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Pregnancy Exclusions in State Living Will and Medical Proxy Statutes

by

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Preface: After the landmark Supreme Court decision in *Cruzan v. Director, Missouri Department of Health,* the importance of advanced directives was brought center stage as a patients' rights issue. Presently, every state in the United States has a statute regarding an individual's right to create an advance directive. However, many of these laws strip women of the constitutional rights embedded in lines of precedent developed by the Court. Because of pregnancy clauses present in 31 states' laws (as of 1992), terminally ill women may have beem forced to merely exist as human incubators and have their wishes, as declared in a living will or advance directive, cast aside. Even if a woman's advance directive states that she does not want life-prolonging treatment, if she is pregnant at the time it is to be executed, pregnancy exclusions require that her directive be ignored and that she be forced to carry the fetus to term.

In 1992, The Center for Women Policy studies published a groundbreaking report on pregnancy exclusions and their effect on women's rights. The report concluded that these laws violate both a woman's right to refuse life-sustaining treatment, as well as her right to abortion guaranteed under *Roe v. Wade*. Since publication of that report, new Supreme Court rulings and changes to state laws call for an update on the status of these statutes and their consequences for women. However, despite changes, those state laws that allow these exclusions set a dangerous precedent that diminishes a woman's legal rights the moment she becomes pregnant or incapacitated.

Background: In its 1990 decision in *Cruzan,* the Supreme Court drew national attention to the ways in which advance directives are handled in the United States. An advance directive is a legal document that allows a person to declare her/his wishes regarding the scope and duration of life-sustaining medical treatment before the treatment is needed. After suffering brain damage due to oxygen deprivation from a traumatic car accident, Nancy Cruzan remained in a persistent vegetative state, kept alive by life-sustaining treatment. Her parents requested that this treatment be withheld, as they testified that their daughter had verbally expressed a desire not to continue in such a state before she was injured. While the Court determined that life-sustaining treatment could not be withheld from Cruzan because her parents did not meet the required burden of proof to show that their daughter would not want such treatment, for the first time, the Court did determine that there exists a constitutionally protected right to refuse life-

sustaining treatment that must be honored by medical facilities and the state, more commonly known as a "right to die."

The Supreme Court's 1973 decision in *Roe v. Wade* found that the right to privacy under the Due Process Clause of the 14th Amendment ensured the right for women to have an abortion, making abortion a fundamental right. The ruling in *Roe v. Wade* established a trimester framework which attempted to balance the interest of the state in prenatal life and maternal health with the woman's right to control over her own body. The Court ruled that the State's interest increased as prenatal life advanced and established that a woman may seek an abortion freely in her first trimester, in an authorized clinic during the second trimester, and that states may forbid abortions during the third trimester. This issue came before the Court again in 1992 in *Planned Parenthood of Southeastern Pennsylvania v. Casey,* which challenged the constitutionality of several Pennsylvania state regulations under *The Pennsylvania Abortion Control Act*, including: an informed consent rule requiring women to receive information about health risks associated with the procedure; a spousal notification rule requiring women to give prior notice to their husbands; a parental consent rule requiring minors to receive consent for the procedure from a parent/guardian; a required 24 hour waiting period; and, the imposition of certain reporting requirements on facilities providing abortion services.

The Supreme Court upheld the essential holding of *Roe* in that it reaffirmed the right to abortion as constitutionally protected under due process. However, the plurality eliminated the trimester framework established by *Roe*, finding that a fetus might be considered viable at 22 or 23 weeks rather than at the 28 weeks that was more common at the time of *Roe*. The plurality recognized viability as the point at which the state interest in the life of the fetus outweighs the rights of the woman and abortion may be banned entirely "except where it is necessary, in appropriate medical judgment, for the preservation of the life or health of the mother." Finally, *Casey* also replaced the "strict scrutiny" standard previously used to assess abortion laws with the "undue burden" test. A legal restriction posing an undue burden was defined as one having "the purpose or effect of placing a substantial obstacle in the path of a woman seeking an abortion of a nonviable fetus."

Moving from the judicial to the legislative, the National Conference of Commissioners on Uniform State Laws drafts model legislation addressing areas of law that are under state jurisdiction but where uniformity of the law among states is desirable (for example, the Uniform Commercial Code). These model laws are not at all binding on states, but serve as suggestions or starting points for legislation. The *Uniform Rights of the Terminally Ill Act (URTIA)* was drafted by the Commissioners, but only covers living wills, not medical proxies, and only applies to situations where a person is in a terminal condition, not a permanently comatose or vegetative state. It states that: "Life sustaining treatment must not be withheld or withdrawn pursuant to a declaration from an individual known to the attending physician to be pregnant so long as it is probable that the fetus will develop to the point of live birth with the continued application of life-sustaining treatment." The original URTIA, adopted by the conference in 1985, also included the phrase "unless the declaration otherwise provides" but this phrase was removed and is not in the current provision.

Following *Cruzan* in 1990, the Congress passed the *Patient Self-Determination Act* of 1991, which requires hospitals, nursing homes, home health agencies, and hospices receiving federal Medicare or Medicaid funds to inform all adult patients of their constitutional right to prepare an "advance directive," which is a written legal document, made in advance of a serious illness, stating an individual's choices for health care or naming someone else to make these

decisions for her/him if the individual is unable to do so. Advance directives can take two forms: a living will or a medical proxy (also known as a "durable medical power of attorney"). Living wills specify the kind of life-prolonging medical treatment the individual wishes to be carried out in the event it is needed. A medical proxy is a person named to make health care decisions for the individual in the event that she/he is unable to do so, and may include guidelines about the type of treatment desired under different circumstances. While the law requires that patients be informed about their right to issue an advance directive, it does not specify the amount of detail or specific facts that should be included when information is provided to patients. Therefore, for women who live in states whose advanced directive statutes include pregnancy exclusions, there is no requirement for medical professionals to inform them that their wishes may be ignored if they are pregnant.

How State Advance Directive Statutes Address Pregnancy: At the time of the Center's previous report, 37 states had pregnancy exclusions in their advance directive statutes. In assessing them, the Center placed the statutes into four major categories:

1. The law states that pregnancy at any stage automatically invalidates the advance directive;
2. The law contains pregnancy restrictions similar to those in the model *Uniform Rights of the Terminally Ill Act*;
3. The law uses a viability standard to determine enforceability of the declaration; or
4. The law is silent with regard to pregnancy.

There is now an additional category of statutes which explicitly explain that a woman has the option of writing into her advanced directive what type of medical treatment she desires if she is pregnant at the time her advance directive should be executed, thus giving women the option to decide for themselves what medical treatment they want without intrusion from the state.

State laws vary in their treatment of pregnancy and pregnant women's rights are variously protected, depending on the state in which they live.

Automatic Invalidation of A Pregnant Woman's Advance Directive: Currently, 12 state statutes (**Alabama, Idaho, Indiana, Kansas, Kentucky, Michigan, Missouri, South Carolina, Texas, Utah, Washington**, and **Wisconsin**) automatically invalidate a woman's advance directive if she is pregnant, as compared to 22 states with such provisions at the time of the Center's 1992 report. These are the most restrictive of the pregnancy exclusion statutes, stating that, regardless of the progression of the pregnancy, a woman must remain on life-sustaining treatment until she gives birth.

Most of these statutes are brief declarations; for example, **South Carolina**'s law states that: "If a declarant has been diagnosed as pregnant, the Declaration is not effective during the course of the declarant's pregnancy." None of these statutes makes an exception for patients who will be in prolonged severe pain or who will be physically harmed by continuing life-sustaining treatment.

The Uniform Rights of the Terminally Ill Act (URTIA): The number of states following the URTIA model increased from 10 (**Alaska, Arkansas, Illinois, Minnesota, Nebraska, Nevada, Pennsylvania, Rhode Island**, and **South Dakota**) in 1992 to 14 (**Alaska, Arizona, Arkansas, Illinois, Iowa, Montana, Nebraska, Nevada, New Hampshire, North Dakota, Ohio, Pennsylvania, Rhode Island**, and **South Dakota**) in 2011. URTIA requires that a pregnant woman be given life-sustaining treatment if she is pregnant and if it is "probable" that the fetus will develop to the point of "live birth."

The original intent of URTIA in regard to pregnancy was to limit statutory pregnancy exclusions only to those cases in which a woman's living will was silent on her wishes. However, the original introductory phrase,"unless the declaration otherwise provides," was removed. This modification makes it clear that life-sustaining treatment may not be withdrawn from a woman who is known to be pregnant if it is probable that the fetus will develop to live birth with continuation of treatment, regardless of the woman's expressed desires to the contrary. The **New Hampshire, North Dakota, Pennsylvania**, and **South Dakota** statutes stipulate that an exception may be made if continuing treatment will be physically harmful to the woman or prolong severe pain which cannot be alleviated by medication.

Viability Standard to Determine Enforceability of Declaration: As was the case in 1992, when the original Center report was published, four states use a viability standard to determine the enforceability of an advance directive. However, the actual states have changed. Previously, **Colorado, Georgia, Iowa** and **Ohio** followed a viability standard statute. Currently, **Colorado, Delaware, Florida** and **Georgia** use the viability standard. Essentially, viability standard statutes slightly modify the language of the URTIA model, making the relevant point of development of the fetus slightly different. For example, the **Delaware** statute states: "A life-sustaining procedure may not be withheld or withdrawn from a patient known to be pregnant, so long as it is probable that the fetus will develop to be viable outside the uterus with the continued application of a life-sustaining procedure." The **Georgia** statute states that, to remove life-prolonging treatment, the fetus must not be viable and the woman must have written into her advance directive that the directive should be carried out in the event the fetus is not viable. If both of these criteria are not met, any directive stating that she should be removed from life-sustaining treatment will be ignored.

Statutes That Are Silent In Regard to Pregnancy: When The Center prepared its report in 1992, 11 states (**Louisiana, Maine, Massachusetts, New Mexico, New York, North Carolina, Oregon, Tennessee, Vermont, Virginia** and **West Virginia**) and the **District of Columbia** lacked statutory language regarding the validity of advance directives in the case of pregnancy. As of June 2011, 14 states fell into this category (**California, Hawaii, Louisiana, Maine, Massachusetts, Mississippi, New Mexico, New York, North Carolina, Oregon, Tennessee, Virginia, West Virginia**, and **Wyoming**) and the **District of Columbia**. In these states, it may be left to the courts to determine how to proceed. As going through the court system takes significant time, a pregnant woman may be forced to endure prolonged treatment -- for weeks or even months -- before the provisions of her advance directive can be carried out. Further, most states that are silent on the issue do include "conscience clauses," which allow medical professionals or institutions to opt out of withholding life-sustaining treatment. For example, the **Hawaii** advance directive statute states:

> A health-care provider may decline to comply with an individual instruction or health-care decision for reasons of conscience. A health-care institution may decline to comply with an individual instruction or health-care decision if the instruction or decision is contrary to a policy of the institution which is expressly based on reasons of conscience and if the policy was timely communicated to the patient or to a person then authorized to make health-care decisions for the patient. (HRS § 327E-7).

Statutes That Offer A Clear Option Regarding Pregnancy: As of June 2011, laws in five states (**Maryland, Minnesota, New Jersey, Oklahoma**, and **Vermont**) clearly allowed women to write their wishes regarding pregnancy into their advance directives and to guarantee that their instructions will be followed. **New Jersey**'s statute states that: "A female declarant

may include in an advance directive executed by her, information as to what effect the advance directive shall have if she is pregnant." Most of these statutes provide sample forms which direct women to explain what type of treatment they would like to receive if their advance directives need to be carried out while they are pregnant. **Maryland**, for example, provides a sample advance directive which includes a section that states: "F. In case of pregnancy: (Optional, for women of child-bearing years only; form valid if left blank) If I am pregnant, my decision concerning life-sustaining procedures shall be modified as follows:"

These statutes give a woman control over her body under all circumstances and protect her rights as a patient. Moreover, they inform women that a pregnancy could complicate the execution of their advance directive – a fact of which most women are unaware – and provide women with an avenue to assure that their wishes are followed.

Constitutional Issues: The Center's 1992 report explored multiple constitutional issues arising from pregnancy clauses, addressing ways in which these exclusions violate what the Court has ruled is a fundamental right to a natural death. In addition, the 1992 report analyzes how pregnancy exclusions may violate the right to abortion assured to women through a long line of legal precedent. In the intervening years, this has become an even more pressing issue.

In 1992, *Roe v. Wade* was the authoritative law on abortion rights in the United States. Using their balancing test, the Court ruled in *Roe* that during the first trimester of pregnancy, the state may not impose any significant restrictions on abortion procedures. However, this understanding was slightly altered after *Planned Parenthood of Southeastern Pennsylvania v. Casey* (1992). Here, the Court threw out the trimester framework established in *Roe*, determining that viability may occur earlier than the third trimester.

The Court declared that viability was the point at which a compelling state interest in the fetus outweighs the rights of the woman to have an abortion. This understanding diminished abortion as a fundamental right, and instead replaced the standard that laws must meet with the "undue burden" test. A legal restriction posing an undue burden was defined as one having "the purpose or effect of placing a substantial obstacle in the path of a woman seeking an abortion of a nonviable fetus." Thus, while still upholding the right to abortion, the Court's ruling in *Casey,* made it easier for states to impose restrictions on women's access to abortion.

However, pregnancy exclusions so blatantly trample on the right to abortion that even in light of the restrictions set forth in *Casey,* the exclusions are still in conflict with women's constitutional rights. Those that automatically invalidate are the clearest and most direct violation as the undue burden test requires that a law not have the effect of imposing a substantial obstacle in the path of a woman seeking to abort a fetus that has not yet reached viability. Pregnancy exclusions which automatically invalidate an advance directive at any stage of pregnancy wholly prevent a woman from exercising her right to abortion whether the fetus is developed to 22 weeks or simply two days. These laws have two effects: first, women already in an incapacitated state cannot communicate their choice to have what, in other circumstances, would be a perfectly legal abortion; second, women who are capable of voicing their decision are still ignored because the law prohibits any termination of the pregnancy if that termination is done to carry out the removal of life-sustaining treatment. In other words, there is no way for a woman seeking to withdraw life-prolonging treatment to obtain an abortion in these states.

This is also the case in states that follow the URTIA model. The language in the URTIA states that "life-sustaining treatment must not be withheld or withdrawn pursuant to a declaration from an individual known to the attending physician to be pregnant so long as it is probable that

the fetus will develop to the point of live birth with the continued application of life-sustaining treatment." The term, "probable live birth" is extremely vague and can easily be stretched to encompass any stage of pregnancy. A fetus will "probably" develop to live birth from any point in development as long as the woman carrying it continues to receive life-prolonging treatment, barring severe complications. This creates the same problem that arises with statutes that invalidate advance directives for pregnant patients altogether. No doctor, judge or legislative body can possibly determine with any certainty when a fetus has reached a point in development at which it will "probably" reach live birth.

States that use a viability standard pose a somewhat different problem to reproductive rights. Currently, the term "viability" is a hotly contested issue and one that has no specific definition. Where "probable live birth" has theoretical breadth and vagueness, "viability" continues to be debated within the scientific community, especially with the advancement of reproductive technologies. In fact, the term is so disputed that the courts have yet to specifically define viability by putting a specific number to it. This may explain why so few states use this terminology in their statutory language for pregnancy exclusions. It is also part of what makes this statutory phrasing so dangerous to reproductive rights. In addition to encompassing the threats previously discussed, the term "viability" also is susceptible to the influence of politics. Its definition varies among political agendas. and is malleable by the individual, including the doctors who are in charge of determining the fate of their patients. Further, it is impossible for doctors to avoid relying on their own ideological beliefs to some extent, particularly as the definition of "viability" is fluid and deliberated within science and medicine. However, no individual right, especially one with a history of constitutional protection, should be subject to the ever-changing landscape of politics and public opinion.

Further, where no law exists to protect the reproductive rights of terminally ill women, their fate rests almost entirely in the hands of the judicial system. While we often rely on the courts to apply rational, even-handed justice that protects our rights, the uniqueness of this situation virtually eliminates a woman's ability to speak on her own behalf. Clearly, if she is in a situation in which she is already reliant on life support, a court appearance is practically impossible. There have been several cases in which a woman has tried to bring this problem before the courts while she is still able to advocate for herself, but it was determined that she did not have standing because she was neither pregnant, nor terminally ill, so she was not injured by the existing law.

Additional Issues: Women and their families and physicians also may face additional difficulties, including lack of notice and awareness of pregnancy exclusions, public policy requirements, and potential "parent-child" conflict.

Lack of Notice: One of the biggest problems with pregnancy exclusions is that there is virtually no public awareness that they even exist, in part because there is no uniformity in the way in which pregnancy exclusion clauses are written into state statutes and they often appear under ambiguous or unrelated titles. For example, **Alabama** lists its statutes that deal with advance directives under the chapter dealing with "Health Care," while **Alaska** organizes these statutes under the chapter entitled "Descendants' Estates, Guardianships, Transfers, and Trusts."

In addition, there is inconsistency in the actual content of statutes among the states. **Kentucky**, for example, has different pregnancy exclusion standards for living wills (in which pregnancy invalidates the directive) and medical proxies (in which pregnancy invalidates the directive if it is probable that the fetus will develop to live birth). Further, most of the "sample forms" provided by states do not include any language about pregnancy, even if the state's laws

are not silent on the subject. Therefore, the woman who is attempting to write an advance directive does not receive notice that, in the case of her pregnancy, her directive might be invalidated.

Public Policy: As they stand, pregnancy exclusions place an unreasonable responsibility on physicians. By writing statutes that contain purposefully vague language, lawmakers require doctors to take the place of the Legislature in determining the meaning of such terms as "probable" and "viability." There are few options to correct this issue, as it is impossible to craft a statute that is not vague. Both legal and public understanding of the stages of fetal development are hotly contested and constantly evolving. Essential wording, in fact the entire crux of the standard, rests on words that are indefinable. This creates policy that can neither be followed nor enforced. If doctors cannot understand what the law means, they certainly cannot obey it; and, if judges cannot consistently interpret the language of the law, there is no way to distribute even-handed justice. The harm to pregnant women whose preferences as stated in their advance directives are therefore at risk remains a serious problem – not only for women and their families, but also for physicians who seek to honor their patients' wishes.

Maternal/Fetal Conflict: Such laws also set a dangerous and never before seen precedent for legal demands on the parent/child relationship, as it values placing a child's rights above the rights of its parents. This is particularly difficult when the fetus is thereby extended the rights of a born-alive child. As clarified in *Roe v. Wade*, a fetus, up to a certain developmental stage, is not considered a person in the eyes of the law, with a full set of rights. Yet many of these laws are placing the rights of a fetus above those of a woman.

This situation raises further questions of parent/child rights and responsibilities and the extent to which we can or should enforce this ideology on parents whose children are born and have a full set of functioning rights. For example, could a parent whose child needs a transplant and is a donor match be forced to give up an organ? This completely rails against our legal system which has never forced one person to give up their own rights or safety to save another.

Recommendations

Law Reform: States should follow the examples of laws such as those passed in **Maryland** and **New Jersey**, where the language is explicit and allows a woman to make the decision in her advance directive as to how she would like the condition of her pregnancy to be handled. Language should follow those already in existence to promote uniformity and clarity, such as that in the **Vermont** statute, which states: (a) An adult may do any or all of the following in an advanced directive: (8) direct which life sustaining treatment the principal would desire or not desire if the principal is pregnant at the time an advance directive become effective; (18 V.S.A. § 9702). At least 45 states still require such legislative reform.

Modification of the *Patient Self-Determination Act of 1990*: Until all 50 states have enacted laws that protecting women's rights, the *Patient Self-Determination Act* should be updated to require health care providers to inform women of the pregnancy stipulations in their state laws on advance directives in their states. As of 2006, 29 percent of adults reported having an advance directive, more than doubling the number from 1990,[1] before the Act was passed. While the law is helping to inform people on their right to create an advance directive, it gives little guidance on the specific information that should be discussed with the patient and it nowhere covers information on pregnancy exclusions.

With the vagueness and complex structure of how advance directive legislation is written, it is important that patients are informed of the particulars in a way that is clear and easy to understand. This is especially true for women, who may have no idea that a pregnancy may

invalidate her declared wishes. Thus, the ***Patient Self-Determination Act*** must be amended to include the requirement that women are informed of these issues so that they may make the most well-informed decisions possible and take whatever actions are necessary to protect their right to control over their bodies.