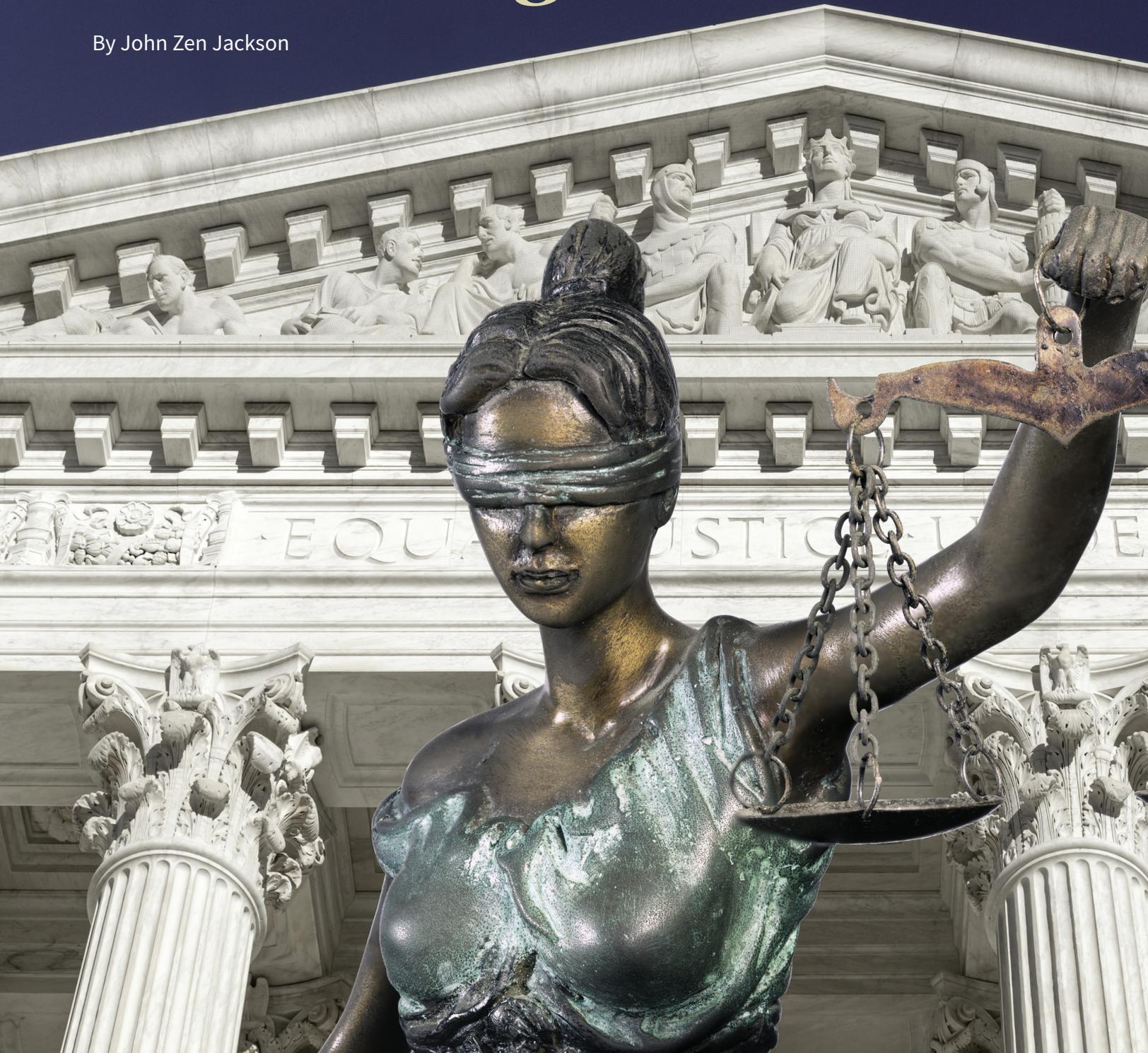


A Case Note Regarding
**Force-Feeding of
Anorexic Patients
and the Right to Die**

By John Zen Jackson





ON FEBRUARY 20, 2017, a 30-year-old woman, publicly identified only as “A.G.,” died at a hospice facility in Morristown, New Jersey. A.G. was a young woman with anorexia nervosa, refractory to appropriate management efforts, who had expressed a clear decision to forego artificial nutrition and hydration at a time when her illness had resulted in a malnourished and likely life-threatening condition. Her death was the culmination of a controversy with legal proceedings in the Superior Court of New Jersey that had commenced in June 2016 and ended with a ruling on November 21, 2016 that prohibited the forced feeding of the patient and authorized her transfer to palliative care in a hospice setting rather than a return to the psychiatric facility where she had been involuntarily committed for the two preceding years.¹ This appears to be the first time that an American court has upheld the withdrawal of nutritional support for a person with anorexia.

A.G.’s circumstance prompts a renewed examination of end-of-life decision-making, especially regarding a mentally ill individual’s wishes with respect to medical care. The case provides stimulus for thought concerning ethical and legal aspects impacting the type of care such a patient ought to receive and the circumstances under which she might—or might not—be permitted to exercise her right of self-determination. It also offers insight into the roles played in the decision-making process by the affected individual, family, treating physicians and the institution(s) providing care.

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THE CASE

According to the court record, patient A.G. had struggled with her body image and anorexia nearly all of her life, starting at age five. Over many years, A.G.'s parents had attempted to get treatment for their daughter's anorexia with admissions to hospitals and eating disorder facilities, attendance at therapy sessions and management of her medication. This was without sustained effect.

In 2012, after the recent enactment of the Physician's Orders for Life-Sustaining Treatment Act, A.G. completed a POLST form. Her stated goals of care were "to live freely, not being bothered by anyone." She specifically indicated that she did not want artificial nutrition and hydration. She later reasserted this position in testimony to the court.²

In 2013, A.G. was involuntarily committed to a state psychiatric hospital. Her continued resistance to therapy and weight loss led the Attorney General to go to court in 2016 asking for a temporary guardian to consent to surgical placement of a percutaneous endoscopic gastrostomy tube. An order was entered and treatment was administered, but the patient experienced the complication of "re-feeding syndrome," damaging her heart. She eventually pulled out the tube.²



Following extensive consultations among the guardian, legal counsel, the patient's parents, her treating physician and psychiatrist and a hospital ethics committee, a request was made to the court to permit A.G. to refuse force feeding and enter palliative care. Contending the patient was not competent, the Attorney General opposed the request and proposed treatment consisting of nasogastric tube insertions for nutrition, administration of ketamine for her depression and improvement in the quality of her life with more frequent family visits and therapy.

The legal touchstone for the issues presented in A.G. is the 1976 New Jersey Supreme Court decision of *In re Quinlan*.³ Superior Court Judge Paul W. Armstrong* noted that *Quinlan* and its progeny gave "New Jersey the richest body of decisional case law in the nation addressing the right to refuse life-sustaining treatment."² (Judge Armstrong was uniquely qualified

to make that observation since he had been the Quinlan family lawyer in the New Jersey Supreme Court case.) In analyzing A.G.'s circumstances, the judge summarized the impact of various leading New Jersey Supreme Court cases and distilled the *Quinlan* legacy to nine principles:²

1. Competent patients have a constitutional right of privacy and a common law right of self-determination that included the right to accept or refuse treatment, including life-sustaining treatment.
2. While no right was absolute and countervailing interests in preserving life, preventing suicide, safeguarding the integrity of the medical profession and protecting innocent third parties from harm must be considered, the instances in which these societal interests outweigh a patient's right to refuse life support when terminally ill or permanently comatose were rare.
3. The right to refuse treatment encompassed all life-sustaining treatments, including artificially provided nutrition and hydration.
4. These rights are not lost with a patient's loss of decisional capacity and may be exercised by families, healthcare proxies and other appropriate surrogates on behalf of incompetent patients.
5. Decision-makers should seek first and foremost to follow the patient's wishes. In the exercise of this fiduciary responsibility, the proxy, family and physician should rely on a patient's advance directive if one has been written, and should look for the patient's past statements, values and beliefs, such as contained in a POLST form or, if available as in this instance, the testimony of the patient.
6. When this subjective assessment proves inadequate, the decision may also be based upon the best interests of the patient, but decisions to terminate life support usually find some basis in the patient's prior expressions.
7. Withholding or withdrawing treatment from a terminally ill or permanently comatose unconscious patient merely allows the natural dying process to take its course. It does not constitute killing or suicide, assisted suicide or euthanasia.
8. A local process in the clinical setting, such as hospital ethics committees or ethics consultation services, should be employed to facilitate resolution of misunderstandings and disagreements. Recourse to the courts should be pursued only in exceptional or intractable cases.
9. The right to refuse treatment applies in hospitals, nursing homes and other care settings.

*The Honorable Paul W. Armstrong, J.S.C. (retired) is a member of the Editorial Board of *MDAdvisor*.

In applying these principles to reach its decision given “the inauspicious circumstance of a dire diagnosis and a poor prognosis, coupled with the limits of modern medicine’s ability to reverse her condition,” the court placed much weight on A.G.’s testimony.² It was “forthright, responsive, knowing, intelligent, voluntary, steadfast and credible.”² This testimony, combined with the prior statements of intent in the POLST form, played a key role in ascertaining A.G.’s wishes. The court noted that the Ethics Committee had previously utilized the POLST form even when a person currently lacked decisional capacity. There was unanimity of the patient, parents, treating psychiatrist, treating internist and the hospital Ethics Committee in supporting A.G.’s refusal of force-feeding and of her entering palliative care. The consensus was that this was in the best interests of the patient. The court placed great emphasis on A.G.’s physicians having consulted with the Ethics Committee, an action that had been strongly endorsed in the *Quinlan* opinion. The court was particularly mindful of the prolonged effort at treatments without sustained success, the risks of physical injury from the proposed three-pronged treatment regimen with the imposition of terror and suffering and the seemingly inescapable status of A.G. having an untreatable, irreversible and inevitably terminal condition. While her entry into palliative care was with the understanding that death was or could be a possible outcome, A.G. retained the option to consent to some feeding.

THE RIGHT TO VOLUNTARILY STOP EATING AND DRINKING

The choice to voluntarily stop eating and drinking (sometimes referred to as VSED) is not something new in end-of-life cases. In 1985, the Supreme Court stated: “A competent patient has the right to decline any medical treatment, including artificial feeding, and should retain that right when and if he becomes incompetent.”⁴ Nourishment by artificial feedings was equivalent to artificial breathing using a respirator: “All prolong life through mechanical means when the body is no longer able to perform a vital bodily function on its own.”⁴ The United States Supreme Court later adopted a similar position.⁵

In the context of patients facing fatal or severe degenerative conditions, an individual’s choice to withdraw or refuse nutrition and hydration has been upheld despite self-destructive and suicidal overtones. Two elements account for this permissive response to a patient’s rejection of care. The first is a combination of sympathy and empathy for a person facing fatal or chronic degenerative disease where the condition has imposed frustrations, burdens and anxiety so as to render one’s quality of life intolerable. The other is judicial distaste at overriding the patient’s will and restraining an afflicted and distressed person. Courts have often made a point of distinction and refused to apply the suicide label.



IMPLICATIONS SPECIFIC TO ANOREXIA NERVOSA

While previously reported New Jersey decisions on refusal or cessation of nutrition and hydration involved incompetent or unconscious patients, none of them involved a patient with a recognized mental illness such as anorexia nervosa (a psychological illness with Diagnostic and Statistical Manual of Mental Disorders criteria).

Two aspects of the A.G. decision stand out. The first involves the patient’s decision-making. The second revolves around the nature of the illness.

The fact that a person is mentally ill is not necessarily determinative of that individual’s competence to make decisions about life-saving treatment. The test for mental capacity to consent to medical treatment, approved in a 1985 Supreme Court case,⁴ is whether the patient is able to reasonably understand the condition, the nature and effect of the proposed treatment and attendant risks in having the treatment or not having the treatment.

The judge in A.G. had vividly described the patient’s mindset in giving her testimony, but the court did not make a ruling as such on this patient’s competence to decide to refuse treatment. Rather it used a “paradigm of cooperative spirit” of the patient, parents, treating psychiatrist, treating internist and hospital ethics committee members presenting “one compassionate, solicitous and uniform voice”² for this purpose. This approach was an amalgam of the bioethical principles of autonomy, beneficence and nonmaleficence.

Eating disorder specialists and bioethicists have struggled with the challenges of determining competence and capacity of people with anorexia to refuse treatment.⁶ Important considerations in determining capacity involve the patients’ insight or lack thereof into the gravity of the disorder and their health status as well as organic impairments that can affect cognitive abilities. If a person experiences cerebral pseudoatrophy and/or biochemical changes as a result of nutritional deficiencies, there can be cognitive impairments affecting judgment and decision-making. There appears to be a threshold in all starvation-related situations where a person can no longer think rationally because of chemical changes in the body.⁷

People with anorexia can have multiple dysfunctions in information-processing: perception of the input of information, interpretation, decision-making process and output. They may be unable to recall information stored in memory and to utilize it to identify new information coming from the outside. The interpretation of information may also be distorted. And yet, commentators have stated:

[W]e should not conclude that all people with anorexia are necessarily incompetent to refuse treatment. On the contrary, we should “be open to the possibility that sufferers are actually as competent as anyone else to make decisions about the quality of their lives, and to assess the relative value of their lives in the light of its quality.”⁸

The A.G. court had described the patient’s condition as being no longer treatable, irreversible and terminal.² Some will challenge that conclusion, asserting that there is no clarity or strict medical definition of *terminal* for eating disorders. Although eating disorders are often disabling and frequently fatal, it is not the disease that causes death but rather the lack of proper treatment. For people with anorexia, what appears to be a “desire” to avoid eating, a “wish” to end treatment and “refusal” to eat can actually be symptoms of a severe brain disorder.

In December 2016, the Academy of Eating Disorders responded to the A.G. decision, saying: “[D]espite the potentially fatal consequences of these illnesses, full recovery from an eating disorder at any age can be possible.”⁹ Some longitudinal studies have shown recovery from anorexia even after 10 to 20 years duration, which argues against the case for palliative care.¹⁰ And yet within the community of eating disorder specialists, a role for palliative care is recognized. That palliative care should be withheld because of the possibility of recovery even for a patient with a poor prognosis has been rejected as being as invalid in the context of anorexia, as it is in the context of cancer patients.¹¹

Speaking in absolutes is fraught with difficulty. For long-suffering, refractory patients unresponsive to competent treatments and continuing to decline physiologically and psychologically, “palliative care and hospice may be a humane alternative.”¹² In moving away from a long-standing series of decisions directing force-feeding of anorexic patients, in February 2016 a British judge reached a somewhat similar conclusion and authorized the discharge of a patient from further attempts at forced feeding, describing this as “the least worst option.”¹³

CONCLUSION

The A.G. decision appears to be the first time an American court has upheld the right of a person with anorexia to refuse force-feeding or other treatment. Since the case ended with

a decision at the trial level with no officially reported opinion and no appellate review, the A.G. matter has somewhat limited binding effect as a legal precedent. Its power rests in its persuasiveness.

This case once again requires the medical community to focus on the fundamental bioethical principles of autonomy and beneficence that come into conflict when a person with anorexia resists or refuses medically indicated treatment. The challenges are how to respect an individual’s right to make an informed choice without coercion or undue influence while the healthcare providers do what is good and in the best interests of the person for whom they are providing care.

As is true of much in healthcare, this is not easy. Overcoming this challenge requires balancing factors favoring continued treatment with force-feeding with factors favoring refusal of life-saving treatment and palliative care. It is no profound observation that this balancing process does not inevitably result in a single universal correct answer. But what is important is that this balancing process be undertaken and that relevant factors be evaluated and not ignored. 

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2. *In the Matter of A.G.*, Transcript of Decision of the Court (November 21, 2016).
3. 70 N.J. 10 (1976).
4. *In re Conroy*, 98 N.J. 321 (1985).
5. *Cruzan v. Director, Missouri Dept. of Health*, 497 U.S. 261, 273 (1990).
6. See e.g., Tan, J. O., Hope, T., Stewart, A., & Fitzpatrick, R. (2006). Competence to make treatment decisions in anorexia nervosa: Thinking processes and values. *Philosophy, Psychiatry, & Psychology*, 13(4), 267–282; Draper, H. (2000). Anorexia nervosa and respecting a refusal of life-prolonging therapy: A limited justification. *Bioethics*, 14(2), 120–133.
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13. *Re Miss W*, [2016] EWCOP 13.