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Disjointed Custody

BY CHARLOTTE HUFF

Who has legal rights to your egg or sperm?

Like many cancer patients who explore fertility preservation before cancer treatment, Adrienne Rathert didn't have the luxury of much time to mull over options. The lump on her back, after a series of laboratory analyses, had been diagnosed as Ewing's sarcoma, a cancer of the soft tissue. Her oncologist wanted to begin aggressive chemotherapy as soon as possible.

Rathert, 28 at the time, hadn't considered the possibility of treatment-related infertility until her physician asked: Did she want to freeze some of her eggs or, alternatively, some embryos just in case? Her live-in boyfriend was supportive; so Rathert began hormonal injections immediately to stimulate egg production. "I've always wanted to be pregnant," she says.

Together, the couple met with an attorney to hammer out the legal paperwork. In a spirit of egalitarianism, they settled upon joint access to the embryos, including related parental rights and responsibilities. The night before her eggs were extracted, though, Rathert recalls "really freaking out. I think I had doubts about my relationship at the time. I think my gut feeling was there—I just ignored it. I just went along with what made sense at the time."

Attorneys and clinicians who work in the field of fertility preservation relay similar stories about patients and couples wrestling with reproductive and interpersonal complexities amid the time pressures and emotional strain of a cancer diagnosis. The legal issues at stake not only vary based on the fertility technique pursued, but also other factors, such as the state in which the patient lives. Above all, they say, fertility preservation is so cutting edge that the relevant case law hasn't even begun to catch up.



Adrienne Rathert hopes to gain full custody of embryos she created with her ex-boyfriend. Photo by Shauna Bittle.

“The good news is that more oncologists are recognizing fertility issues and presenting them to their patients,” says Susan Crockin, a Boston-area attorney who specializes in reproductive law. But the time factor can be significant, she adds. “So the legal issues are part and parcel of the choices that need to be made,” she says. “But they can certainly get pushed aside depending upon how urgent other (medical) issues are.” Only to potentially reemerge, she stresses, if the cancer survivor later decides to start a family.

Nearly two years after her 2007 diagnosis, Rathert is feeling physically strong following a year of chemotherapy. She’s had two post-chemo checkups with no signs of cancer.

The status of the eight embryos is a little more in limbo, at least in the Chicago woman’s mind. Five months after Rathert, now 30, began chemotherapy, the couple split up. “It was not a friendly breakup,” she says. Last year, she contacted her ex-boyfriend about changing the legal documents to provide her full custody of the embryos. At that point, he was resistant, she says.

Lining up the Paperwork

In a given month, social worker Jill Trainer, MSW, LCSW, meets with 15 to 20 recently diagnosed cancer patients in her role as patient navigator for fertility preservation at Northwestern University’s Robert H. Lurie Comprehensive Cancer Center in Chicago. She describes a typical patient as a recently diagnosed breast cancer patient in her mid-30s who is engaged or married and had planned to start a family very soon. Commonly, the patients already know which technique they want to pursue and can be quite passionate about moving forward, Trainer says.

In regard to time pressures, men have an innate advantage, clinicians say. A sperm donation doesn’t require preparation and potentially many vials can be stored prior to treatment. For women, two to four weeks may be required for hormone stimulation and egg retrieval.

Fertility clinics will have their own consent forms, which can vary in specifics

from clinic to clinic, Crockin says. They may differ, for example, in specifying whether a court order is required in the event of a couple's disagreement. But cancer patients may need to develop a supplemental consent form, ideally with the assistance of an outside attorney experienced in reproductive law, to ensure their own unique circumstances are addressed, she says.

Most of the available techniques, including freezing eggs or sperm, are relatively straightforward legally because they involve material exclusive to the man or the woman, says Greg Dolin, MD, JD, who authored a soon-to-be-published article in the *Santa Clara Law Review* exploring legal issues related to oncofertility. The catch, at least for women, is that frozen embryos hold the greatest potential for a later pregnancy because they are easier to freeze and store than unfertilized eggs. However, frozen embryos also pose the greatest risk of legal headaches for the couple involved, he says.

To best protect themselves, both men and women—regardless of whether they are married at the time—should specify in writing what they want done with their genetic material (sperm, eggs, or embryos), including if either person should die, Crockin says. Be clear not only whether a spouse can use that material, but anyone else, including family members.

Also, it's important that patients stipulate whether they want to be considered the legal parent if the child is either created or implanted after their death, Crockin says. Putting that desire in writing would be relevant to arguing that the child is a legal heir and thus eligible for Social Security and other benefits, although the final determination will depend upon state law, she says.

Legal Uncertainties

With frozen embryos, it's more difficult to nail down all of the legal corners, given that two people are involved and their initial desires may shift over the years, attorneys say.

Legal documents can be drawn up prior to creation of the embryos, specifying who will have access, both while the cancer patient is alive and following her death. (Female cancer patients are more likely to pursue the creation of embryos, as men have the easier option of banking sperm.) Those documents can stipulate, for example, that the embryos should be the exclusive property of the woman, Dolin says. But if the couple later splits up or has a disagreement regarding use of the embryos, Dolin is not optimistic that such an agreement would hold up in court.

"I would imagine those contracts would be unenforceable in at least a number of states if not everywhere," he says, "because our courts have held that the right not to become a parent is a fundamental privacy right that must be protected."

A cancer survivor could potentially bring an additional argument to bear in such a dispute, Crockin says. Specifically "that she has lost all opportunity to recreate embryos. She can no longer produce eggs and be a genetic parent."

Still, Crockin is similarly doubtful that such an argument, which she says has yet to be tested in the U.S. courts, would prevail given the legal system's reluctance to

force parenthood against someone's will.

““ It might seem like it's the wrong time to have these conversations. But they need to happen. ””

—Adrienne Rathert

One way to bypass such legal conflicts would be to use an anonymous sperm donor to create embryos, Dolin says. “That, of course, can create problems within the marriage or the relationship.” But women have pursued that option, in part to limit later legal issues, says Clarisa Gracia, MD, a specialist in reproductive endocrinology, including fertility preservation, at the University of Pennsylvania Health System.

Rathert, who recently celebrated her first post-chemo menstrual cycle, hopes her existing quandary will become moot. But she doesn't regret storing those embryos as a “last resort option.” In her next breath, though, she advises other unmarried women—despite a racing clock and muddled emotions—to raise some potentially uncomfortable questions with their partners. Among her suggestions: Is marriage in our future? Are you committed to me? What's your vested interest in this? Do you want a child with me?

“It's not easy,” she says. “It might seem like it's the wrong time to have these conversations. But they need to happen. And that's something that didn't happen with us.”