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The Role of Mediation in Article 17-A Guardianships  
Creating the New Normal for Health Care Directives  
A Recap on Last 30 Years: Mental Hygiene Law Article 81

# Creating the New Normal for Health Care Directives

By Deanna M. Eble and Jeffrey R. Neuman



As elder law attorneys, we often encourage our clients to plan for their future medical care. Our namesake is well deserved; historically, the clientele most often serviced by such counseling has been the elderly. But . . . maybe it's time this changed. Maybe, by the devastating impact of COVID-19, we have learned that a person's potential health care is a topic to be discussed regardless of age. Should these difficult scenarios arise, our clients are then best served by having an open and honest conversation with their families about their wishes and thereafter taking control of their future by advanced planning. While COVID-19 is shedding a brighter light on these concepts, including end-of-life decision making, the model is certainly not new.

As we so often explain:

A health care proxy is a document used for a person (known as a principal) to designate an individual (known as an agent) or preferably, a list of individuals (agents), who will be available to make medical decisions for the principal if the principal is unable to do so. The standard for the agent to act is a determination of the principal's lack of capacity to make health care decisions.<sup>1</sup> Lack of capacity does not equate to a principal's age. A caution to the drafting practitioner, a validly executed health care proxy must not only be signed by the principal but dated by the principal as well.<sup>2</sup>

In addition to general medical decision-making capability, the health care proxy also allows the client to state their wishes regarding organ donation. However, when it comes to artificial nutrition and hydration, the agent cannot unilaterally make those decisions unless the client

makes those wishes known.<sup>3</sup> Additionally, and particularly relevant for the COVID-19 times, is the ability for a principal to make any views known regarding ventilators, intubation and respiratory care. When drafting a health care proxy, think about the changing landscape of the medical field, and discuss express authorizations that consider visitation restrictions, advocacy from a distance, virtual communication and written instructions. Health care proxies are not only for the principal, but they also provide caregivers with guidance and peace of mind in advocating for their loved ones. Now is the perfect time for everyone over 18 to make sure they have a health care proxy, and for those who have previously signed one, to revisit and review it.

It should be noted that a health care provider is legally required to follow the instruction of that health care agent in good faith.<sup>4</sup> As noted above, a health care proxy importantly allows an agent to direct, withdraw or withhold life-sustaining treatment. A direction of said treatment by an agent must be adhered to, even over the objection of a hospital or health care provider, subject to judicial review.<sup>5</sup>

If a health care proxy has not been properly executed and an adult is unable to manage their medical needs, New York State's Family Health Care Decisions Act<sup>6</sup> of 2010 (FHCDCA or the Act) allows a health care surrogate to stand in and make the necessary medical decisions. There is a hierarchy of authority to make those decisions. First would be a court-appointed guardian, followed then by spouse/domestic partner, an adult child, parent, adult sibling and finally a close friend.<sup>7</sup>

While the Family Health Care Decisions Act is an essential practical alternative, it is not an adequate substitute for a health care proxy. Importantly, under the FHCDA there is no distinction between your adult children. In other words, any child present has the authority to act, even if the child was estranged or holds different beliefs regarding care and treatment. While the FHCDA prefers decisions based on the patient's wishes, the surrogate's authority is likely presenting itself under the Act because these were never discussed. In this common scenario, the standard shifts to a substituted judgment or best-interest standard,<sup>8</sup> which can often deviate from one's wishes. Further, even if a surrogate knows the patient's wishes for

age of 68, Robert decided that this was no longer the life that he wanted to live. As a result, he was no longer willing to seek additional treatment. As a competent adult, Robert had the right to refuse treatment at any time.

Robert asked his wife to take him to the hospital the weekend before he passed away. While at the hospital, Robert's heart stopped. Despite having a health care proxy and living will stating that he did not wish to have life sustaining treatment, she could not bring herself to refuse the treatment and let him go and initially allowed the doctors to try and revive him. Only after a conversation with their daughter, the successor health care agent, did the wife re-

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withholding or withdrawing life-sustaining treatment, the implementation is subject to certain condition precedents under the Act.<sup>9</sup> For these reasons, and many more, it is very important to have that health care proxy in place.

The living will often supplements that health care proxy. This document helps to outline the treatments that a client would or would not want under certain circumstances and serves as a guideline for the named agent(s) under a health care proxy. While living wills are not governed by statute, case law upholds their validity when it is shown by “clear and convincing” evidence that the document is an expression of the principal's wishes.<sup>10</sup> Another similar health care directive is a MOLST or Medical Orders for Life-Sustaining Treatment form, which acts like a medical order, signed by a physician, dictating the patient's wishes for certain end-of-life health care treatments.

Once the advance directives are complete, how do they help with end-of-life decision making on a practical level?

Meet Robert. Robert was a vibrant man who suffered a massive heart attack at the age of 46. While it severely limited his physical functional ability, he had full capacity until the moment he took his last breath. His body slowly declined over the years and Robert often found himself needing medical attention. Robert always engaged with his doctors, but preferred to have his wife or children accompany him to the appointments because he was concerned that he would not understand what was being explained. Ultimately, his care required dialysis, confinement to his home, and a loss of his independence. At the

alize she was trying to revive him because of her wishes, not Robert's. It was important to Robert not to be suffering any longer and it took a strong heart to accept this in saying good-bye the way Robert wanted.

This is why it is so very important to stress to clients that it is not enough to name an agent in a health care proxy, but they must also discuss their wishes with their agents and choose someone that they know will follow through. Thus, naming children in age order is not always the best decision.

Meet Anna. Anna was a funny and loving woman who enjoyed sharing life hacks with her seven great-grandchildren. One Sunday afternoon, while having dinner with her family, Anna suddenly fell off her chair and her life changed in that instant. This 88-year-old woman, who was generally independent and used to caring for her own family, suddenly could not take care of herself. It was as if a switch had been flipped and Anna didn't know who she was any more. She was a child again and needed to be reminded to get dressed, toilet and eat. Hastily Anna's health care agent signed her up for hospice. Not because she had a true understanding of the program, but because someone told her that Medicare would cover many of her equipment needs. After only two months of hospice, the family felt that Anna's needs would be better suited for palliative care in a long-term care facility.

Anna's health care agent was confused and initially misinformed. She did not understand the difference between hospice and palliative care. While Anna had done her part to plan in advance, it was now the responsibility

of her agents to understand her needs and make medical decisions based on her wishes.

Palliative care is for patients with serious illnesses. It gives relief from pain and symptoms while still allowing the patient to receive medical treatment for their illness. It focusses more on the quality of life. The Palliative Care Access Act (PCAA) of 2011 mandates informing patients with advanced, life-limiting conditions or illnesses that such care exists.<sup>11</sup> Additionally, Anna had a Do Not Resuscitate Order (DNR). This order can only be signed by a medical professional and only addresses a client's desire to not be resuscitated in the case that their heart stops or they stop breathing. Anna's health care proxy and living will were consistent with this desire.

Anna received palliative care in the nursing facility where she spent her last six weeks of life. She had expressed in her health care proxy and living will that she didn't want extreme measures, but that she wanted to be free of pain. Once her family understood her options, they were better able to help her live out her last days with dignity.

Finally, meet Grayce. Grayce was an amazing artist. Grayce was diagnosed with cancer late in life. She had been living alone for almost six years after her husband passed. She tried living with family for a few weeks as her illness progressed, but this did not work well because she was set in her ways. Stubborn as she was, she and the family decided to give independent living another try with occasional supervision. This lasted only a few months and then Grayce recognized that she needed 24/7 care. Not wanting a stranger in her home, she reluctantly went back to living with family.

Grayce had a conversation with her doctor and completed her Medical Orders for Life Sustaining Treatment (MOLST). The difference between a DNR and the MOLST is that here, Grayce noted her wishes regarding life sustaining treatment, long-term care services, CPR, artificial hydration, nutrition, antibiotics, intubation, and comfort care.

With the guidance of her family, Grayce began receiving hospice. After a few weeks of hospice care, Grayce, who was fully competent, also began to voluntarily stop eating and drinking (VSED). Choosing this path allowed Grayce to exercise her right and control her dying process. Grayce passed peacefully 10 days later, on her terms.

It is our job as elder law attorneys to encourage clients, regardless of age, to have these important conversations with their families and to document their desires. As Robert, Anna and Grayce show us, making these types of decisions, especially on a moment's notice, is not as easy as it seems. Now more than ever, the full spectrum of advanced planning documents available must be at the forefront of our services. Let us also learn from these unprecedented times and expand the scope of people protected by making their wishes known. This must be the "new normal."



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## Endnotes

1. PHL § 2981.
2. *Id.*
3. PHL § 2982(2).
4. PHL § 2984.
5. *Id.*
6. PHL Article 29-CC.
7. PHL § 2994-d.
8. *Id.*
9. PHL § 2994-d(5).
10. Nancy Beth CRUZAN, by her Parents and Co-Guardians, Lester L. CRUZAN, et ux., *Petitioners v. DIRECTOR, MISSOURI DEPARTMENT OF HEALTH, et al.*, 497 U.S. 261, 110 S.Ct. 2841, 111 L.Ed.2d 224.
11. PHL § 2997-d.