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END OF LIFE, ELDER ABUSE, AND GUARDIANSHIP: AN EXPLORATION OF NEW YORK'S SURROGATE DECISION- MAKING FRAMEWORK

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CASE STUDY

Ms. S,¹ an 82-year-old woman, was referred to the Harry and Jeanette Weinberg Center for Elder Justice at the Hebrew Home at Riverdale, a shelter for older adults experiencing abuse, by her Article 81 guardian due to her 56-year-old son's neglect, psychological abuse, and financial exploitation.

Prior to her shelter admission, Ms. S had been living in New York City for over 40 years. She has diagnoses of Parkinson's and dementia and requires significant assistance with all of her activities of daily living. Her son, Shawn, who has been struggling to manage his substance use and mental health for much of his life, moved back in with her 10 years ago. Despite his struggles, Ms. S appointed him as her agent under a Health Care Proxy and a Power of Attorney.

As Ms. S's health deteriorated, Shawn took control of her life. He isolated her from close family members – sending threatening text messages to her niece, Nicole, and arguing with anyone that visited the apartment. Although Ms. S's care needs increased, Shawn became more hostile to nurses and home health aides assisting Ms. S. Multiple aides quit due to Shawn's hostility and frequent shouting about their work. Without consistent care, Ms. S's health suffered. She developed pressure ulcers and was not eating enough.

Shawn was also mismanaging and misappropriating Ms. S's income and savings. He stopped contributions to her pooled trust, risking loss of health care coverage. Instead, he used her money to buy himself video games and a car.

Due to a neighbor's concern about Ms. S's capacity and safety, Adult Protective Services became involved in the case, and she was ultimately appointed a guardian of person and property under New York Mental Hygiene Law Article 81. The Health Care Proxy and Power of Attorney appointing Shawn were vacated on grounds of his violation of his fiduciary duty. No order of protection was issued against Shawn, but the court specified that, due to Shawn's harmful actions as Health Care Proxy, the guardian was expressly prohibited from consulting with Shawn about Ms. S's medical care.

¹ “Ms. S” is illustrative of a typical resident of the Weinberg Center for Elder Justice shelter program, a shelter for older adults experiencing abuse in the community. This case study does not represent any one individual's experience. All names and other identifying features have been changed.

After appointment, the guardian sent a doctor to Ms. S's apartment to evaluate her. Once there, the extent of the neglect and maltreatment became clear: Ms. S was frail, malnourished, and had pressure ulcers and an unexplained laceration. She was immediately brought to the hospital to be medically stabilized. The guardian made a referral to the Weinberg Center shelter, where she would receive continuing clinical care and trauma-informed support from the multi-disciplinary team to address the abuse and assist in returning Ms. S home safely.

Upon her admission to the Weinberg Center and because of her health status, the medical staff asked Ms. S's guardian to review and execute the Medical Orders for Life-sustaining Treatment ("MOLST") form. By this time, Ms. S's health was rapidly declining and her body was weak. For a person with her health status and prognosis, end of life care discussions is a vital component of care planning. However, despite their major medical decision-making power, the guardian refused to engage in advance end of life care planning or to execute a MOLST. Without any selections to the contrary on the MOLST, the medical team must treat Ms. S as "full code" – meaning that all life-sustaining interventions, including CPR and intubation, are employed. Although the guardian was attempting to avoid "making a choice," without any action, a decision was being made.

While in the shelter, and with the support of the Weinberg team, Ms. S was able to reconnect with supportive family members, including her niece, Nicole. Nicole started visiting Ms. S regularly, and informed the Weinberg Center team that Ms. S had discussed end of life care values and preferences with her. Ms. S had been clear she did not want painful life-sustaining interventions if she became very ill, and she wished to die naturally. When asked, Ms. S could express that she "did not want to be hooked up to machines." Even with this knowledge of Ms. S's contrary wishes, the guardian maintained their position, leaving Ms. S with a full code status.

I. ELDER ABUSE AND GUARDIANSHIP

Stories like *Ms. S's* are far too common: in the United States, an estimated "1 in 10 people aged 60 and older" experience abuse.²

² *Violence Prevention: Preventing Elder Abuse*, CTR. DISEASE CONTROL & PREVENTION (June 2, 2021),

Worldwide, this estimate increases to 1 in 6,³ and even these numbers likely fail to grasp the true scope of the problem. For every 24 older adults experiencing abuse, only one has formally reported the abuse to law enforcement or a social services or legal agency.⁴ There are a variety of reasons why an older adult may not report their experience of abuse, including: fear of escalation; feelings of shame or guilt; lack of (or perceived lack of) alternatives; impaired cognition; cultural barriers to disclosure; inaccessible reporting mechanisms; and/or concern about consequences for the person causing harm.⁵

The Centers for Disease Control and Prevention (“CDC”) defines elder abuse as “intentional acts, or failures to act by a caregiver or another person in a relationship involving an expectation of trust that causes or creates a risk of harm to an older adult.”⁶ By definition, elder abuse occurs within complex trusting relationships. In the majority of elder abuse cases, a family member is the person causing harm.⁷

Elder abuse can present in many forms, including physical abuse, financial/economic exploitation, emotional or psychological abuse, neglect,⁸ sexual abuse,⁹ and/or cultural/spiritual or identity

<https://www.cdc.gov/violenceprevention/elderabuse/fastfact.html> [hereinafter CDC].

³ *Elder Abuse*, WORLD HEALTH ORG. (Oct. 4, 2021), <https://www.who.int/news-room/fact-sheets/detail/elder-abuse> (citing Yongjie Yon et al., *Elder Abuse Prevalence in Community Settings: A Systematic Review and Meta-Analysis*, 5 LANCET GLOB. HEALTH 147 (Feb. 2017), <https://www.ncbi.nlm.nih.gov/pubmed/28104184>).

⁴ LIFESPAN OF GREATER ROCHESTER, INC. WEILL CORNELL MEDICAL CENTER & N.Y.C. DEP’T FOR THE AGING, UNDER THE RADAR: NEW YORK STATE ELDER ABUSE PREVALENCE STUDY 2 (2011).

⁵ *Patient Barriers to Disclosure*, STANFORD MEDICINE, https://elderabuse.stanford.edu/screening/pt_barriers.html (last visited Oct. 31, 2021).

⁶ JEFFREY HALL ET AL., ELDER ABUSE SURVEILLANCE: UNIFORM DEFINITIONS AND RECOMMENDED CORE DATA ELEMENTS (2016), https://www.cdc.gov/violenceprevention/pdf/EA_Book_Revised_2016.pdf.

⁷ *Get the Facts on Elder Abuse*, NAT’L COUNCIL ON AGING (Feb. 23, 2021), <https://www.ncoa.org/article/get-the-facts-on-elder-abuse>.

⁸ CDC, *supra* note 2.

⁹ *Id.* Sexual abuse of older adults is widely underreported. Ageist views of older adults as non-sexual obscures both healthy sexuality and sexual abuse, leading to lack of screening for sexual abuse of older adults or discussions of healthy sexuality and consent in the context of changing capacity. See Malya Levin et al., *Putting the*

abuse.¹⁰ At the center of all abuse is the exertion of power and control over the target of abuse, with the types and tactics of abuse frequently overlapping and co-occurring. Due to forced social isolation and societal ageism, elder abuse can occur for months or years before it is reported or identified. This is particularly true for older adults with diminished capacity who may not be viewed as credible when reporting abuse or may have difficulty identifying patterns of abuse.¹¹

For *Ms. S*, abuse created an immediate threat to her physical and mental health, financial security, and relationships. She was fearful in her own home and completely socially isolated. Although some of these immediate harms can be addressed through trauma-informed social services, legal interventions, and rekindled social connections, the lasting impacts of abuse have continued to ripple throughout *Ms. S*'s life. Shawn's harmful behavior prevented *Ms. S*'s support system from providing support and care. His unlawful actions as her agent under the Health Care Proxy and Power of Attorney sabotaged her advanced planning, leaving her with voided advanced directives and, ultimately, in need of a court appointed guardian.

"Sex" in Sexagenarian: Older Adults, Dementia and the Case of Henry Rayhons, 26 *ELDER L. & SPECIAL NEEDS J.* 32, 33-34 (2016).

¹⁰ Cultural/spiritual or identity abuse is the use of spiritual, cultural, religious, or other identities to manipulate, coerce, or control an older adult. Examples include prohibiting use of culturally appropriate clothing, limiting access to culturally appropriate foods or cooking methods, destroying or preventing use of religious articles, denying access to religious services or rituals, and restricting or denying access to gender affirming care. See e.g. *Power and Control*, NYS OFF. PREVENTION DOMESTIC VIOLENCE, https://dos.ny.gov/system/files/documents/2021/03/aep_handout_participant_power-and-control-wheel_vfinal.pdf (last visited Apr. 4, 2022); *Cultural and Spiritual Abuse*, WOMEN'S L. SERV. TASMANIA (Feb. 2021), <https://womenslegaltas.org.au/wordy/wp-content/uploads/2021/03/Cultural-and-Spiritual-Abuse-February-2021.pdf>; Julie Woulfe & Lisa Goodman, *Identity Abuse as a Tactic of Violence in LGBTQ Communities: Initial Validation of the Identity Abuse Measure*, 36 *J. INTERPERSONAL VIOL.* 1 (March 11, 2018).

¹¹ *Research, Statistics, and Data: Dementia and Elder Mistreatment*, NAT'L CTR. ON ELDER ABUSE, <https://ncea.acl.gov/What-We-Do/Research/Statistics-and-Data.aspx#dementia> (last viewed April 4, 2022).

A. Complexity of Guardianship for Older Adults Experiencing Abuse

Each state has developed its own legal system of surrogate decision making for a person found to lack capacity by a court, referred to as guardianship (or, in some states, as conservatorship). This state-by-state approach has led to significant variations in guardianship systems. However, the basic tenets remain: a guardian is appointed to make decisions about another individual's person and property when the court finds that they are no longer able to make informed decisions for themselves.¹²

Like *Ms. S*, many older adults with diminished capacity that are experiencing abuse are ultimately appointed a guardian. Diminished capacity is often associated with lack of judgment, impaired reasoning, and memory loss - all of which can heighten the risk of abuse. In fact, between 34% to 62% of people with dementia experience some form of abuse or neglect from their caregiver.¹³ Because of the increased risk of abuse among this population, facts indicating elder abuse are often either the impetus for initiating a guardianship or emerge over the course of the guardianship process. For example, financial abuse, in the form of others stealing or commingling the individual's funds, can itself be a sign that a guardianship is necessary.¹⁴

For people with dementia, abuse may present differently. The person causing harm can weaponize the dementia symptoms or the diagnosis itself as a tactic of power and control: calling the individual's credibility into question; utilizing confusion to elicit feelings of shame or fear; intentionally disorganizing a space to increase confusion; or using the dementia diagnosis to explain use of surveillance or confinement.¹⁵ Many people who have been diagnosed with dementia

¹² *Guardianship and Conservatorship*, NAT'L ACAD. OF ELDER L. ATT'YS, https://www.naela.org/web/consumers_tab/consumers_library/consumer_brochures/elder_law_and_special_needs_law_topics/guardianship_conservatorship.aspx (last viewed April 4, 2022).

¹³ *How at Risk for Abuse are People with Dementia*, NAT'L CTR. ON ELDER ABUSE, http://centeronelderabuse.org/docs/ResearchBrief_Dementia_508web.pdf (last visited Jan. 1, 2022); see also Aileen Wigglesworth et al., *Screening for Abuse and Neglect of People with Dementia*, 58 J. AM. GERIATRICS SOC'Y. 493, 493 (2010).

¹⁴ See, e.g., *In re Kustka*, 622 N.Y.S. 2d 208, 211-12 (Sup. Ct. Queens Cnty 1994).

¹⁵ *Power and Control Wheel for People with Dementia*, Harry & Jeanette Weinberg Ctr. for Elder Justice at the Hebrew Home at Riverdale (2021),

are able to credibly report experiences of abuse. For example, a study of older adults across the capacity spectrum demonstrated the consistent ability to indicate the cause of intentionally inflicted bruises when asked.¹⁶ Regardless of a court finding of incapacity, it is important to take allegations of abuse seriously.

B. Guardianship in New York: Article 81

In New York, the guardianship process is defined in New York Mental Hygiene Law Article 81 (“Article 81”). Article 81 mandates the least restrictive form of intervention required to meet the personal and property management needs of person under guardianship, while ensuring the greatest degree of independence and self-determination possible.¹⁷ A court may determine that a guardian is necessary to provide for some or all of the individual’s personal needs (including providing food, clothing, or shelter; making health care decisions; ensuring safety) or to manage their property and financial affairs.¹⁸ The person must either agree to the appointment or the petitioner must prove, by clear and convincing evidence and through specific factual allegations, that the individual is incapacitated.¹⁹ The petitioner has the burden to show that the alleged incapacitated person (“AIP”) is likely to suffer harm because they are unable to provide for their own personal needs and/or property management and that they cannot adequately understand and appreciate the nature and consequences of such inability.²⁰

If an AIP is found in need of a guardian, then the court may appoint a trusted other to serve as guardian. However, in cases of elder abuse, the person causing harm to an older adult frequently isolates them from all other family, friends, and community. In these cases, there may be no appropriate, trusted other to serve as guardian.

https://theweinbergcenter.org/wp-content/uploads/2022/02/Power-and-Control-Wheel-FINAL_Weinberg-Center.pdf.

¹⁶ Laura Mosqueda et al., *The Life Cycle of Bruises in Older Adults*, 53 J. AM. GERIATRICS SOC’Y. 1339, 1339 (2005).

¹⁷ N.Y. MENTAL HYG. LAW § 81.01 (McKinney 2021).

¹⁸ *Id.* § 81.02(a)(1).

¹⁹ *Id.* at (b); *In re Meisels*, 10 Misc. 3d 659, 663 (Sup. Ct. N.Y. 2005) (dismissing a petition for Article 81 Guardianship because it failed to contain any specific factual allegations of any incapacity that would warrant the appointment of a guardian).

²⁰ N.Y. MENTAL HYG. LAW § 81.02 cmt. b, (McKinney 2021).

Instead, the court must appoint a professional that has no pre-existing relationship with the person who has been found to lack capacity to serve as guardian. Once appointed, the guardian will stand in the shoes of the incapacitated person (“IP”) in all circumstances prescribed in the court order appointing the guardian.

II. END OF LIFE CARE

For some, guardianship is time-bound, ending when the IP regains decisional capacity, but for many older adults with court appointed guardians and progressive dementia, guardianship will continue throughout their lives. In these cases, court appointed guardians with major medical decision-making power will ultimately be called upon to make end of life care decisions for the IP.

Even in the best circumstances, end of life planning involves complicated, emotional work that requires reflection on personal values, beliefs, and cultural traditions. For many professional guardians, who may not have known the IP before their appointment, this decision is fraught. Professional guardians do not have a prior relationship with the IP, and the IP may no longer be able to clearly communicate their values and wishes to the guardian. For older adults experiencing abuse, family and friends who knew them and could have attested to their value system, are now gone, pushed out by the person causing harm. With an IP unable to express their wishes and without the involvement of someone who would otherwise have been able to attest to the end of life wishes of the older adult, a guardian may be the only person empowered to make end of life decisions for an IP.

A. Role of the Guardian: Divergent State Approaches

Within the United States, there are diverging legal approaches to a guardian’s power to make end of life care decisions for an incapacitated person with no advance directives.²¹ It is generally agreed upon that the IP’s wishes, or what they would have chosen were they able, should guide the surrogate’s decision making, when

²¹ Andrew B. Cohen et al., *Guardianship and End-of-Life Decision Making*, 175 JAMA INTERNAL MED. 1687, 1692 (2015); Peter M. Macy, *A Guardian’s Authority to Consent to DNR/DNI Orders in Massachusetts*, 102 MASS. L. REV. 117, 121-22 (2021).

possible. This approach is most evident in the court's priority for validly executed advance directives: if an IP had executed an advance directive earlier in life, that document can control the guardian's decision making²² or obviate the need for a guardian at all.²³

When there is no clear instruction for the guardian, the guardian's decision making is guided by the state guardianship law, surrogate decision-making laws, and case law. There are three broad approaches: (1) state statute expressly grants a guardian independent authority to make end of life decisions; (2) state statute expressly prohibits a guardian from making independent end of life decisions; or (3) state statute does not squarely address a guardian's authority to make end of life decisions.²⁴

A minority of states expressly allow a guardian to independently make end of life care decisions for the IP.²⁵ In some of these states, the grant of major medical decision making authority is inclusive of end of life care planning unless expressly excluded.²⁶ In others, end of life decision making authority must be expressly granted.²⁷ An increasing number of state guardianship laws include end of life decision making authority through the incorporation of broader, pre-existing state surrogate decision making frameworks that include end of life care planning.²⁸

²² See e.g., KAN. STAT. ANN §59-3075(e)(7)(B) (West 2021); Okla. Stat. Ann. tit. 30, § 3-119; VT. STAT. tit. 14, § 3075(g)(1)(D) (2021).

²³ See e.g., N.Y. MENTAL HYG. LAW §§ 81.02(a)(2), 81.03(e) (requiring courts to consider all available resources, including existence of power or attorney or health care proxy, in determining whether appointment of a guardian is necessary); WIS. STAT. § 54.46(1)(a)(2).

²⁴ Andrew B. Cohen et al., *Guardianship and End-of-Life Decision Making*, 175 JAMA INTERNAL MED. 1687, 1692 (2015).

²⁵ ARIZ. REV. STAT. ANN. § 14-5303(B) (2021); CAL. PROB. CODE § 2355(a) (West 2021); 755 ILL. COMP. STAT. ANN. 5/11a-17(a) (West 2021); OR. REV. STAT. ANN. § 125.315(c) (West 2021); TENN. CODE ANN. § 34-3-107(B) (2021); N.Y. MENTAL HYG. LAW § 81.22(a).

²⁶ See e.g., CAL. PROB. CODE §§ 2355(a), 4617 (West 2021); OR. REV. STAT. ANN. § 125.315, citing OR. REV. STAT. ANN. § 127.505 (West 2021).

²⁷ See, e.g., ARIZ. REV. STAT. ANN. § 14-5303(B) (West 2021).

²⁸ See e.g., OR. REV. STAT. ANN. § 125.315(c) (West 2021), and OR. REV. STAT. ANN. § 127.635(1) (West 2020); see also N.Y. MENTAL HYG. LAW § 81.22(a)(8), and N.Y. PUB. HEALTH LAW § 2994-d(4), (5) (McKinney 2020).

These frameworks prioritize the substituted judgment standard for surrogate decisions about end-of-life care.²⁹ This standard requires the guardian to make the decision the IP would have made, were they able to make the decision themselves.³⁰ Under this standard, courts generally look to a number of factors to determine the IP's wishes and values, including: previously stated preferences regarding treatment; religious beliefs; age and prognosis with or without treatment; and side effects of treatment.³¹ Where such indication of the IP's wishes or values cannot be ascertained, these statutes direct the guardian to employ a "best interest" standard, which directs the guardian to consider objective factors, including the adverse side effects of treatment, consequences of withholding or continuing treatment, and the patient's prognosis for recovery.³²

The goal of this dual approach to end-of-life care decision-making is to safeguard the IP while better enabling a guardian to approach end of life care holistically, hopefully with an understanding of the IP's values, wishes, current clinical needs, and a pre-existing relationship with the IP's physicians and care team.

Conversely, another minority of states expressly prohibit a guardian from making end of life decisions without a court order.³³ One state, Alaska, prohibits a guardian from making independent end of life decisions entirely.³⁴ The framework of these statutes also utilize the substituted judgment and/or best interest standards described

²⁹ See e.g., D.C. CODE ANN. § 21-2047 (West 2008); N.Y. MENTAL HYG. LAW § 81.22(a)(8), citing N.Y. PUB. HEALTH LAW § 2994-d(4)(a)(i).

³⁰ *Id.*

³¹ See e.g., OR. REV. STAT. ANN. § 125.315(h) (West 2021); N.Y. PUB. HEALTH LAW § 2994-d(4)(i) (McKinney 2020).

³² See e.g., OR. REV. STAT. ANN. § 125.315(i) (West 2021); N.Y. PUB. HEALTH LAW § 2994-d(4)(ii) (McKinney 2020).

³³ KAN. STAT. ANN. § 59-3075(e)(7)(C) (2021); MONT. CODE ANN. § 72-5-321(2)(C) (2021); ARK. CODE. ANN. § 28-65-302(2)(B) (West 2021); IOWA CODE § 633.635(3)(a)(b)(1) (2021); MD. CODE ANN., EST. & TRUSTS § 13-708(c)(1)(ii) (LexisNexis 2021); OKLA. STAT. tit. 30, § 3-119(1)(a) (2021); VT. STAT. tit. 14, § 3075(g)(1)(C) (2021).

³⁴ ALASKA STAT. § 13.26.316(e)(3) (2021). Interestingly, this scheme shifts the deliberation to the medical provider, referring to the guardian as a more passive actor who must "oppose" or "not oppose" the cessation of life sustaining treatment. *P.C. v. Dr. K.*, 187 P.3d 457, 457 (Alaska 2008).

above, however, the deliberation process is shifted away from the guardian to the court.³⁵

When proposing limitations on guardians' authority or more oversight of guardian decision making, policy makers generally cite past instances of guardian misuse of power.³⁶ With respect to end of life care specifically, guardians have pointed to the fact that, by the time a guardian has been appointed, many guardians are unable to ascertain the IP's wishes or values.³⁷ By requiring formal court involvement in these critical decisions, family members and others involved in the IP's life are able to testify before the court about past conversations or other indications of the IP's wishes and values.³⁸

The majority of states fall into the third category, with the guardianship statute silent on the express issue of end-of-life decisions. As a result, in these states, end of life decision making frameworks have been developed through case law.³⁹ Here, initial review of case law indicates that case law tends to mirror the same process established by state surrogate healthcare decision-making laws: requiring the guardian's decision-making to be guided by the substituted judgment standard or, if the older adult's wishes cannot be ascertained, then the best interest standard.⁴⁰ However, this approach could lead to a lack of clarity about who may act as the surrogate for end of life decision-

³⁵ See e.g., MONT. CODE ANN. § 72-5-321(2)(C) (West 2021).

³⁶ See e.g., *Public Hearing Record on the Limitations of Guardianship Act of 2014* B20-0710, 20th Leg. Sess. (D.C., 2014) [hereinafter *Public Hearing on the Guardianship Act*], available at https://lims.dccouncil.us/downloads/LIMS/31335/Hearing_Record/B20-0710-HearingRecord1.pdf.

(Testimony from Carolyn Dunge Nicholas, President Hilda & Charles Mason Charitable Foundation, Inc, Laura Francois-Eugen, member Nat'l Assoc. to Stop Guardianship Abuse, & Dari Pogach, Staff Att'y Univ. L. Services).

³⁷ Zachary Sager et al., *Making End-of-Life Care Decisions for Older Adults Subjects to Guardianship*, 27 ELDER L. J. 1, 19 (2019).

³⁸ See e.g. *In re Doe*, 37 N.Y.S. 3d 401 (Sup. Ct. Kings Cnty. 2016); *Public Hearing Record on the Guardianship Act*, *supra* note 36 (Testimony from Laura Nuss, Director of the Dep't on Disability Servs.).

³⁹ See e.g., Macy, *supra* note 21 (discussing the development of guardian authority to consent to end-of-life care plans in Massachusetts).

⁴⁰ See e.g., *In re Guardianship of Hamlin*, 689 P.2d 1372, 1375-76 (Wash.1984); *Superintendent of Belchertown State Sch. v. Saikewicz* 370 N.E.2d 417, 432-34 (Mass. 1977); *John F. Kennedy Mem'l Hosp., Inc. v. Bludworth*, 452 So. 2d 921, 926 (Fla. 1984); *In re Quinlan*, 355 A.2d 647 (N.J. 1976), *cert. denied*, *Garner v. New Jersey*, 429 U.S. 922 (1976).

making or, as is seen in the other states, variation in approach depending on the court and guardian appointed.⁴¹

B. Spotlight on New York: Article 81 Guardianship and the Family Health Care Decisions Act

Understanding the unique complications of surrogate decision-making at end of life, New York passed the Family Health Care Decisions Act (“FHCDA”) in 2010.⁴² The FHCDA established a clear surrogate decision making framework for individuals who do not have advance directives or capacity to make healthcare decisions for themselves, including those with and without guardians.⁴³ Before this legislation was passed, an incapacitated person with no advance directive or surrogate in place was left without any decision-maker until order of the court. This system led to delayed care, confusion among health care providers and family members, and unnecessarily extended pain and suffering at end of life.⁴⁴

The New York City Bar Association, a supporter of the FHCDA, praised the law as “bringing decision making out of the courtroom and to the patient’s bedside.”⁴⁵ The Association believed this allowed for the freeing of already burdened courts from unnecessary involvement in end-of-life care choices that they are not particularly well equipped to answer.⁴⁶ Other supporters of the FHCDA include the New York State Bar Association, the New York State Nurses Association, and The American Association of Retired Persons.⁴⁷

The FHCDA established surrogate authority to make health care decisions for a person without decisional capacity or advance directives, including decisions regarding life-sustaining treatment and care at end of life.⁴⁸ A major goal of the FHCDA is to empower the

⁴¹ See also Macy, *supra* note 21; Sager et al., *supra* note 37.

⁴² New York’s Family Health Care Decisions Act of 2010, ch. 8, art. 29-CC (codified as N.Y. PUB. HEALTH LAW §2994-d (McKinney 2020)).

⁴³ N.Y. PUB. HEALTH LAW §2994-d (McKinney 2020).

⁴⁴ S.J. Res. 3164, 2009 Leg., Reg. Sess. (N.Y. 2009).

⁴⁵ N.Y.C. BAR ASS’N, REP. ON LEGIS. BY THE COMM. ON HEALTH LAW AND THE COMM. ON BIOETHICAL ISSUES, at 6 (2010).

⁴⁶ *Id.*

⁴⁷ New York Bill Jacket, 2010 A.B. 7729, ch. 8, at 42-46, 68-69, <https://digitalcollections.archives.nysed.gov/index.php/Detail/objects/21983>.

⁴⁸ N.Y. PUB. HEALTH LAW § 2994-D(3)(ii) (McKinney 2020).

people closest to the incapacitated person to make health care decisions. This law established a comprehensive framework to guide *who* is empowered to make the decisions and *how* they should direct care. FHCDA surrogates are listed in order of priority. Article 81 guardians with medical decision-making authority are given top priority, followed by a spouse, child, other family member, or a close friend.

In addition to identifying the surrogate, the FHCDA established a framework to guide the substance of the surrogate's decisions. Mirroring the approach in many states, the FHCDA requires the surrogate's decisions be made "in accordance with the patient's wishes, including the patient's religious and moral beliefs" (substituted judgment standard).⁴⁹ 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" in making decisions.⁵⁰

When making a decision to withdraw or withhold life sustaining treatment under the FHCDA, additional requirements must be met. In addition to meeting the substituted judgment or best interest standard described above, decisions to withhold or withdraw life sustaining treatment requires that either: (1) the treatment would be "an extraordinary burden to the patient and" the patient is "permanently unconscious" or is "expected [to die] within 6 months", regardless of treatment or (2) the "treatment would involve such pain, suffering or other burden that it would reasonably be deemed inhumane."⁵¹

The FHCDA also changed New York's approach to end-of-life decision making by guardians. Before the FHCDA, Article 81 provided that the statute neither "prohibit[s] a court from granting [n]or. . .authorize[s] a court to grant, to any person the power to give consent" to withholding or withdrawing life sustaining support for an IP.⁵² With the passage of the FHCDA, this provision was repealed, and "Article 81 of the Mental Hygiene Law was amended ... to direct

⁴⁹ *Id.* § (4)(a)(i).

⁵⁰ *Id.* § (ii).

⁵¹ *Id.* § (5)(a)(i), (ii).

⁵² N.Y. MENTAL HYG. LAW § 81.29(e) (repealed 2010).

that health care decisions by a personal needs guardian be made in accordance with the standards set forth in the FHCDA.”⁵³

Case law interpreting this new directive is sparse, but the published cases that do are clear in their reading of the law. In *Matter of Restaino*, the court interprets the new FHCDA surrogate list, reaffirming the Article 81 guardian’s priority: “Of note, the highest priority in surrogate designation is the guardian appointed by the court pursuant to article 81 of the Mental Hygiene Law.”⁵⁴

Courts have also discussed the scope of decision-making authority under the FHCDA. The *Restaino* court stated that: “The scope of authority of the surrogate is limited to making *any and all health care decisions on the adult patient's behalf that the patient could make* and only after an attending physician has determined that the patient lacks decision-making capacity.”⁵⁵ A few years later, in *Matter of Doe*, the court spoke specifically to (though in critique of) the new standard for determining health care decisions at the end of life:

Specifically, the clear and convincing evidentiary standard resulting from the “presumption of life” inference relied on in New York's decisional case law which protects against error *has been replaced with a legal and medical framework that allows a surrogate to make decisions based on a holistic assessment of the patient including his wishes, values, and beliefs.*⁵⁶

This new standard directs the guardian to make end of life care decisions that are consistent with the wishes and values of the IP. If the IP’s wishes and values are not reasonably ascertainable, then the guardian must make decisions in the best interests of the IP. As noted by the court in *Matter of Doe*, this did signal a departure from past practice of preserving life above all else—instead, directing surrogates to consider the whole person: their values, wishes, their pain and prognosis, when making these important choices.⁵⁷

⁵³ *In re Doe*, 37 N.Y.S. 3d 401, 401 n.24 (Sup. Ct. Kings Cnty. 2016).

⁵⁴ *In re Restaino* (AG), 950 N.Y.S.2d 687, 690 (Sup. Ct. Nassau Cnty. 2012) (emphasis added).

⁵⁵ *Id.* (emphasis added).

⁵⁶ *Doe*, 37 N.Y.S.3d at 424 (Sup. Ct. Kings Cnty. 2016) (emphasis added).

⁵⁷ *Id.*

C. Special considerations in cases of elder abuse

This already complicated process is made even more complex when end of life decisions are made within the context of abuse. End of life care and changing capacity creates unique vulnerability to abuse for people at end of life, and the dynamics of power and control that permeate relationships of abuse may present differently at end of life.

A person causing harm may leverage their power as surrogate or close family member to direct the IP's care in opposition to the IP's wishes such as refusing hospice or other palliative care measures. They may continue to isolate the older adult by withholding information about the older adult's medical state, prognosis, or location from other family or loved ones. End of life surrogate decision makers, including guardians, must be attuned to these dynamics, and prepare to act pursuant to the IP's wishes or best interest, even in the face of incredibly complex social dynamics.

III. PRACTICAL BARRIERS TO ALIGNING END OF LIFE CARE WISHES WITH CLINICAL CARE

While a handful of states continue to expressly prohibit guardians from making end of life care decisions in the same manner that all other health care decisions are made, the trend seems to be moving toward more comprehensive surrogate decision making frameworks. However, despite these efforts to address surrogate decision-making at end of life, many practical barriers to aligning end of life wishes and clinical care remain.

A. New York Application: Revisiting Ms. S

Consider again the case of *Ms. S*: she no longer had any advance directives, she was appointed a guardian with major medical decision-making power, she was nearing end of life, she was still able to indicate her general wishes for end-of-life care, and family members were able to attest that she would not want to receive life sustaining medical intervention with her current prognosis and quality of life.

According to Article 81, the FHCDA should guide health care decisions, including decisions to withhold or withdraw life sustaining treatment. The FHCDA instructs the surrogate to first attempt to

ascertain the IP's wishes.⁵⁸ Here, *Ms. S* indicated she did not want to be "hooked up to machines" and her family members independently corroborated that she had expressed her wish to die naturally, without medical intervention earlier in life, as well.

Because this involved a decision to withhold life sustaining treatment, the conditions in PHL 2994-d(5) must also be met.⁵⁹ Here, *Ms. S*'s body was contracted and she weighed under 90 pounds. Due to her physical frailty, the provision of CPR, intubation, or feeding tube insertion would have (likely) caused pain and discomfort and, in the case of CPR, could cause blunt trauma to her body. Her Parkinson's and dementia diagnoses are both irreversible and incurable conditions, and her care team, including her physician and palliative care nurse practitioner, all concurred in this decision. In a residential health care facility, which includes the shelter at the Weinberg Center for Elder Justice, PHL 2994-d(5)(b) requires that the facility's ethics review team or a court of competent jurisdiction must determine the above standards are met.⁶⁰ In *Ms. S*'s case, the ethics review team at the residential healthcare facility made that determination.

Despite the guardian's power to align *Ms. S*'s care with her wishes and values by executing a MOLST form indicating that life sustaining treatment should be withheld, they refused to do so without a hearing and an order from the court. After months of distress from *Ms. S*'s family and medical care team, the guardian finally requested a hearing on the matter. At the hearing, *Ms. S*'s family, physician, social worker, and case manager testified to *Ms. S*'s wishes, medical condition, and prognosis. Finally, the judge ordered the guardian to align *Ms. S*'s care plan with her wishes by appropriately executing the MOLST form.

After significant delay and risk of unwanted and painful life sustaining intervention, *Ms. S*'s care was finally aligned with her wishes and values. For many older adults with a court appointed guardian and no family or professionals to advocate for their interests, this alignment never comes.

⁵⁸ N.Y. PUB. HEALTH LAW § 2994-d(4)(i) (McKinney 2020).

⁵⁹ *Id.* § (5).

⁶⁰ *Id.* § (b).

B. Practical Barriers

A number of factors can contribute to a guardian's reticence or refusal to engage in end of life care planning, including: a court's discomfort with a guardian making end of life care decisions; a guardian's difficulty in discerning the IP's wishes or the guardian's religious or moral discomfort in carrying them out; a guardian's lack of understanding of the clinical implications of their choices or personal religious or moral belief; and/or court and guardian confusion about the role of the guardian and their legal authority.

Even in states that clearly allow guardians to make independent end of life care decisions, each guardian holds only the powers granted to them in that individual's case. This personalized approach to guardianship allows a person with diminished capacity to maintain a maximum amount of independence. However, in some cases, judges tailor the guardian's powers in ways that do not align with the IP's functional abilities. For example, granting the guardian major medical decision-making authority, but expressly excluding end of life decision-making from this power. In these cases, a person declared to lack the requisite capacity to make major medical decisions on their own behalf is left without anyone empowered to make those decisions without additional judicial intervention. Although these tailored orders are intended to maximize the IP's autonomy, in practice, this patchwork approach can leave the IP without a decision-maker at all – preventing their wishes from being honored.

When the guardian does have the power to direct end of life care, real concerns regarding an inability to discern the IP's wishes and a lack of clinical understanding of the IP's condition and prognosis lead to fear of liability and confusion for some guardians. Disputes about what the IP would have wanted sits at the heart of most litigation about surrogate decision-maker's end-of-life care choices. The surrogate decision-maker's own values and moral beliefs can also impact their comfort making these decisions, even when the IP's wishes are ascertainable. These types of disputes have played out very publicly in cases like *Cruzan v. Director, Missouri Department of Health*⁶¹ and *Schiavo*.⁶² These same issues appear in the guardianship

⁶¹ *Cruzan v. Director, Missouri Dep't of Health*, 497 U.S. 261, 274 (1990).

⁶² *Schiavo ex rel. Schindler v. Schiavo*, 403 F.3d 1223, 1226-27 (11th Cir. 2005).

context, too – frequently with even less information about the IP’s prior conversations and values than in the hotly debated cases above.

Without advance directives or reliable people to attest to the IP’s wishes, guardians can have an understandably difficult time confidently discerning wishes or values of the IP. By the time a guardian has been appointed, a court has determined the IP is unable to understand and evaluate their care needs and so cannot direct their medical care. However, even those who lack the requisite capacity to direct their own care may still be able to express their general wishes about care and values when engaged appropriately.

Finally, surrogate decision-making and guardianship frameworks vary widely across the country.⁶³ These differing approaches leads to confusion and divergent legal interpretations of the role and power of guardians. Without uniformity, guardian or institution-specific practices can have an outsized impact on the IP’s life, with care received impacted by the IP’s care team, the guardian appointed, and the judge involved.⁶⁴

IV. RECOMMENDATIONS

The best end of life care is always that which aligns with the wishes and values of the incapacitated person. For individuals with the capacity to execute advance directives, these documents and conversations with appointed surrogates are the clearest way to make care values known. However, the time, access, and ability to engage in advance planning is not an opportunity equally afforded.

For those without advance directives and now involved in a guardianship proceeding, the party petitioning or otherwise involved in the case should consider addressing end of life decision-making directly in the guardianship hearing when major medical decision-making power may be granted. Although this is not necessary in all guardianship proceedings, older adults with progressive diagnoses that are found to lack capacity are likely to have a guardian at the end of life. The hearing may present a unique opportunity to explore end of life wishes before capacity is further impacted or diminished over time. Clarity about who the surrogate decision-maker is and any indication

⁶³ Andrew B. Cohen et al., *Guardianship and End-of-Life Decision Making*, 175 JAMA INTERNAL MED. 1687, 1692 (2015).

⁶⁴ See also Macy, *supra* note 21.

of the AIP's wishes' and values can be invaluable. When available, testimony about conversations addressing end of life care values and wishes from family members, friends, or professionals should be elicited during the guardianship proceeding.

To ensure the guardian's powers are clear, involved parties can advocate to specifically include "end of life care" in the petition and request the same language in the final guardianship order. This provides an opportunity to address this power before the court while clarifying the role and responsibilities of the parties involved.

Once appointed, guardians with major medical powers must directly discuss end of life care questions with the IP. If the IP'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. Particularly when the IP has progressive disease that impacts cognition, the earlier the guardian can have these conversations, the better. By the time these decisions must be made, the IP may no longer be able to indicate their wishes.

Even in states that do not allow a guardian to make end of life decisions without a court order, genuine attempts to have these conversations must be made. Although the guardian will have to go back to court before making any decisions, these conversations and indications of wishes and values will be key information for any hearing or request to the court.

Unique tools have been developed to facilitate these difficult conversations. For example, tools like Five Wishes,⁶⁵ Prepare for Your Care,⁶⁶ and The Conversation Project⁶⁷ all offer clear questions and topics to address some of the complicated scenarios and care choices at end of life.

These complex conversations and decisions are a vital—and often overlooked or ignored—part of the guardian's role. Some guardians try to avoid the topic all together in an attempt to avoid this

⁶⁵ *Who We Are: Ensuring Human Dignity Through Conversations That Matter*, FIVE WISHES (Jan. 5, 2020), <https://fivewishes.org/five-wishes/who-we-are/about-us/our-history-and-mission>.

⁶⁶ PREPARE FOR YOUR CARE, <https://prepareforyourcare.org/en/welcome> (last visited, Jan. 5, 2022).

⁶⁷ Inst. for Healthcare Improvement, *About Us*, CONVERSATION PROJECT (Jan. 5, 2020), <https://theconversationproject.org/about>.

responsibility or feared liability, but this attempt to avoid making the decision is a decision in itself.