50 YEARS LATER:

THE ENDURING LEGACY OF KAREN ANN QUINLAN CONTINUES TO INFLUENCE END-OF-LIFE DECISIONS

The case of Karen Ann Quinlan remains a watershed moment in both Catholic bioethics and secular ethical and legal thought. On its 50th anniversary, its impact resonates in evolving understandings of dignity, autonomy and the role of modern medical technology.

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On April 15, 1975, 21-year-old Quinlan collapsed at a party in New Jersey after ingesting alcohol and tranquilizers, resulting in two 15-minute periods of anoxia and irreversible brain injury. Her friends initially put her in bed to recover; then, when she stopped breathing, one of them performed mouth-to-mouth resuscitation. They then called emergency services when she continued to be unresponsive.

She was transported to Newton Memorial Hospital in Newton, New Jersey. Upon clinical examination, she had a temperature of 100 degrees, her pupils were unreactive and she was unresponsive even to deep pain. The attending physician, Dr. Paul McGee, requested a consultation from neurologist Dr. Robert Morse.

Morse found that Quinlan was comatose with evidence of decortication, a condition relating to derangement of the cortex of the brain. The condition causes a physical posture in which the upper extremities are flexed and the lower extremities are extended. She required a respirator to assist her breathing. Subsequently, she was transferred to St. Clare's Hospital, which was Catholic, under the care of Morse. He and other physicians diagnosed Quinlan as being in a persistent vegetative state.[1]

To distinguish between a persistent vegetative state and the determination of death by neurological criteria (brain death), persistent vegetative state is a diagnosis of severe damage to the "thinking" parts of the brain; however, those parts of the brain that control autonomic nervous system responses (for example, breathing and temperature regulation) are still intact. So, there is a lack of consciousness, but the body will still maintain some regulatory functions. The determination of death by neurological criteria has as its standard the irreversible cessation of all functions of the entire brain. It is established through clinical tests, such as apnea testing, when a patient is removed from a respirator to determine if they breathe on their own.[2]

So, according to her physicians, Quinlan was not dead. She was in a persistent vegetative state and required a ventilator and feeding tube for survival.

Her devout Catholic parents were conflicted about how to proceed with her care. According to one author, Quinlan's mother, Julia, and her siblings, Mary Ellen and John, believed that the ventilator should be discontinued. Quinlan's father, Joseph, was not initially convinced.[3] The family consulted with their parish priest, who said that discontinuing treatment was not sinful. Quinlan's father then agreed that her ventilator should be discontinued. The family had evidence that Quinlan did not wish to be kept alive by extraordinary measures.

A FAMILY AND HOSPITAL DIVIDED

Central to Catholic moral thought is the distinction between *ordinary* (proportionate) and *extraordinary* (disproportionate) means of preserving life.[4] This doctrine, based on St. Thomas Aquinas and many centuries of theological reflection, maintains that individuals must use ordinary means to preserve their life, but may forgo extraordinary treatments. So, for example, one is morally obligated to have regular medical appointments to assess one's health, but does not have to undergo chemotherapy if the burden ex-

ceeds the benefit. Quinlan's ventilator aptly illustrated a potentially extraordinary intervention.

Generally, every person should make their own decisions regarding medical treatment. In situations where the patient is no longer competent to decide, like Quinlan, a person should be appointed to act in their name, making choices the person would have made for themself. This is important. If a surrogate decision-maker acts for the incompetent patient, they are not making decisions *for* them. Instead, they are making decisions *as* them. Usually, today, the person who is incapacitated will have made the decision of who will act on their behalf when they are competent. Otherwise, the selection of that person is made under legal requirements. But it is also essential to note that during Quinlan's time, this was not yet a usual practice.

So, having made the judgment that the ventilator was extraordinary care, the family asked Morse and St. Clare's Hospital to remove Quinlan from the ventilator. They both refused, arguing that since Quinlan was diagnosed as being in a persistent vegetative state, it would be contrary to medical ethics to remove her from the respirator. Since she was not dead, their position was that life-sustaining technologies should be used to preserve her life.[5]

The Quinlan family made their request to discontinue the ventilator based on their Catholic beliefs and theology. They were supported by their local parish priest, Msgr. Thomas Trapasso, and Bishop Lawrence Casey of the Diocese of Paterson, New Jersey. But those beliefs and theology were not sufficient in changing the decisions of the physician and the hospital. With their request denied, the Quinlans filed a civil lawsuit in 1975 against Morse and St. Clare's Hospital.

A RIGHT TO PRIVACY

In their suit, the Quinlans made three arguments. First, it was argued that denying the choice to remove the ventilator based upon their Catholic beliefs was a violation of religious rights under the First Amendment to the U.S. Constitution. Second, keeping Quinlan on a ventilator was a form of "cruel and unusual punishment," which violated the Eighth Amendment to the U.S. Constitution. Lastly, they argued that Quinlan had a right to privacy, to make her own medical decisions, and that her father should be empowered to make them for her as a surrogate decision-maker.

The New Jersey Superior Court ruled in favor of Morse and the hospital. It argued that the decision to discontinue care was a medical one, not a personal one. Further, it said that even if Quinlan had said that she would not want extraordinary treatment, she said this as a young person while discussing a theoretical situation, not the one she was in now. The Quinlans appealed to the highest state court.

The New Jersey Supreme Court rejected the first two arguments of the suit. For the first argument, that of religious freedom, the court wrote that "Simply stated, the right to religious beliefs is absolute but conduct in pursuance thereof is not wholly immune from governmental restraint."[6] With regard to the argument that keeping Quinlan on a ventilator was "cruel and unusual punishment," the court stated that the context for the Eighth Amendment was related to penal punishment, not medicine. However, the court agreed with the third argument, that Quinlan had a right to privacy, overturning the ruling by the New Jersey Superior Court.

The recognition of a right to privacy was first proposed in a *Harvard Law Review* article in 1890.[7] However, it did not become formally recognized as a legal principle in a judicial decision until 1965, in the U.S. Supreme Court case of Griswold v. Connecticut. That case involved a suit by Estelle Griswold, the executive director of the Planned Parenthood League of Connecticut, who was arrested and charged with violating a Connecticut law passed in 1879 that banned the use of any drug, medical device or other instrument in furthering contraception. Griswold argued that the law violated the right to privacy of married couples. They had a right to be left alone with their choices regarding sexual relations. The U.S. Supreme Court agreed and ruled in favor of Griswold.

From 1965 until the New Jersey Supreme Court reached its decision on Quinlan, the right to privacy was invoked in several cases.[8] The Quinlan decision stated that the right to privacy also extended to medical interventions. Although Quinlan never met the legal criteria for brain death, the court concluded that the withdrawal of ventilatory support, once deemed medically futile, did not constitute homicide. In the words of the court:

We have no hesitancy in deciding ... that no

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> external compelling interest of the state could compel Karen to endure the unendurable, only to vegetate a few measurable months with no realistic possibility of returning to any semblance of cognitive or sapient life. We perceive no thread of logic distinguishing between such a choice on Karen's part and a similar choice which, under the evidence in this case, could be made by a competent patient terminally ill, riddled by cancer and suffering great pain ... .[9]

Further, the court appointed Quinlan's father, Joseph, to be her surrogate decision-maker.

Quinlan's physicians gradually weaned her from the respirator during May of 1976. She continued to breathe on her own. The family did not want artificial nutrition and hydration stopped, because they thought that these interventions were ordinary, proportionate care, although the State Supreme Court gave permission for all life support to be withdrawn. Quinlan lived another 10 years, dying on June 11, 1985.

A LEGACY THAT AFFIRMS HUMANITY

The Quinlan case created a national template for later decisions like Cruzan v. Director, Missouri Department of Health (1990). In Cruzan, the Supreme Court upheld states' ability to require "clear and convincing" evidence before allowing surrogates to refuse treatment for incompetent patients.[10] It also underscored the importance of advance directives. Public awareness following Quinlan's case led to widespread adoption of advance directives and living wills. The federal Patient Self-Determination Act (1990) required health care institutions to inform patients of these legal tools — a direct outgrowth of the Quinlan precedent.

Quinlan continues to inform discussions on assisted suicide, artificial hydration, brain death and definitions of personhood. More advanced technologies, from artificial intelligence-guided interventions to gene editing, heighten these ethical stakes, but the core of the Quinlan teachings — dignity, consent and reasoned restraint — remain vital.

The shift championed by Quinlan's case — from paternalism toward collaborative, patient-centered care — continues as clinicians integrate medical insight with value-sensitive choices, mediated by ethics committees and ethics consultants. As can be seen in the New Jersey Superior Court's decision, prior to Quinlan, the tendency was to empower physicians to have the final choice in decision-making. After this case, the emphasis has been on informing patients about their choices so that they can choose to accept or reject medical treatments. This shift, however, does not mean that they can compel physicians to provide any care that they want.

On its 50th anniversary, the Quinlan case stands as an ethical landmark. For the Catholic Church, it validated theological distinctions between ordinary and extraordinary care and gave momentum to formal guidance grounded in compassion. For secular bioethics, it laid the groundwork for the autonomy movement, institutional ethics, legal precedents and public policies that empower individuals facing end-of-life dilemmas.

Centuries from now, as new medical capabilities emerge, the Quinlan principles — balancing respect for life with a humane acceptance of death — will continue to guide society in difficult moments. In honoring Quinlan's journey, we honor a legacy that transcends technology and ideology, affirming our shared humanity.

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NOTES

1. "In Re Quinlan," Justia, https://law.justia.com/cases/new-jersey/supreme-court/1976/70-n-j-10-0.html.
2. In 1968, Harvard Medical School released a report titled "A Definition of Irreversible Coma," which proposed brain death as a new legal standard for determining death based on the irreversible loss of neurological function. See: "A Definition of Irreversible Coma:

Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death," *JAMA* 205, no. 6 (1968): 337–340, https://doi.org/10.1001/jama.1968.03140320031009 (requires paid access). This report, often referred to as the "Harvard definition," significantly impacted the understanding and legal acceptance of brain death as a criterion for death in the United States. In 1975, at the time of Karen Quinlan's condition, the Harvard definition was not yet fully enacted as law in all states. It was not until 1980 that the Uniform Law Commission adopted the Uniform Determination of Death Act, which would become the model for states enacting legislation that would establish neurological criteria for the determination of death. It would take many years after that for states to adopt the language. At the present time, most, but not all, states recognize neurological criteria for the determination of death. It is important to note that there are other tests beyond apnea testing.

3. Matthew Stonecipher, "The Evolution of Surrogates' Right to Terminate Life-Sustaining Treatment," *Virtual Mentor* 8, no. 9 (2006): 593-598, https://doi.org/10.1001/virtualmentor.2006.8.9.hlaw1-0609.

4. Rev. Donald Henke, "A History of Ordinary and Extraordinary Means," *National Catholic Bioethics Quarterly* 5, no. 3 (2005): 555-575, https://doi.org/10.5840/ncbq20055333.

5. This 1975 article from *The New York Times* gives context to Dr. Morse's decisions: Joseph F. Sullivan, "Doctor Tells Court He'd Refuse to Let Woman in Coma Die," *The New York Times*, October 21, 1975, https://www.nytimes.com/1975/10/21/archives/doctor-tells-court-hed-refuse-to-let-woman-in-coma-die-her-doctor.html.

6. "In Re Quinlan," Justia.

7. Samuel Warren and Louis Brandeis, "The Right to Privacy," *Harvard Law Review* 4, no. 5 (1890): 193-220, https://doi.org/10.2307/1321160. Louis Brandeis was a future U.S. Supreme Court Justice and Samuel Warren was his law partner. The article came about in part because of intrusions by reporters and newspaper photographers into the life of the Warren family. Together, he and Brandeis argued in their article that there was an implied right of privacy, to be left alone in their own lives to make decisions, in the U.S. Constitution.

8. See, for example, the following cases: "Eisenstadt v. Baird, 405 U.S. 438 (1972)," Justia, https://supreme.justia.com/cases/federal/us/405/438/; "Roe v. Wade, 410 U.S. 113 (1973)," Justia, https://supreme.justia.com/cases/federal/us/410/113/.

9. "In Re Quinlan," Justia.

10. "Cruzan v. Director, Missouri Department of Health 497 U.S. 261 (1990)," Justia, https://supreme.justia.com/cases/federal/us/497/261/.