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Can the Right to Stop Eating and Drinking be Implemented by a Surrogate?

Can the Right to Stop Eating and Drinking be Exercised via a Surrogate Acting Pursuant to an Advance Instruction?

Norman L. Cantor

The right of a grievously stricken, competent patient to hasten death by ceasing eating and drinking is increasingly recognized. See T. Pope & L. Anderson, VSED, 17 Widener L.Rev. 363 (2012); Cantor, http://blogs.harvard.edu/billofhealth/2016/11/18/patients-right-to-stop-eating-and-drinking/ In the typical scenario, a person afflicted with a serious degenerative disease reaches a point where the immediate or prospective ordeal has become personally intolerable. The stricken person decides to shorten the ordeal by stopping eating and drinking, precipitating death by dehydration within 14 days. The dying process is not too arduous so long as there is a modicum of palliative care available – emotional support, lip and mouth care, and provision of a sedative if patient agitation or disorientation ensues.

A further question is whether a person can dictate a similar fatal course for his or her post-competence self by advance instruction to an agent. The instruction would be that -- once a pre-defined point of dementia has been reached -- either no food or drink should be offered to the incompetent patient or no manual assistance should be provided where the patient is not self-feeding. This post-competence SED tactic appeals to persons who view the prospective demented status as intolerably demeaning and wish to hasten their demise upon reaching that state. The legal claim would be that if a competent patient has a right to SED, the right ought to subsist post-competence when exercised by clear advance instruction. According to this claim, just as an advance instruction to reject a respirator would be upheld as an exercise of prospective autonomy, so an instruction for cessation of nutrition should be respected.

A person who undertakes responsibility for a demented person normally has a fiduciary duty to promote the well-being, comfort, and dignity of the ward. A guardian who forgoes available care measures such as shelter, warmth, hygiene, and food is chargeable with unlawful neglect. Provision of food and assistance in eating are normally part of that fiduciary obligation. A legal exemption might apply, though, if the guardian – in discontinuing hand feeding pursuant to an advance instruction -- is simply respecting the right of the ward to exercise prospective autonomy. The question becomes: Is the acknowledged right to SED exercisable by means of an advance instruction?

As a person intent on avoiding being mired in deep dementia, I wish I could declare that the described post-competence SED tactic is legally sound. But I can't. In the form it is currently recognized, the right to SED cannot readily be translated to the context of a moderately demented person. Here's why.

A competent stricken patient who hastens death by initiating SED is not simply invoking the well-established liberty right to reject life-sustaining medical intervention in order to let a natural affliction take its course. Unusual suicidal overtones are present. For example, an ALS patient who stops accepting food and drink is undertaking a deviant

course (SED) that will precipitate death. The proximate cause of death will be self-initiated dehydration rather than the underlying ALS disease process. Common judicial willingness to overlook the suicidal overtones, and to accept a right to SED, hinges on 2 factors: a) a patient's contemporary judgment that the serious medical affliction entails such intolerable debilitation and/or suffering that death by dehydration is preferable; and b) the repulsive inhumanity of the prospective medical intervention. (In the context of a stricken person determined to resist feeding, the contemplated medical solution -- forced feeding -- involves unwanted bodily invasions and physical or chemical restraints widely deemed inhumane).

Neither of these factors underpinning the right to SED is present once a patient is no longer mentally competent. The stricken patient is no longer capable of deciding that the current deteriorated status is so intolerably undignified or distressing that death by dehydration is preferable. And the contemplated medical intervention – hand feeding to a willing patient – entails no revolting indignity. Without these elements, even with an advance instruction in hand, a surrogate decision maker who seeks to initiate SED for a moderately demented patient willingly accepting oral feeding is treading in euthanasia or assisted dying territory. The legal tolerance for self-destruction implicit in acceptance of a "right" to SED might well not be extended to a now-demented patient.

All this does not mean that advance directives are inapplicable to post-competence matters of nutrition and hydration. For when hand feeding becomes a form of medical intervention, a person's prerogative of using prospective autonomy (advance instructions) to shape post-competence medical treatment does come into play.

This prospective control of medical intervention is not dependent on living will statutes with their typical constraints like a "terminal illness" requirement. Long before widespread living will legislation, prominent courts recognized that a patient's basic common law right to control medical measures extends to a post-competence stage so long as clear prior instructions exist. State courts led the way in ruling that a person's common-law and/or constitutional liberty to control medical choices does not vanish upon incompetence. E.g., In re Browning, 568 So.2d 4 (Fla. 1990); In re Jobes, 529 A.2d 434, 451 (N.J. 1987). The U.S. Supreme Court concurred in dictum in Cruzan. This judicial recognition is reinforced in the many states that statutorily provide for advance appointment of health care agents with authority to make the same range of medical decisions as competent patients. Such statutes commonly require the designated agent to implement the patient's known wishes concerning post-competence medical care.

This "prospective autonomy" legal framework for post-competence cessation of nutrition is applicable where the relevant feeding techniques qualify as medical intervention. For example, where dementia produces swallowing or digestive disorders necessitating ANH (by nasogastric tube or PEG tube), medical intervention is clearly in issue and the now-incompetent patient's prior instructions should govern.

The harder question is whether hand feeding necessitated by common eating deficits accompanying progressive dementia qualifies as medical treatment. Reduced nutritional intake can flow from cognitive decline (such as non-recognition of food or eating utensils) or physical deterioration (such as loss of mechanical skills for self-feeding). From one perspective, hand feeding is then a therapeutic "medical" response to pathology associated with the degenerative affliction. However, if the demented patient is still willing to eat and is accepting hand feeding, and eating assistance can be performed by non-medical personnel, such feeding might be classified as basic personal care rather than medical treatment. (Whether basic personal care can be rejected by a binding advance instruction is an open issue).

Even if the presence of an eating disorder emanating from dementia qualifies manual feeding as medical intervention, implementation of an advance instruction rejecting hand feeding is fraught with hurdles – at least at stages of decline preceding advanced dementia. Keep in mind the common profile of a moderately demented person. Despite significant cognitive debilitation, that person is not perceptibly suffering and may ostensibly be deriving modest pleasures from life. (E.g., listening to music). That moderately demented person no longer recalls his or her once strong aversion to the perceived indignities of debilitation and dependency. I.e., that person no longer remembers their previously expressed determination to reject hand feeding in order to hasten their post-competence demise. In those circumstances, even a clear prior instruction to forgo all forms of nutrition and hydration faces complications or challenges in implementation.

The first complication relates to the nature of the dying process for the moderately demented person whose advance instruction rejects all nutrition, including hand feeding, at the stage of cognitive decline now at hand. A competent person who undertakes SED needs a resolute will to overcome normal hunger and thirst pangs as well as to resist entreaties from people opposing the fasting plan. That resolve must remain firm for 6 to 10 days until the fasting patient slips into coma; ingesting even small amounts of nutrition or hydration may substantially prolong the dying process. A moderately demented person may lack the requisite motivation and determination, thus creating potential for a much more protracted and distressful dying process. Such a person might be expecting and seeking food and drink and might be distressed by their absence. Some caregivers might capitulate to sporadic entreaties and provide nutritional intake extending the dying process.

On the other hand, perhaps palliative interventions (sedation) can ease the confusion or agitation of the moderately demented patient. And perhaps some demented patients will be unperturbed and indifferent to absence of nutrition. In such instances, a placid death by dehydration might be available for the demented patient. In short, the process of death by dehydration for an uncomprehending patient is uncharted territory. A modicum of dignity in the dying process might, or might not, be available in the context of surrogate- initiated cessation of hand feeding.

Another potential obstacle to post-competence SED is caregivers' reluctance to cooperate with a surrogate-initiated cessation of hand feeding. Some physicians, nurses, or health care aides see provision of food and water by mouth as a symbolic gesture of caring for fellow humans that is demanded by the caregivers' ethical or conscientious principles. Such moral compunctions may also underlie institutional policies (in Catholic and some other elder-care facilities) opposed to withholding of hand feeding. Professional and institutional reluctance to cooperate with non-feeding will be most intense where the moderately demented person is still engaged in positive interactions with their surroundings. While the conscientious objections of some caregivers should not override a clearly expressed advance rejection of medical intervention, finding replacement caregivers may pose a significant practical obstacle to implementation of the advance instruction declining hand feeding.

A final challenge lies in interpreting the conduct of a demented patient who is now seeking or accepting hand feeding despite a prior instruction rejecting post-competence hand feeding. A person who dictates an advance instruction is entitled to change their mind and revoke. Does a demented patient's acceptance of hand feeding or utterance of a verbal request for food and drink constitute an effective revocation of a prior instruction?

A counter perspective is that the demented, uncomprehending patient is acting by reflex rather than by volition or is being manipulated by surrounding people exploiting the suggestibility of the now-incompetent patient. The legal reality is that no established judicial standard exists for assessing cognitive capacity needed to revoke an advance instruction invoking a right to prospectively reject medical care. Note that statutes speaking to living wills typically make advance directives revocable even by post-competence utterances. These statutes don't apply to prospective exercise of the basic common-law right to reject medical intervention. But they still reflect a customary willingness to defer to contemporaneous life-extending expressions – even from mentally incapacitated persons. And at least one court has ruled that a totally uncomprehending acceptance of spoon feeding is legally sufficient consent to hand feeding. See Bentley v. Maplewood Seniors Care, 2014 BCSC 165 (Feb. 2014), affirmed 2015 BCCA 91 (British Columbia Ct. App. 2015). (That case did not deal with a clear prior instruction rejecting hand feeding).

What, then, are the tentative conclusions regarding the legal status of advance instructions rejecting post-competence hand feeding? One is that the recognized right of a competent, stricken patient to SED is not readily translatable to the context of a now-incompetent patient. Another is that a legally sound theoretical framework exists for enforcing advance instructions to reject nutrition and hydration, including hand feeding, so long as the hand feeding can be classified as medical intervention necessitated by pathologies associated with progressive dementia. Despite that sound legal framework, though, a variety of complications or hurdles exist in implementing an advance non-

feeding instruction regarding a moderately demented patient (as opposed to a patient who has reached advanced dementia).

These complications or hurdles face any person whose aversion to the indignities of cognitive debilitation fuels a desire to hasten death once a significantly demented status has been reached. That desire might prompt advance instructions to forgo even the most simplistic medical interventions such as antibiotics for any infection. Such instructions encounter an instinctive human reluctance to hasten the death of a person who, while cognitively debilitated, is not suffering, derives some satisfaction from continued existence, and no longer recalls the dignity and life-image concerns that motivated a prior instruction to forgo even simplistic medical interventions. That topic goes beyond provision of nutrition and hydration and deserves to be addressed further. Stay tuned.