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Health Care Proxies – Ten Difficult Issues

By Robert N. Swidler

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Health care proxies have proven valuable and popular among New Yorkers because they enable a person to appoint a trusted family member or friend to make health care decisions for the person if he or she loses the capacity to make those decisions personally.[1] Health care providers like proxies as well, because they clarify who has the legal authority to act for an incapable patient,[2] and often provide guidance about the patient's wishes regarding end of life care. Each day, in hospitals, nursing homes and other care settings across New York State, providers seek and accept decisions from health care agents on behalf of incapable patients, with few or no problems.

But difficult problems and questions can still arise. This article addresses 10 difficult issues in connection with the creation and use of health care proxies, through FAQs and brief answers. Elder Law attorneys may find it useful to consider these issues and anticipate these problems. Again, these are difficult issues, and not all attorneys will agree with the conclusions below.

1. Can a Person Who Lacks Health Care Decision-Making Capacity Still Create a Health Care Proxy?

Yes, as long as the person is "competent." More specifically, the health care proxy statute ("the proxy statute") provides in Public Health Law § 2981.1 (PHL) that:

> (a) A competent adult may appoint a health care agent in accordance with the terms of this article.
>
> (b) For the purposes of this section, every adult shall be presumed competent to appoint a health care agent unless such person has been adjudged incompetent or otherwise adjudged not competent to appoint a health care agent, or unless a committee or guardian of the person has been appointed for the adult pursuant to article seventy-eight of the mental hygiene law[3] or article seventeen-A of the surrogate's court procedure act.[4]

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In contrast, "capacity to make health care decisions" means "the ability to understand and appreciate the nature and consequences of health care decisions, including the benefits and risks of and alternatives to any proposed health care, and to reach an informed decision."[5] A determination under the statute that a patient lacks capacity to make health care decisions triggers the authority of the agent.[6]

The difference in these standards is significant. It means that in some instances an adult who would be found to lack capacity to make health care decisions nonetheless is still competent, and therefore can still lawfully appoint a health care agent.[7]

This opportunity to allow a person who lacks health care decision-making capacity to create a health care proxy can be quite valuable in appropriate cases. For example, a patient with dementia or a developmental disability who needs surgery may not be able to make a complex health care decision, but may be able to understand that he or she is appointing a family member to make the decision for him or her. It is helpful, lawful, and ethical for such a patient to execute a health care proxy.

However, the practitioner must recognize that a determination of incapacity to make health care decisions, made at or about the time of the execution of the proxy, could be proffered to rebut the presumption of competence.[8] Accordingly, before allowing a person who lacks health care decision-making capacity to execute a proxy, it would be important to secure an evaluation by a qualified professional who can document that the person is competent to create the proxy, even though incapable to make the pending health care decision.

And obviously no one should coax a person into signing a proxy when the person does understand what he or she is doing. That is neither helpful (because the presumption of competence would be rebutted) or ethical, and could be fraudulent.

2. Can an Adult With an MHL Article 81 Guardian Still Appoint a Health Care Agent?

Sometimes. A person who has a guardian is no longer presumed competent to create a health care proxy.[9] But, as noted above, in some cases an incapacitated person will still have the ability to understand what it means to appoint someone to make health care decisions for them. The MHL Article 81 guardianship statute directs the court and the guardian to take into account the incapacitated person's wishes and preferences, and to impose the least restrictive form of intervention.[10] In an appropriate instance, a person with a guardian may be able and permitted to appoint a health care agent. But a practitioner would need to carefully review the guardianship order and secure a qualified professional's evaluation and documentation of the person's ability to understand what they are signing. If the guardian supports the appointment, that documentation should be sufficient. If the guardian opposes the appointment, a judicial determination should be sought.

3. Where There Is Both an MHL Article 81 Guardian and a Health Care Agent, Who Makes Health Care Decisions?

In general, a health care agent has priority over a guardian. The proxy statute states very clearly:

> Health care decisions by an agent on a principal's behalf pursuant to this article *shall have priority over decisions by any other person*, except as otherwise provided in the health care proxy or in subdivision five of section two thousand nine hundred eighty-three of this article.[11]

Moreover, the guardianship statute includes a consistent provision that provides that

> "No guardian may . . . 2. Revoke any appointment or delegation made by the incapacitated person pursuant to . . . [the proxy statute].[12]

However, a guardian could always commence a proceeding to try to invalidate the proxy, or remove the agent, or override an agent's decision based on specified findings.[13]

4. Can a Person Appoint Co-Agents and Provide for Decisions by Agreement or by Majority Vote of Co-Agents?

No. The statute authorizes an adult to appoint "a health care agent" and "an alternate agent" to serve if the agent is not reasonably available, willing and competent, or is disqualified, or under conditions described in the proxy.[14] This rather clearly contemplates the appointment of only a single agent.

This was intentional. While some individuals might prefer to have decisions made by co-agents, or by a majority vote of a group, those procedures can impose enormous burdens and risks on health care providers who may need a prompt, clear, authoritative decision. In any case, the adult can always direct the agent to consult with others before making a decision.

5. Does a Health Care Agent Have Any Authority While the Patient Still Has Capacity?

No. The statute is very clear that the agent's authority commences only upon a determination that the principal lacks capacity to make health care decisions.[15]

Despite that clarity, in health care settings it is very common for a family member or friend to try to make decisions for a patient who has not been found to lack capacity "because I'm my Mom's health care proxy." And indeed, in many instances health care providers accept decisions from such a person on behalf of the patient. There is no support in the statute for this practice.

To be sure, sometimes this practice causes little harm because the patient clearly lacks capacity and the absence

of a determination is just a procedural defect that can be remedied. But in other instances, the participants are contravening a fundamental ethical principle: when a patient has capacity, providers must seek a decision from the patient, not someone else.

6. Does a Health Care Agent Need a HIPAA Authorization to Get Access to Medical Records?

No. First of all, the Health Care Proxy Law itself gives the agent a limited right "to receive medical information and medical and clinical records necessary to make informed decisions regarding the principal's health care."[16] Based on that provision an agent can access records relating to pending decisions, and according to one court, records useful for ongoing care decisions.[17]

But the HIPAA privacy rule extends the agent's authority even further: it gives an individual the right to access his or her own medical record,[18] and further provides that when an individual lacks capacity, his or her HIPAA privacy rights may be exercised by a "personal representative." It defines the personal representative as a person who under applicable law has "the authority to act on behalf of an individual who is an adult or an emancipated minor in making decisions related to health care."[19] That person is the health care agent.

Accordingly, a health care agent can access some medical records pursuant to the health care proxy law, and a broader range of medical records by virtue of being the patient's legal representative under HIPAA.

7. Can the Agent Override a Decision Previously Expressed by the Patient?

In general, no. While the law empowers the agent to make "any and all [health care] decisions on the principal's behalf that the principal could make,"[20] it goes on to provide as follows:

> 2. Decision-making standard. . . . the agent shall make health care decisions: (a) in accordance with the principal's wishes, including the principal's religious and moral beliefs; or (b) if the principal's wishes are not reasonably known and cannot with reasonable diligence be ascertained, in accordance with the principal's best interests . . . .

If, for example, a patient directly tells staff, or leaves a written instruction, that he or she consents to a do-not-resuscitate (DNR) order, and then loses capacity, the agent is obligated to honor those instructions.[21] Conversely, if a patient expresses a wish for aggressive care, the agent is obligated to honor that wish.

To be sure, the agent may sometimes have a valid reason to override the patient's prior decision. For instance, in the DNR case described above, the agent might have information that the patient never actually agreed to the DNR order, or was pressured or coerced. The agent might have proof that the patient did not understand what he or she was agreeing to, or that the patient subsequently changed his or her mind.[22] The agent might contend that the clinical circumstances are different now and the patient would no longer want the DNR order. More generally, an agent has broad latitude to interpret the patient's wishes and apply them to actual decisions, when there is room for such interpretation.

But what the agent does not have is the authority to do is to interpose his or her own wishes and values as a basis to override the prior expressed wishes of a capable patient. That would defeat a key purpose of the statute: to ensure that such wishes would be respected in the event of a loss of capacity. Put differently, the agent cannot simply say, "I don't care what mom told you, I'm telling you this."

Conflicts such as this also raise procedural issues: can a provider simply disregard the instructions of an agent who appears to be acting contrary the patient's wishes? For one thing, in the example above where the agent opposes a DNR order, the practitioner needs to consider the applicability of PHL § 2984.5, which provides:

> 5. Notwithstanding the provisions of this section or subdivision two of section twenty-nine hundred eighty-nine of this article, if an agent directs the provision of life-sustaining treatment, the denial of which in reasonable medical judgment would be likely to result in the death of the patient, a hospital or individual health care provider that does not wish to provide such treatment shall nonetheless comply with the agent's decision pending either transfer of the patient to a willing hospital or individual health care provider, or judicial review in accordance with section twenty-nine hundred ninety-two of this article.

But this provision rather specifically applies to a disagreement between the agent *and the provider*: it refers to "a hospital or individual health care provider that does not wish to provide such treatment." In contrast, this FAQ and the example above posits a conflict between the agent *and the patient's clearly expressed prior wishes*. For that reason, in this author's view, PHL § 2984.5 is inapplicable.

No published court decision has addressed this issue. Until it is resolved, a provider and its attorney understandably will be wary about withdrawing or withholding life-sustaining treatment in defiance of an agent's instructions, and may be inclined to seek a court ruling before proceeding. But if the patient's decision is very clear, and the clinical decision cannot wait for judicial review, legal and ethical principles support honoring the patient's decision.

8. Can a Health Care Agent Exercise Other Personal Rights on Behalf of the Patient, Such as Deciding Who Can Visit?

No. The health care proxy law gives the agent only the authority "to make health care decisions,"[23] which it defines as "any decision to consent or to refuse to consent to health care."[24] It further defines health care as any

"treatment, service or procedure to diagnose or treat an individual's physical or mental condition."[25]

In practice, providers tend to interpret "health care" broadly enough to encompass decisions closely linked to treatment, like discharge planning. But a health care proxy does give an agent authority akin to that of a guardian of the person, such as who can visit or call, or whether the patient can sign documents, etc.

However, the person who is the health care agent may have much broader authority based on other instruments (like a power of attorney) or sources (such as the Department of Health regulations regarding the "designated representative" of a nursing home resident).[26]

9. Can a Health Care Agent Remove a Patient From a Hospital Against Medical Advice (AMA)?

Yes – provided the decision is consistent with the patient's reasonably known wishes.

A discharge "Against Medical Advice," or AMA, occurs when a patient leaves the hospital before it is safe to leave, and despite being warned that leaving could jeopardize the patient's health or life.

Capable patients can and sometimes do leave the hospital AMA. As noted previously, the agent can make "any and all decisions on the principal's behalf that the principal could make."[27] As also noted previously, discharge decisions are generally regarded as health care decisions within the meaning of the statute. So it follows that a health care agent could remove an incapable patient AMA.

But the statute's decision-making standard provides for a reality check on such a decision:

> 2. Decision-making standard. . . . the agent shall make health care decisions: (a) in accordance with the principal's wishes, including the principal's religious and moral beliefs; or (b) if the principal's wishes are not reasonably known and cannot with reasonable diligence be ascertained, in accordance with the principal's best interests . . . .

Accordingly, before a hospital allows an agent to remove a patient against medical advice, it should and usually will probe the agent's rationale carefully to determine whether it is based on the patient's reasonably known wishes – because by definition it will not be in the patient's best interests.

10. Can a Health Care Agent Complete a MOLST for an Adult?

Yes, if the patient has been determined to lack capacity. A Medical Order for Life Sustaining Treatment (MOLST) is a medical order (a physician's directive to staff) regarding end-of-life decisions that includes the necessary patient, agent or surrogate consents, and that is portable – it will remain valid if the patient is transferred from one setting to another. New York state law specifically recognizes the MOLST's validity as a DNR order.[28] But if completed by a competent patient, or by a duly authorized agent or surrogate acting under the Family Health Care Decisions Act, it is valid for other end-of-life decisions as well.

And indeed, the DOH-approved MOLST form includes a signature line for the "Decision-Maker," asks below that line "Who made the decision?" and provides optional answers – including "Health Care Agent." ■

1. N.Y. Public Health Law (PHL) Article 29-C, Health Care Agents and Proxies, 1990 N.Y. Laws, c. 752.

2. This article uses the term "patient" to describe the person for whom a health care agent is making decisions because it conveys a sense of the clinical context better than the statutory term "principal" does.

3. N.Y. Mental Hygiene Law Article 78, which was repealed in 1981, provided for a "Committee of the Incompetent or Patient" to care for the person and property of an incompetent person. It was replaced in 1981 by the current guardianship statute, Surrogate's Court Procedure Act (SCPA) Article 17-A. References to MHL Article 78 are now deemed to refer to SCPA Article 17-A. Bills that would correct this reference along with other minor corrections to surrogate decision-making laws have been introduced repeatedly since 2011, but have not been passed. *E.g.*, S.4791 (Hannon) (2015), A.6936 (Clark) (2015).

4. This article creates a guardianship for developmentally disabled persons.

5. PHL § 2980.3.

6. PHL § 2981.4.

7. *See, e.g., In re Mildred M.J.*, 43 A.D.3d 1391 (4th Dep't 2007).

8. *See, e.g., In re Rose S.*, 293 A.D.2d 619 (2d Dep't 2002); *In re Camoia*, 48 Misc. 3d 1221 (Sup. Ct., Kings Co. 2015) (Reported in Westlaw); *In re Cox*, 47 Misc. 3d 1211(A) (Sup. Ct., Kings Co. 2015) (Reported in Westlaw).

9. PHL § 2981.1.

10. SCPA art. 17-A or MHL § 81.22(a).

11. PHL § 2982. The exception, PHL § 2983.5, relates to decisions by the patient himself or herself.

12. MHL § 81.22(b).2.

13. PHL § 2992. *See e.g., In re Walter K.H.*, 31 Misc. 3d 1233 (Sup. Ct., Erie Co. 2011).

14. PHL § 2981.6.

15. PHL § 2981.4.

16. PHL § 2982.3.

17. *Mougiannis v. N. Shore – Long Isl. Jewish Health Sys., Inc.*, 25 A.D.3d 230 (2d Dep't 2005).

18. 45 CFR § 164.524.

19. 45 CFR § 164.502(g)(2).

20. PHL § 2982.1

21. In fact, where the patient previously, when capable, provided clear consent to treatment or the withdrawal of treatment, there generally is no legal requirement to secure a redundant consent from an agent or surrogate at all. The Family Health Care Decisions Act is more explicit than the Proxy Law this regard. PHL § 2994-d(3)(a)(ii). But even in such cases, for a variety of legal, ethical, risk management and professional reasons, providers often will seek a decision from the agent or surrogate as well.

22. *E.g., Univ. Hosp. of the State of N.Y. Upstate Med. Ctr.*, 194 Misc. 2d 372 (Sup. Ct., Onondaga Co. 2002).

23. PHL § 2982.

24. PHL § 2980.6.

25. PHL § 2980.4.

26. 10 N.Y.C.R.R. §§ 415.2(f); 415.3.

27. PHL § 2982.1

28. PHL § 2994-dd; 10 N.Y.C.R.R. § 400.21(e). See https://www.health.ny.gov/professionals/patients/patient_rights/molst/.