early and clearly. At the Weinberg Center, we have had success advocating for express language regarding end of life decision-making in guardianship orders and working directly with guardians and judges in cases of continual inaction. Courts must also be responsive and educated about the impact of informed end of life decision-making, including through swift action to remedy cases of continual inaction.

Our roles as attorneys can easily extend beyond finite transactions, and our work can directly affect the dignity, comfort, and agency of our clients at the end of life, which often, and particularly in the time of COVID-19, can come at any moment.

Endnotes

Authors

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