New York Law Journal

Elder Abuse, Guardianship and End-of-Life Decision-Making

Attorneys can play a critical role in assisting and encouraging their clients to think about, express, and document end-of-life wishes.

By **Deirdre Lok, Tristan Sullivan-Wilson and Joy Solomon** | March 26, 2021

End-of-life planning involves complicated, emotional work that requires reflection on personal values, beliefs, and cultural traditions. Legal professionals can and should play a critical role in this process, encouraging individuals to think about and document their wishes regarding surrogate decision-makers and medical intervention during illness and the dying process. Executed appropriately, these documents are powerful tools to assert autonomy and self-determination, empowering individuals to guide their health care decisions through end of life.

Legal Framework for Surrogate Decision-Making at End of Life

A Health Care Proxy allows the principal to choose a surrogate health care decision-maker. If the principal becomes incapacitated, the named surrogate is empowered to make decisions on their behalf, including execution of a MOLST form (https://www.health.ny.gov/professionals/patients/patient_rights/molst/), which directs provision of life-sustaining treatment in hospitals and residential health care facilities.

In New York, when a person loses capacity to make health care decisions and does not have advance planning documents, surrogate decision-makers are determined by law.

When a person has been adjudicated to lack capacity under Mental Hygiene Law §81, this surrogate decision-making is formalized through the court appointment of a guardian for personal and/or property needs, an "Article 81 guardian."

When an individual without an Article 81 guardian is in a hospital or residential health care facility and lacks decision-making capacity, the Family Health Care Decisions Act (https://www.nysenate.gov/legislation/laws/PBH/A29-CC) (FHCDA) controls surrogate decision-maker selection in the absence of other advance planning documents. The FHCDA establishes surrogate authority to make health care decisions for that person, including decisions regarding life-sustaining treatment and care at end-of-life. The FHCDA was passed (http://digitalcollections.archives.nysed.gov/index.php/Detail/objects/21983) to empower the people closest to the incapacitated person to make health care decisions for them and to avoid overuse of the courts to determine surrogates.

FHCDA surrogates are listed in order of priority (https://www.nysenate.gov/legislation/laws/PBH/2994-D), with Article 81 guardians with medical decision-making authority given top priority, followed by a spouse, child, other family member, or a close friend. Understanding the importance and deeply personal experience of end-of-life care, the FHCDA expressly centers (https://www.nysenate.gov/legislation/laws/PBH/2994-D) the wishes and values of the incapacitated person in the decision-making process, requiring that surrogate decisions be made "in accordance with the patient's wishes, including the patient's religious and moral beliefs." Only when the "patient's wishes are not reasonably known and cannot with reasonable diligence be ascertained" may the surrogate look to the patient's "best interests

(https://www.nysenate.gov/legislation/laws/PBH/2994-D)" in making decisions. Under this framework, Article 81 guardians are often required to make difficult end-of-life care decisions for a person whom they may not be able to communicate with or have only met after their appointment.

Impact of Elder Abuse

Older adults who have experienced physical, psychological, sexual, financial, and spiritual abuse are often isolated from their family, friends, and community by their abuser. Family and friends who knew the older adult, and could have attested to their value system, are now gone, pushed out by the abuser. This isolation may prevent the involvement of loved ones who would otherwise have been able to express the end-of-life care values and wishes of the older adult.

As a tactic of power and control, abusers assert themselves in all aspects of the older adult's life, including as financial and medical decision-makers, by destroying pre-existing advance planning documents, preventing the creation of new documents that detail the values and preferences of the older adult, or insisting on execution of new documents appointing themselves. Without validly executed advance directives, older adults are at higher risk of receiving unwanted, excessive medical intervention.

For older adults who have experienced abuse and have an Article 81 community guardian, that guardian may be the only person empowered and available to make end-of-life choices. However, some community guardians 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 can lead to tragic outcomes, including continued involvement of abusers or painful and unwanted life-prolonging medical interventions at the end of life. For many older adults, these interventions, like cardiopulmonary resuscitation (CPR) and intubation, rarely result in a return to independence, rather, only prolonging the experience of dying.

Patients often misunderstand (https://emj.bmj.com/content/37/10/611) the realities of CPR, which requires compressions 100 times per minute and at least two inches deep. CPR can cause (https://www.nytimes.com/2020/01/31/health/cpr-elderly.html) major trauma to an older adult's body, including fractures to the ribs, sternum, and spine, damaged airways, internal bleeding, and pulmonary complications; aspiration and vomiting are the most frequent occurrence. Even successful resuscitation of an older adult can result in further neurological and functional impairments due to lack of oxygen to the brain. Only 2% (https://doi.org/10.1093/ageing/afu035) of patients over 80 that received CPR after cardiac arrest survived long enough to leave the hospital; only 20-40% (https://doi.org/10.1093/ageing/afu035) of those that survived were discharged from the hospital without significant support.

The best outcome is one in which the older adult's values are known and honored. However, for an older adult experiencing abuse—who does not have documentation indicating end-of-life wishes, whose family and friends have been pushed out by an abuser, and whose guardian is unwilling to act—there is significant risk of undergoing painful, forced procedures that are not in their best interest.

Case Study

Ms. H was one such case. Ms. H was referred to the Weinberg Center for Elder Justice at the Hebrew Home at Riverdale (https://theweinbergcenter.org/), an elder abuse shelter within a long-term care facility, by a hospital in New York City due to emotional abuse and financial exploitation by her daughter. Pending admission to the Weinberg Center, an Article 81 guardianship proceeding was initiated, and Ms. H was appointed an Article 81 guardian of person and property by the court. The order expressly stated that the guardian could not confer with the daughter regarding medical decisions due to the nature of the abuse.

Upon her admission to the Weinberg Center, and pursuant to the New York Department of Health regulation (https://govt.westlaw.com/nycrr/Document/I4fe3211ecd1711dda432a117e6e0f345?viewType=FullText&originationContext=documenttoc&transitionType=CategoryPageItem&contextData=(sc.Default)) requiring medical facilities make the MOLST available to residents or their surrogates, the medical staff asked Ms. H's guardian to review the MOLST. Despite the order granting major medical decision-making power, the guardian refused to engage in advance end-of-life care planning. Without any selections to the contrary on the MOLST, the medical team must treat Ms. H as "full code"—meaning that all life-sustaining interventions, including CPR and intubation, are employed.

Unlike many shelter residents who have been completely isolated from sources of social support by the abuser, Ms. H had been able to remain in touch with some members of her extended family—albeit minimally. Once at the Weinberg Center, Ms. H was able to reconnect with these family members, and they became great sources of support for her. The Weinberg Center team learned Ms. H had discussed end-of-life care values and preferences with these family members. She had been clear she did not want painful life-sustaining interventions if she became very ill, and she wished to pass naturally. The guardian maintained their position, meaning Ms. H remained full code, despite this information.

During the initial peak of COVID-19 cases, Ms. H contracted COVID-19, and her health rapidly declined. As is best practice, the medical staff reached back out to the guardian to review the MOLST due to her changing medical status and prognosis.

Despite the Order's directive not to engage with the daughter, and contrary to Ms. H's wishes, the guardian entirely deferred to the daughter in making health care decisions. Disturbed by this violation of the Order and with the knowledge of her wishes to the contrary, the Weinberg Center legal team requested an emergency case conference with the court.

This case illustrates an alarmingly common phenomenon: a person whose expressed wishes about end-of-life care were denied due to a court appointed guardian's refusal to act.

Recommendations

For individuals with the capacity to execute advance directives, the harm and confusion described above can be pre-empted. However, the time, access, and ability to engage in advance planning is not an opportunity equally afforded.

Attorneys can play a critical role in assisting and encouraging their clients to think about, express, and document end-of-life wishes. Guardians must directly discuss these questions with their wards; if the ward's answer is unclear, the guardian must work diligently to discern their ward's value system and beliefs by reaching out to family, friends, or professionals that may be able to attest to that value system.

In Article 81 proceedings, end-of-life decision-making must be addressed early and clearly. Judges should consider end-of-life care in guardianship cases, eliciting testimony during the hearing and including express language regarding end-of-life decision-making in guardianship orders. Other involved parties should work directly with guardians and judges, and Courts should be responsive and educated about the impact of informed end-of-life decision-making, acting swiftly to remedy cases of continual inaction.

These best practices can directly impact the dignity, comfort, and agency of our clients at the end-of-life. In this time of COVID-19 and always, attorneys should be diligent in planning for this unpredictable, but inevitable, need.

Deirdre Lok *is assistant director and general counsel,* **Tristan Sullivan-Wilson** *is a staff attorney, and* **Joy Solomon** *is director and managing director, at the Weinberg Center for Elder Justice.*