Lessons from *My Sister’s Keeper*: A Minor’s Right to Refuse Life-Saving Treatment

By: Stephanie O’Loughlin

“Do you think it would work?” I asked. “A kidney transplant?”
Kate looked at me. “It might.” She leaned over, her hand on the light switch. “Don’t do it,” she repeated, and it wasn’t until I heard her a second time that I understood what she was really saying.

—Jodi Picoult, *My Sister’s Keeper*¹

I. Introduction

Jodi Picoult’s *My Sister’s Keeper* is a novel that explores the difficult topic of terminal illness of a sixteen-year-old girl, and the lengths that her family goes through in order to preserve her life. Much of the literature that has been written on this novel focuses on Anna, the sister who was born in order to become a donor for her sister, Kate, and the ethics of forcing such donations from a child. Anna hires a lawyer to sue her parents for the “rights to [her] own body” so that cannot be forced to donate a kidney to her sister. While Anna is providing testimony in court, however, it is revealed that Kate had appealed to Anna, and asked her to let her die. This reveal not only transforms Anna’s seemingly selfish act, but also raises two important questions: what lengths must a minor go through in order to die with dignity, and when is it possible for a minor to refuse life-saving treatment?

Generally speaking, minors are presumed to be incompetent to consent to their own medical treatment, but some states accept the mature minor doctrine, which allows minors to independently consent to certain medical procedures if certain criteria are met. But even in the states where this doctrine is accepted, there is no universal standard that dictates when a minor is mature enough to consent to medical procedures without the involvement of her parents. Although *My Sister’s Keeper* is a work of fiction, it presents a compelling narrative of a minor that is desperate to have agency over her body, and the medical treatment that her body undergoes. Minors who are terminally ill may feel trapped in their bodies, and feel forced to prolong what is

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3 PICOULT, supra note 1, at 19–21.
4 Id. at 377–78.
6 See infra Part II.A.
ultimately their physical suffering. Based on the constitutional right to bodily integrity, a minor should have the right to invoke the mature minor doctrine in order to refuse life-saving medical treatment.

II. The Development of the Mature Minor Doctrine

A. The Emergence of the Doctrine

Reproductive rights have been imperative to the inception of the mature minor doctrine. One of the earliest authoritative decisions using the mature minor analysis was *Smith v. Seibly*, 431 P.2d 719 (Wash. 1967).\(^7\) In this case, the plaintiff had elected to undergo a vasectomy at eighteen years old, which at the time in Washington state law, was in the age of minority.\(^8\) When the plaintiff reached the age of majority, he filed suit against the physician who had performed the procedure, claiming that he had been unable to consent to the surgery because of his age.\(^9\) The Washington Supreme Court held that the plaintiff was an emancipated minor at the time that he had given his consent to the surgery because, at eighteen years old, he was already married, the head of his household, was economically independent, and had completed high school.\(^10\) The court had previously determined in *Grannum v. Berard*, 422 P.2d 812 (Wash. 1967) that a minor’s ability to consent to surgical procedures required case-by-case analysis,\(^11\) and stated that “age, intelligence, maturity, training, experience, economic independence or lack thereof, general conduct as an adult and freedom from the control of parents”\(^12\) were all factors that, when weighed together, would determine whether a minor was mature for the purpose of making medical decisions.

\(^7\) *Id.* at 2.
\(^9\) *Id*.
\(^10\) *Id.* at 723.
\(^12\) *Seibly*, 431 P.2d at 723.
Similar factors appear in other early cases that helped shape the mature minor doctrine. In *Cardwell v. Bechtol*, 724 S.W.2d 739 (Tenn. 1987), the Tennessee Supreme Court decided that “age, ability, experience, education, training, and degree of maturity or judgment obtained by the minor, as well as . . . the conduct and demeanor of the minor at the time of the incident involved” would determine whether a minor had the capacity to consent to medical treatment. In various states, the doctrine has been adopted by either judicial decision or statute with slight variations. Some states’ interpretations of the doctrine are more accommodating than others. In Alabama, for example, any person aged fourteen and over has the authority to consent to medical procedures. In Delaware, any minor may lawfully consent to certain medical treatments if reasonable efforts were made to first obtain consent from the parents. For some states that provide the mature minor doctrine by judicial decision, the minor must meet certain criteria to prove that she can provide informed consent to the procedure, and sometimes it must be determined that the medical procedure would be in the minor’s best interests.

1. The Best Interests of the Child

Best interests of the child is a varying, paternalistic standard that complicates a minor’s access to certain medical treatment, including the refusal of medically-accepted, life-saving treatment. In certain states, an evaluation of a minor’s best interests is built into statutes that give minors access to abortions. In North Carolina, for example, a judge may choose to waive the

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13 Cardwell v. Bechtol, 724 S.W.2d 739, 748 (Tenn. 1987).
14 Statutes that grant minors certain rights to consent to medical treatment are sometimes called “medical emancipation” statutes. Medical emancipation can either be general or limited according to the structure of the statute. See Sharon Smith, *The Medical Emancipation of Minors: A California History*, 11 J. CONTEMP. LEGAL ISSUES 637 (1999) for an example of how these statutes may differ.
16 ALA. CODE ANN. § 22-8-4 (West 2017).
17 DEL. CODE ANN. tit 13, § 707(b)(5) (West 2017).
parental consent requirement for a minor seeking an abortion if “it would be in the minor’s best interests that [it] not be required.” However, North Carolina’s statute concerning a minor’s consent to other medical procedures does not have such a bypass. Minors are only allowed to seek whatever treatment they need if they are emancipated, or if there are seeking treatment for venereal disease, pregnancy, substance abuse, or “emotional disturbance.” An exception can be made for emergency medical treatment, but the statute is limited to the aforementioned circumstances. In abortion contexts, it seems that “best interests of the minor” is actually an evaluation of the parent-child relationship. In Florida, the court uses the following factors to determine whether notifying a parent that their minor-child is seeking an abortion is in her best interests:

- the minor’s emotional or physical needs;
- the possibility of intimidation, other emotional injury, or physical danger to the minor;
- the stability of the minor’s home and the possibility that notification would cause serious and lasting harm to the family structure;
- the relationship between the parents and the minor and the effect of notification on that relationship;
- and the possibility that notification may lead the parents to withdraw emotional and financial support from the minor.

Many of the concerns evident in the Florida court’s analysis are applicable to a minor’s desire to refuse life-saving medical intervention. Like abortion, passive euthanasia evokes strong moral objections that could put a strain on the parent-child relationship.

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20 § 90-21.5(b).
21 § 90-21.5(a)(i)–(iv).
22 § 90-21.5.
23 In re Doe, 973 So.2d 548, 553 (Fla. Dist. Ct. App. 2008).
In jurisdictions where the mature minor doctrine can be invoked in all medical decision-making, an analysis of the minor’s best interests includes a greater variety of criteria. Massachusetts’s “best interests” standard is applicable to minors wishing to refuse certain medical treatments through *In re Rena*, 705 N.E.2nd 1155 (Mass. App. Ct. 2008). Although the issue in the case was moot, the Massachusetts Appellate Court listed the factors considered when determining whether allowing the child to make certain medical decisions is in her best interests. The first two criteria focus on the minor-patient’s expressed preferences for the operation as well as the patient’s religious convictions. The next factor considers the impact that the desired treatment would have on the patient’s family. The fourth and fifth criteria examine the probability of adverse side effects from the treatment and the minor-patient’s prognosis without treatment. Finally, the court determines the present and future incompetency of the patient in making that decision. The factors that focus on the minor-patient (i.e., her expressed wishes, religious beliefs, and incompetency) must also be weighed against the maturity of the minor-patient “to make an informed choice.” Even though this standard seems more child-centered, parental preferences still invade the evaluation of a minor’s best interests. Massachusetts may be progressive in that it makes the mature minor doctrine applicable to procedures outside of those relating to reproductive rights, the type of treatment the minor seeks could inform the court’s decision, implying that even if a minor meets all other criteria and is deemed to be mature in all other respects, the type of treatment she is choosing (not) to undergo can influence the court’s decision.

26 *In re Rena*, 705 N.E.2nd at 1157.
27 *Id.*
28 *Id.*
2. Informed Consent Standards

In Massachusetts, a determination of a minor’s maturity is also influenced by the minor’s ability to demonstrate that she is capable of giving her informed consent to the procedure.\textsuperscript{31} This legal standard also exists in Arkansas, Idaho, Illinois, Kansas, Maine, Nevada, Tennessee, and West Virginia.\textsuperscript{32} Generally speaking, consent is considered informed if the patient demonstrates the capacity to make decisions, if she is provided with adequate information so that a reasonable person in her position would be able to make an informed decision, if an appropriate amount of information is disclosed to the patient, and if the patient’s decision was made without the influence of fraud, coercion, or duress.\textsuperscript{33} Minor-patients, however, do not have the same rights to informed consent when they are under the care and custody of their parents.\textsuperscript{34} This is justified not only under umbrella of parental rights, but also because of the presumptions that parents always act in their child’s best interests, that children are incapable of making their own medical decisions, that parents bear the burden of medical treatment costs, and that parents have the capacity and maturity to make difficult decisions.\textsuperscript{35} A minor-patient must rebut these presumptions in order to demonstrate that she is capable of rendering informed consent.

Under Tennessee law, in order for a minor-patient must demonstrate that she has the “capacity to consent to and appreciate the nature, the risks, and the consequences of the medical treatment involved.”\textsuperscript{36} In the leading case regarding this issue, parents on behalf of their minor

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\textsuperscript{29} Id.
\textsuperscript{30} Id.
\textsuperscript{32} Coleman & Rosoff, supra note 15, 790–91 tbl. 1.
\textsuperscript{34} Lawrence Schlam & Joseph P. Wood, Informed Consent to the Medical Treatment of Minors: Law and Practice, 10 HEALTH MATRIX 141, 148 (2000).
\textsuperscript{35} Id. at 149–50.
\textsuperscript{36} Cardwell v. Bechtol, 724 S.W.2d 739, 749 (Tenn. 1987).
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child sued an osteopath who had treated for subluxation of the spine and bilateral sacroiliac slip.\textsuperscript{37} The minor-plaintiff sought treatment with the defendant by herself after informing her parents of her intent to see him so that he could treat her back pain.\textsuperscript{38} The court determined that, under the Rule of Sevens,\textsuperscript{39} the minor-plaintiff was presumed to have the capacity to consent to the defendant’s treatment.\textsuperscript{40} Additionally, the court stated that a minor’s capacity to consent is also contingent upon the minor’s abilities, experiences, education, training, and degree of maturity, as well as the minor’s ability to understand the risks and consequences of treatment.\textsuperscript{41} The court also elected to consider the “totality of the circumstances” as well as the actual nature, risks, and probable consequences of the treatment the minor seeks.\textsuperscript{42}

It seems then that the informed consent requirement of the mature minor doctrine is circular in its reasoning: a minor-patient must demonstrate that she is a mature minor by proving her ability to give informed consent, but she must demonstrate a certain level of maturity to prove her capacity to make informed decisions about her medical treatment. If the nature of the treatment is also considered in these circumstances, then a fact-finder could potentially decide a minor’s lack of maturity based on the course of treatment she chooses. This substantially limits the choices that a minor actually may have when undergoing medical treatment. A refusal to undergo medical treatment may be considered an “immature” decision simply because it is a refusal. Although

\textsuperscript{37} Id. at 741–42.
\textsuperscript{38} Id. at 741.
\textsuperscript{39} The Rule of Sevens is a common law rule of capacity that states that under the age of seven, a minor lacks capacity, between the ages of seven and fourteen, there is a rebuttable presumption of no capacity, and between ages fourteen to twenty-one, there exists a rebuttable presumption of capacity. Id. at 745.
\textsuperscript{40} Id. at 755.
\textsuperscript{41} Cardwell, 724 S.W.2d at 748.
\textsuperscript{42} Id.
informed consent rights include rights to informed refusal, the right to informed consent is, as with most child rights, curtailed for minors.

B. *In re Cassandra C.* and a Minor’s Right to Refuse Life-Saving Treatment

A minor’s right to refuse life-saving treatment are limited, even when that minor can otherwise demonstrate that she is mature. Few cases have recognized a minor’s right to refusal, and the circumstance under which this refusal is granted are limited. Perhaps the strongest and only successful way that a minor has refused life-saving treatment is in the context of religious freedom. One of the most-cited cases on this issue, and on the mature minor doctrine in general, is *In re E.G.*, 549 N.E.2d 322 (Ill. 1989). At seventeen years old, E.G. was a devout member of the Jehovah’s Witnesses who wanted to refuse life-saving blood transfusions to treat her acute nonlymphatic leukemia. The State filed neglect petitions on behalf of E.G. against her mother, relying on the dire circumstances that lack of medical treatment would create. The appellate court reversed the trial’s court’s order to appoint E.G. a guardian who would consent to the blood transfusions, and determined that E.G. was a “mature minor” who was entitled to exercise her religion freely, and therefore could refuse the blood transfusions. The Illinois Supreme Court held that mature minors have the right to consent to and refuse medical treatment. The court declined to address the constitutional issue present in the case, implying that in Illinois at least, religious grounds are not the only circumstances under which a minor may refuse medical treatment.

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43 Kroft, *supra* note 33, at 462.
45 *Id.*
46 *Id.*
47 *Id.* at 328.
48 *Id.*
Massachusetts and Oregon were introduced to the issue of a minor refusing life-saving treatment in a religious context in *In re Rena*, 705 N.E.2nd 1155 (Mass. App. Ct. 2008) and *In re Connor*, 140 P.3d 1167 (Or. Ct. App. 2006). Because Massachusetts’s best interests standard takes into consideration a minor’s expressed religious preferences as part of its balancing test, the Supreme Judicial Court stated that the lower court had erred in ordering the petitioner to receive the blood transfusions without weighing her religious objections as a component of the mature minor doctrine. However, the respondent-minor had turned eighteen by the time that this issue reached Massachusetts’s highest court, and the Court vacated the final order because it had become moot, thereby declining to hold definitively whether the respondent-minor was a “mature minor,” or whether her constitutional rights had been violated. Similarly, the Oregon Court of Appeals declined to consider the constitution issues raised in *In re Connor* because the issue became moot when the petitioner turned eighteen.

The Maine Supreme Court decided the mature minor doctrine in a non-religious refusal of life-saving (or more accurately, life-preserving) treatment in *In re Swan*, 569 A.2d 1202 (Me. 1990). The court was asked to consider statements that a patient in a persistent vegetative state had made prior to a life-threatening accident, which occurred when he was seventeen-and-a-half years old. Coincidentally, the patient had a tangential connection to the case controlling this decision, *In re Gardner*, 534 A.2d 947 (Me. 1987), and in light of the publicity surrounding it, had made a statement to his mother that, were he to become comatose, he would want his mother to “let [him] go to sleep.” While accompanying his brother on a hospital visit for a comatose friend,

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49 *See supra* Part II.A.1.  
51 *Id.*  
53 *In re Swan*, 569 A.2d 1202, 1202–03 (Me. 1990).  
54 *Id.* at 1205.
the patient again made similar remarks, stating, “I don’t ever want to get like that . . . I would want somebody to let me leave—to go in peace.” The court failed to find a reason that the patient’s pre-comatose statements should be disregarded, determining that the patient’s age did not detract from the principle in *Gardner* that “when an individual has clearly and convincingly in advance of his treatment expressed his decision not to be maintained by life-sustaining procedure in a persistent vegetative state, health care professionals must respect that decision.” The Maine Supreme Court has noted that the mature minor has only been applied to this “special circumstance,” suggesting that the mature minor doctrine may not be applicable in other areas, perhaps even those involving other medical decisions.

This muddied body of case law is what the Connecticut Supreme Court had to draw from when it decided *In re Cassandra C.*, 112 A.3d 158 (Conn. 2015). The petitioner, Cassandra, was sixteen years old when she was diagnosed with Hodgkin’s lymphoma. Cassandra was removed from her mother’s care and placed under an order of temporary custody following a serious of missed appointments to begin cancer treatment. Initially, Cassandra and her mother were skeptical of the diagnosis and sought a second opinion. Cassandra’s mother was openly hostile with the doctors, and was specifically worried about chemotherapy treatment, which she viewed as “poisoning” her child. Cassandra also missed several appointments intended to evaluate the stage of her cancer; this alarmed Cassandra’s doctors, who expressed the need to begin Cassandra

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55 *Id.*
56 *Id.* at 1204.
57 *Id.* (quoting *In re Gardner*, 534 A.2d 947, 953 (Me.1987)).
59 *In re Cassandra C.*, 112 A.3d 158, 159 (Conn. 2015).
60 *Id.* at 159–60, 163–64.
61 *Id.* at 163.
62 *Id.* at 161–62.
63 *Id.* at 162–63.
on treatment as soon as possible to increase her prognosis and avoid the need to resort to radiation therapy, which has more harmful side-effects than chemotherapy. Because of the mother’s combativeness and observed unwillingness to have her treated, Cassandra’s doctors contacted the Department of Children and Families (DCF). An investigative social worker attempted to make contact with Cassandra’s mother, who did not return her phone calls a first, but then was openly hostile to the social worker over the phone and insistent that Cassandra’s medical needs were being met. The doctors remained concerned that Cassandra’s had not started her treatment, and thus DCF filed a neglect petition against the mother for her failure to “meet her medical needs,” and filed an ex parte order of temporary custody, which the court granted.

Under the authority of the court, DCF removed Cassandra from her home and took her immediately to the emergency room, where Cassandra expressed her fears about “waking up with ‘tubes sticking out of her’” and about angering her mother, who was distrustful of doctors. At the preliminary hearing on the order of temporary custody, the court appointed Cassandra a guardian ad litem to assist in evaluating Cassandra’s best interests and scheduled an evidentiary hearing. At the evidentiary hearing, her guardian ad litem testified that Cassandra had told him she was willing to undergo treatment only if she could be returned home. He also testified that Cassandra originally refused treatment because she had done her own research on the disease and “needed time to absorb the information.” Cassandra also testified at the evidentiary hearing, and told the court that her mother had wanted her to begin chemotherapy, but Cassandra resisted

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64 In re Cassandra C., 112 A.3d at 161.
65 Id. at 162–63.
66 Id. at 163.
67 Id. Many of the cases mentioned earlier in this note were accompanied by state child protection intervention.
68 Id.
69 In re Cassandra C., 112 A.3d at 164.
70 Id.
71 Id.
because of her fears surrounding its side-effects. She promised the court, “if you let me go home today, I would start chemo tomorrow.” Cassandra complied and went to her first two chemotherapy appointments, and on the morning of her third when a DCF employee came to bring her to the hospital, Cassandra was missing. She returned home several days later, and was brought for a medical evaluation the next day. She revealed that she did not want to continue chemotherapy, had only agreed to start so that she could return home, and that because she would soon turn eighteen, she would no longer be able to be forced into treatment.

Cassandra’s behavior throughout the court proceedings persuaded the Connecticut Supreme Court that she was not a “mature minor” who was competent to make her own medical decisions. Although the mature minor doctrine had not been adopted in Connecticut jurisprudence, Cassandra attempted to use the doctrine to assert her right to choose her own course of medical treatment. The Court agreed with the trial court’s assessment that Cassandra was not a mature minor under any standard, and therefore declined to decide whether to adopt the doctrine. Although Cassandra and her fellow respondents argued that the trial court’s reasoning was circular because of trial testimony that asserted Cassandra’s lack of maturity was evidenced by her unwillingness to undergo treatment, the Court characterized the argument as a claim that Cassandra had the right to refuse lifesaving treatment for any or no reason, and that her assertion of this right could not be used to her detriment when determining whether she was a mature

72 Id.
73 Id.
74 In re Cassandra C., 112 A.3d at 165.
75 Id.
76 Id.
77 Id. at 171.
78 Id. at 167–68.
79 In re Cassandra C., 112 A.3d at 168.
minor.\textsuperscript{80} The Court refused at this time to recognize if adults even had such a right, and stated that “the law is clear that a seventeen year old does not have that right but, to the contrary, is presumed to be incompetent to do so, at least in the absence of proof of maturity.”\textsuperscript{81}

The Connecticut Supreme Court’s reasoning underlines the problem inherent in a child’s medical treatment: no matter how close to the age of majority, minors have no articulated rights to make decisions concerning their bodies. Even in those jurisdictions that employ the mature minor doctrine, minors have the burden to prove their maturity using standards that are sometimes paradoxical, and often circular in logic. Although American jurisprudence does not universally recognize a right to die or an absolute right to refuse medical treatment in adults, it does recognize that adults have a right to bodily integrity, which is the basis for many United States statutory and common law.

III. Finding a Child’s Right to Refuse Treatment

Arguably, a minor’s right to refuse life-saving treatment is grounded in her right to bodily integrity. Treatments that are considered life-saving are almost always invasive, may have harmful side-effects, and are not always guaranteed to actually be life-saving. A minor should have the right to refuse treatment to avoid subjecting herself to unwanted bodily invasion. In certain contexts, this right is already one that is recognized, but overall needs to be expanded upon.

A. The Right to Bodily Integrity

The Supreme Court acknowledged a substantive due process right to bodily integrity in \textit{Rochin v. California}, 342 U.S. 165 (1952), but the right is one that has been long-recognized by common law.\textsuperscript{82} Bodily integrity as a fundamental right safeguards a person’s body from

\textsuperscript{80} \textit{Id.} at 172.
\textsuperscript{81} \textit{Id.}
governmental intrusion, and is considered a right that is “scared.” Recognition of this right has served as the basis for some of the most controversial of Supreme Court decisions including, for example, the reproductive rights cases. *Planned Parenthood of Southeastern Pennsylvania v. Casey*, 505 U.S. 833 (1992), which interpreted its groundbreaking predecessor *Roe v. Wade*, 410 U.S. 113 (1973) as “a rule . . . of personal autonomy and bodily integrity,” characterized the newly-recognized right to abortion as an extension of the powerful right of physical liberty. Bodily integrity is a formidable opponent against governmental interests, even those that are strong and well-established.

The right of a patient to refuse lifesaving medical treatment, which is often characterized as a patient’s “right to die,” has also been recognized as tangential to the right of bodily integrity. In *Cruzan v. Director, Missouri Department of Health*, 497 U.S. 261 (1990), the Supreme Court recognized that the informed consent requirement in medical treatment was derived from the right to bodily integrity. Quoting Judge Cardozo, the Court affirmed that competent adults have “a right to determine what shall be done with his own body,” and an invasion of one’s body without consent constitutes assault. Although the issue decided in *Cruzan* ultimately concerned the constitutionality of the standard of proof Missouri required the patient’s family to establish by clear and convincing evidence that the patient would not have wanted to remain on life support, the Court declared that “[i]t cannot be disputed that the Due Process Clause protects an interest in

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83 *Id.* at 327.

84 *Union Pac. Ry. Co. v. Botsford*, 141 U.S. 250, 251 (1891). “No right is held more sacred, or is more carefully guarded by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law.” *Id.*


86 Neff, *supra* note 82, at 342.


88 *Id.* (quoting Schloendorff v. Society of New York Hospital, 105 N.E. 92, 93 (N.Y. 1914)).
life as well as an interest in refusing life-saving treatment." In his dissenting opinion, Justice Brennan that a State has no legitimate general interest in preserving life that could outweigh a person’s decision to refuse lifesaving medical treatment, and in order for the State to have a legitimate interest, it must be established that the patient wishes to be treated.

Minor’s rights to bodily integrity have been recognized in certain contexts, but are generally less robust than adults’ rights. A minor’s right to bodily integrity against the state is one that has been widely accepted, and is usually explored in the context of the mistreatment of children in schools or juvenile detention centers. Still, courts have applied the right to protect minors from state intrusions in other contexts. In In re E.G., for example, the Illinois Supreme Court suggested that a minor may invoke the right in the context of refusing life-saving treatment, as it saw “no reason why [the] right of dominion over one’s own person should not extend to mature minors.” When it comes to a minor’s right to bodily integrity against her parents, however, her rights are less definitive, primarily because the law presumes for multiple reasons that parents have the right to make medical decisions on behalf of their children.

In the reproductive rights context, minors’ rights have been protected against parental interference. Some scholars consider Planned Parenthood of Central Missouri v. Danforth, 428 U.S. 52 (1976), as an early recognition of a minor’s constitutional right to bodily integrity in the context of these rights. Overall, minors do not have substantial protections from parental

89 Id. at 281.
90 Id. at 313 (Brennan, J., dissenting).
91 Id. at 315 (Brennan, J., dissenting).
93 See id. at 1304 (discussing cases where a minor’s right to bodily integrity against the state has been applied in contexts outside schools and detention centers).
95 Hill, supra note 92, at 1304–05.
96 Id. at 1305.
decision-making in the medical context in American jurisprudence. In foreign jurisdictions, however, minors have recognized rights against actions of their parents that are based in minors’ bodily integrity rights. In October 2013, the Parliamentary Assembly of the Council of Europe adopted Resolution 1952, concerning children’s rights to physical integrity.\(^\text{97}\) The focus of this resolution was on the protection of a child from unnecessary and non-medically justified procedures, including male and female circumcision, genital surgery on intersex children, and piercing, tattooing, and plastic surgery.\(^\text{98}\) The Parliamentary Assembly based its resolution on the United Nations Convention on the Rights of the Child, which protects children against all forms of violence.\(^\text{99}\) The Convention on the Rights of the Child also recognizes a minor’s right to privacy,\(^\text{100}\) which is sometimes considered a companion to the right to bodily integrity.\(^\text{101}\)

B. Foreign Jurisdictions: Belgium & the Netherlands

Belgium made headlines in 2014 when it became the first country in the world to legalize the euthanasia of any terminally ill minor, regardless of age.\(^\text{102}\) This decision, of course, has been met with its fair share of controversy, it is not the first time that Belgium had considered legalizing the voluntary euthanasia of minors; in fact, when the Euthanasia Act of 2002 was first proposed, minors were included in the bill but later removed to ease opposition.\(^\text{103}\) The original act defines euthanasia as “intentionally terminating life by someone other than the person concerned, at the

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\(^{98}\) Id. ¶ 3.

\(^{99}\) 1 U.N.T.S. 11.

\(^{100}\) Id.


latter’s request.”104 While voluntariness is a crucial element in both acts,105 the new legislation extending this right to minors differs significantly from the 2002 act. Adults have the right to seek euthanasia whether their ailment is physical or mental, while with the new law, the minor must be terminally ill to qualify, and also must suffer from “intolerable and inescapable physical pain.”106 The minor must also possess the capacity to understand the meaning of euthanasia, and this capacity must be verified by a psychologist.107 The procedure must be approved by the minor’s parents and a medical team.108

In the Netherlands, certain minors have had the right to choose euthanasia since the law was originally passed in 2001.109 The “Termination of Life on Request and Assisted Suicide (Review Procedures) Act” of 2001 requires that a physician observe certain elements of due care in order to be exempt from criminal prosecution, which all derived from case law.110 First, the patient must voluntarily and consistently express consent to the procedure, and must be in a state of unbearable and incurable suffering.111 In order to make this determination, the patient’s physician must have consulted with at least one other independent physician.112 The physician must also report the euthanasia or assisted suicide to one of the five Regional Review Commissions, whose purpose is to ensure that the physician acted with due care.113 Unlike the

105 Johnson, supra note 104.
107 Id.
110 Id. at 261.
111 Id.
112 Id.
113 Id.
Belgian law, the Dutch law does have restrictions on age in accordance with the laws governing the medical treatment of minors that had already been established in the Dutch Civil Code. Minors must be at least twelve years old in order to consent to the procedure, and all minors below age sixteen must have the consent of their parents; however, if the parents refuse to consent at the minor’s physician is of the opinion that fulfilling the request for euthanization will “spare” the patient of a “serious disadvantage,” the physician may still be able to fulfill the request. Minors that are sixteen and seventeen years old may make the decision without parental consent, but parents must be involved in the decision-making process. Besides these restrictions on age, minors must also be able to demonstrate their capacity to make the decision to voluntarily end their lives, and must have made the decision “independently and after sufficient consideration.”

C. Going Forward: Best Interests and Informed Consent Revisited

Although it is highly unlikely that the United States would welcome a euthanasia law in the near future, the standards of these European laws can be used to inform an approach to a minor’s refusal to undergo life-saving treatment. By limiting the euthanasia laws to minors whose ailments are incurable, who are terminally ill, and who are in a state of unbearable physical suffering, Dutch and Belgian legislatures implicate a standard of the minor’s best interests. In American jurisprudence generally, the best interests of the child are often intertwined with familial and paternal interests, which is exemplified by Massachusetts’s mature minor doctrine. Instead, when it comes to the mature minor doctrine generally, the standard for best interest of the child should focus primarily and perhaps solely on the child, especially when the child is experiencing

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114 Janssen, supra note 109, at 265.
115 Id.
116 Id.
117 Id.
118 See supra Part II.A.1.
profound physical suffering. One complicated, but perhaps necessary, component of best interests that should apply is the child’s prognosis with or without treatment.\textsuperscript{119} If the procedure is technically considered life-saving, but has a low chance of actually saving the minor’s life, then this should work in favor of the minor’s interests. However, if the procedure that the minor is refusing to undergo would produce a very good prognosis, the State’s interests in the preservation of life may overrule the child’s desires. This outcome seems inevitable, even in liberal jurisdictions that allow for the euthanization of minors, which is evidenced in the requirements that the minor’s illness be terminal and incurable, and cause suffering that cannot be alleviated. Although the refusal of life-saving treatment is a passive act as opposed to an active request for euthanasia or assisted suicide,\textsuperscript{120} the same result is still produced. This means that in order for a minor’s right to refuse life-saving treatment to be introduced into American jurisprudence, the standards that a minor has to meet must be high.

A minor’s beliefs and convictions should be at the forefront of the best interests standard, regardless of whether these beliefs are religious or not. Because religious beliefs implicate a fundamental right that is enumerated in the First Amendment to the Constitution, it is understandable that these beliefs are capable of supporting a minor’s decision to refuse life-saving treatment; however, minors are capable of rendering mature decisions without being religiously motivated. This is where an informed consent standard can fill in a gap and allow a minor to prove that she understands and appreciates the outcome of refusing life-saving treatment. In the Dutch and Belgian laws, informed consent in implicated by the requirement that the minor understand and appreciate the nature and permanency of euthanasia. This is in line with American notions of informed consent, and easily transferable to a minor’s right to refuse treatment. But in order to

\textsuperscript{119} This is part of the Massachusetts analysis of a child’s best interests. \textit{See id.}
\textsuperscript{120} Benston, supra note 5, at 8.
prove that she is has provided informed consent, the minor must first prove that she has the capacity to do so. Under the Belgian law, a psychologist must determine the minor’s capacity to make an end-of-life decision, while in the Netherlands, capacity seems to be presumed in minors that reach certain ages, and is therefore more akin to the common law Rule of Sevens.¹²¹ Because court involvement in a minor’s end-of-life decision is inevitable, it should be required that a psychologist make a determination of the minor’s capacity. This would give the court a disinterested party’s opinion of the minor, which is necessary in proceedings that have the potential to be highly charged and emotional. Although the age of a minor does not necessarily speak to that minor’s capacity, in order to make this right more agreeable in American jurisprudence, the right to refuse life-saving medical treatment should only be available to minors who are not close to the age of majority unless the minor meets additional criteria in order to give informed consent. This may include a requirement, like in the Netherlands, that minors under the age of sixteen have the approval of their parents to refuse the treatment.

Perhaps most importantly, a determination that the minor has the capacity to give informed refusal of the life-saving treatment is that it must be done voluntarily. One of the primary concerns that opponents of any child euthanasia law have is that it is merely a legalized version of infanticide.¹²² To avoid this, the psychologist making the minor’s determination of capacity should make an independent determination of voluntariness by observing the interactions between the minor and the consenting parent. This would help ensure that the minor has not been coerced into making the decision to refuse life-saving medical treatment. The minor’s physician should also weigh in on this evaluation, since the physician will likely have had ample interactions with both

¹²¹ See supra note 39 and accompanying text.
minor-patient and parent, and will have insight on the relationship. If the expert testimony suggests that a consent parent has unduly influenced his minor child into refusing treatment, it would necessitate the involvement of the State’s child welfare system if it was not already so invested. If the child welfare agency reasonably believed that the parent unduly influenced the minor, the State would need to remove the minor from that parent’s care. Substantiated allegations of this unlawful influence would invariably lead to criminal charges.

IV. Conclusion

In summary, a minor should have the right to refuse life-saving treatment, based on her right to bodily integrity, if she can show that it is in her best interests. A minor can prove this by giving evidence of the terminality and incurability of her illness, which must cause her great suffering. She must also show that her refusal is informed, which would involve a third-party determination of her capacity to make such a decision, and of the voluntariness of this decision. These limited circumstances under which a minor may refuse such treatment may be agreeable under American law, and if accepted, would open the door to establish a robust right for any person to refuse life-saving treatment.

Minor’s rights over their bodies should not be contingent on their age. As the Illinois Supreme Court pointed out, the age of majority “is not an impenetrable barrier that magically precludes a minor from possessing and exercising certain rights normally associated with adulthood.”\(^{123}\) A minor is not less aware than an adult of intrusions in her body solely because of her age, and her age should not preclude her from making decisions about her body. The mature minor doctrine should ultimately be available to all minors in all situations, and they should enjoy the most freedom from state interference and intrusion. The parent-child relationship is, of course,

\(^{123}\) In re E.G., 549 N.E.2d 322, 325 (1989).
more complicated because the great paradox of child’s rights is that they are often contingent on the rights, or entwined with the rights, of their parents. Children, however, are not merely an extension of their parents, and if the State is able to recognize that in certain contexts—like in termination of parental rights proceedings—then it should also apply in medical decisions.