# Sexuality and a Severely Brain-Injured Spouse

by Kristi L. Kirschner
and Rebecca Brashler

Mrs. Z is a twenty-nine-year-old woman who sustained a severe traumatic brain injury five years ago when she was hit by a car whose driver was drunk. She spent six months recovering, first in the hospital and then in a rehabilitation facility. Since her discharge from the rehabilitation facility, she has been living at home with her husband and her four-year-old twin sons. Mrs. Z is unable to speak, dependent in all mobility and personal care, incontinent, and has a feeding tube. Although alert and able to respond to visual, auditory, and tactile stimuli, Mrs. Z is clearly unable to participate in even basic decisions. She requires twenty-four-hour care.

A few months ago, Mrs. Z suffered abdominal discomfort, and her doctor discovered that she was pregnant. The pregnancy was terminated after physicians consulted on her case and determined that continuing it would compromise her health. Mrs. Z's parents are deceased, but her two older brothers have accused Mr. Z of rape. They contacted the local police asking that criminal charges be filed and have retained a lawyer to begin guardianship proceedings. Based on their sister's severe cognitive impairments, they do not believe that Mrs. Z can make any reasonable sense of what is happening to her and think that any sexual contact with a minimally conscious woman is inappropriate. They believe Mr. Z is abusive and his views self-serving.

Mr. Z is adamant that his wife would have wanted to maintain a physical relationship with him and that what takes place in the privacy of their bedroom is not something that should interest the probate courts or the police. As evidence of his fidelity to his marriage vows he argues that he did not divorce his wife when she became disabled and that he still loves her and finds her attractive.

A guardianship agency is reviewing the case for the judge and asks consultants to give their opinions on these questions: Does Mrs. Z's inability to provide consent to sexual intercourse override Mr. Z's claims of marital privacy? Does Mrs. Z's prior sexual relationship with her spouse constitute clear and convincing evidence that she would want her partner to continue this relationship, even if she is only a passive participant? Should Mrs. Z remain with her husband, or should her brothers be given the authority to remove her from her home?

While conversations about sexuality after disability are commonplace in rehabilitation, this particular case is unlike any we can recall. It is not like those of patients after spinal cord injuries, where the focus is on changed physiology, fertility, and ways to rediscover intimacy. It is unlike cases involving patients with developmental disabilities that prompt us to assess their understanding of sexuality and the consequences of intercourse and their ability to protect themselves from unwanted sexual advances. It is also unlike cases involving patients with severe cognitive disabilities who live in institutions—such as the young girl in a vegetative state who was raped by a staff member—where we address protection. Discussions about sexuality with the spouse of a person who is unconscious, minimally conscious, or as severely brain injured as Mrs. Z rarely occur.

That doesn't mean, though, that we don't discuss physical touch. We encourage family members to help range and massage stiff limbs, for example, and to show their loved ones affection. We teach family caregivers to participate with catheterization and bowel programs. But initiating a frank discussion about sexuality has not felt appropriate with these couples. This case makes us question the wisdom of that practice because of the risks associated with pregnancy and the possibility of rape charges.

In reality, we don't know much about the normative sexual practices of couples when one member has a severe brain injury. How often does sexual contact occur? Do spouses hope, as popular literature might lead us to believe, that the power of their touch might "awaken" the injured brain? Current research may shed light on this.

The question of capacity to consent is enormously difficult in this kind of situation. Consent typically involves

verbal communication, while intimacy often involves subtle nonverbal cues. The Alzheimer literature tells us that when couples have been together for years, the familiar patterns of physical intimacy may be a comfort—a source of support and reassurance amidst an otherwise frightening and disruptive disease.

In this case it seems critical to balance Mrs. Z's privacy, best interests, and need for protection. Does she recognize her husband and welcome his sexual advances? Short of videotaping them in the privacy of their bedroom, we cannot think of a way to discern whether intercourse is consensual, or at least not harmful. We know she cannot take steps to protect herself, and that by allowing her to become pregnant, her husband was at least negligent. But is his negligence criminal? Is it substantial and grievous enough to remove her from his care forever?

Putting aside concerns about pregnancy, if severely disabled adults do not lose the right to refuse or accept medical care due to cognitive impairment (via substituted judgment and best interest standards of proxy decision-making), it seems logical that they also do not lose the right to refuse or accept the opportunity to engage in intimate contact with a spouse. Premorbid wedding vows and a sexual history with a spouse may constitute clear and convincing evidence that the individual desired a physical relationship with their partner. Having a spouse who believes that he married for better or worse, and could seek divorce but does not, seems like a blessing—exactly what many of us would hope for if we sustained a severe brain injury. In the end, assuming that Mrs. Z does not show fear or evidence of negative behaviors in the presence of her husband, we favor giving them a second chance with some safeguards in place due to the patient's vulnerable status.

## [illegible]

by Rebecca Dresser

This case presents two major legal questions. One is whether the law would classify Mr. Z's actions as sexual assault. Many U.S. jurisdictions have rejected the old rule that rape cannot occur in a marriage. One rationale for the old rule was that consent to marry signified consent to intercourse throughout the marriage. That reasoning is now questioned, with many arguing that married women should have the same right as single women to decide about each instance of sexual contact.

Nevertheless, her severe mental disability leaves Mrs. Z incapable of giving valid consent to intercourse. The legal standard for consent varies among the states, but at minimum, a woman must be able to understand the physical nature of the sexual act and that she has a right to refuse to engage in it. Underlying the concern about capacity to consent is knowledge that people with mental disabilities can be exploited by individuals seeking sexual gratification.

On the face of it, Mr. Z's actions could constitute sexual assault under the law. Nevertheless, I believe that few prosecutors would pursue charges in this situation. There is no clear evidence of physical or psychological harm to Mrs. Z from the encounters. And although it could be self-serving, Mr. Z's explanation for his behavior provides a plausible alternative story to exploitation. If we take him at his word, he believed intercourse was part of their relationship and was consensual in some sense. Although one can argue that this belief was unreasonable, the story he tells makes it possible to distinguish this case from the conduct targeted by sexual assault laws.

The remaining legal question is whether Mrs. Z should be cared for at home or somewhere else. Two standards are available to assist in resolving this question. The substituted judgment standard seeks to determine what the impaired individual would choose if she were capable of decision-making and aware of her current circumstances. To apply the standard, we must consider whether the evidence about Mrs. Z's beliefs and behavior before her injury points to a particular result.

The available evidence fails to tell us much about what Mrs. Z would choose, however. Her prior sexual behavior fails to indicate whether she would prefer to continue a sexual relationship with her husband in this drastically different situation. And because of his personal interests in the matter, we cannot rely solely on Mr. Z's claim that she would want to continue having a sexual relationship with him.

When substituted judgment fails to supply clear answers, the best interest standard comes into play. Case law on sterilization for individuals with mental disabilities offers guidance on how to think about Mrs. Z's placement. In those cases, courts consider the potential benefits and harms of the procedure and compare them to the potential benefits and harms of available alternatives, such as long-term contraception. They choose the approach that would produce the greatest net benefit from the disabled woman's perspective.

In deciding where Mrs. Z should live, the judge should consider the potential benefits and harms of keeping her at home, as well as the potential benefits and harms of placing her in another setting. This will require an evaluation of how Mrs. Z responds to her husband and children and how she responds to other potential caregivers. If her behavior suggests that she is most content with Mr. Z and the children, the judge could reasonably allow her to remain at home on a trial basis. With close monitoring to protect Mrs. Z's welfare, keeping her at home could be the best alternative.

by Carol Levine

The language of ethics sits uneasily in the realm of intimate human relationships. Describing sex as a partner's duty, obligation, right, or any other normative word seems both to diminish its meaning and elevate it to an unchallengeable principle. Even the word consent seems misapplied in this context; it implies that one person asks and the other accedes to the request. Nor does the language of science work much better. Locating the pleasure centers in the brain stimulated by sexual activity (and chocolate?) may tell us something about cognition but not much about how to live one's life as a person with a brain injury, or as that person's partner. We lack the words—and, more important, we lack the wisdom—to know what enhances human dignity and respect in these situations.

The essence of the sexual relationship between loving partners is not a contract, a vow in perpetuity, or a mechanical physiological response but a complex expression of their mutual commitment, love, and passion for each other. Sex in a marriage changes over time and often deepens in meaning as it decreases in frequency. Certainly illness and disability create the need for sensitive accommodation to the new reality. Serious brain injury is particularly challenging because it involves not a different body, but a very different self. Mrs. Z will never be the person she used to be. Her body may appear the same, but her ability to understand her identity and the way in which others can relate to her has changed.

Mr. Z does not seem to have accepted his wife's altered state and what that means for their relationship. He continues to see himself as her lover, when his primary responsibility to her now is to protect her from harm, enhance the quality of her life as much as possible, and add her responsibilities as a parent to his own. He has clearly violated the first responsibility by failing to protect her from a pregnancy that could compromise her health. Was he perhaps hoping for a miracle? Does he really believe that "finding her attractive" makes his actions more acceptable? Divorce is not the only alternative. Some people in this situation are able to maintain their caregiving responsibilities only because they find companionship and intimacy outside the marriage. Mrs. Z's brothers, however, have compounded the problem by their actions. Are there other sources of their fury? Was this tension with Mr. Z part of the family dynamics throughout the marriage, or perhaps even earlier?

At its core this case is not about sex. It is about control. And it is a family tragedy, not just an individual or marital tragedy. Who is looking out for the interests of the couple's two children? They have lost the love and nurturing of their mother; their father is engaged in a bitter legal battle with their mother's family. How does this affect them emotionally?

Whatever legal decision is reached about Mrs. Z's custody and placement, there should be a plan in place to counsel the whole family, separately if need be and ultimately as a unit. Perhaps a mediator or other trained professional could assist them in putting aside their individual interests to provide a stable, loving environment for the children. If Mr. Z agrees that he is responsible for protecting the vulnerable people in his care, I would favor keeping Mrs. Z at home. Whether Mrs. Z as she is now would want to have sex with her husband or not, she would surely want her family to come together for the sake of her children.

# Contributors

**Jeffrey T. Berger** is associate professor of medicine at Stony Brook University School of Medicine and director of clinical ethics and chief of palliative medicine at Winthrop University Hospital in Mineola, New York.

**J. Andrew Billings** is the director of the Palliative Care Service at the Massachusetts General Hospital and codirector of the Harvard Medical School Center of Palliative Care.

**Rebecca Brashler** is a clinical social worker who directs care management and family support services and cochairs the clinical ethics consultation service at the Rehabilitation Institute of Chicago. She is also an assistant professor at Northwestern University Feinberg School of Medicine.

**Larry R. Churchill** is Ann Geddes Stahlman Professor of Medical Ethics at Vanderbilt University. He and David Schenck are currently completing a book, *Healing Skills: Extraordinary Clinicians at Work* (Oxford, forthcoming).

**Rebecca Dresser** is Daniel Noyes Kirby Professor of Law and professor of ethics in medicine at Washington University in St. Louis.

**Bernice Elger** is an internist with a diploma in protestant theology. She teaches ethics and health law at the University of Geneva and is a part-time attending physician at the University Hospitals of Geneva.

**Joseph J. Fins** is chief of the Division of Medical Ethics at Weill Cornell Medical College and author of *A Palliative Ethic of Care: Clinical Wisdom at Life's End* (Jones and Bartlett, 2006).

**Kristi L. Kirschner** is professor at Northwestern University Feinberg School of Medicine and attending physician at Schwab Rehabilitation Hospital in Chicago.

**John D. Lantos** directs the Children's Mercy Hospital Bioethics Center in Kansas City and is visiting professor of neonatology at The University of Chicago. He is the author of *Neonatal Bioethics* (Johns Hopkins, 2007).

**Carol Levine** directs the Families and Health Care Project at the United Hospital Fund and is editor of *Always On Call: When Illness Turns Family Members into Caregivers* (Vanderbilt, 2004).

**Patrice Mangin** is a forensic pathologist and head of the University center of legal medicine, Lausanne-Geneva.

**Don Marquis** is professor of philosophy at the University of Kansas. He has written about the ethics of abortion.

**Katarzyna Michaud** is a forensic pathologist who heads the forensic medicine unit in Lausanne, Switzerland.

**David Orentlicher** is Samuel R. Rosen Professor of Law at Indiana University School of Law – Indianapolis and adjunct professor of medicine at Indiana University School of Medicine. He wrote *Matters of Life and Death* (Princeton, 2001).

**Richard Payne** is professor of medicine and divinity at Duke University and the Esther Colliflower Director of the Duke Institute on Care at the End of Life. He is board certified in neurology and palliative medicine.

**Dena Rifkin** is a nephrologist and clinical researcher at the University of California, San Diego. She edits the narrative medicine feature of the *American Journal of Kidney Disease.*

**Nicholas D. Schiff** directs the Laboratory for Cognitive Neuromodulation at Weill Cornell Medical College and coauthored *The Diagnosis of Stupor and Coma*, 4th ed. (Oxford, 2007).

### Submission Guidelines

The *Hastings Center Report* welcomes manuscript submissions. Prospective contributions may take many forms: **articles** that explore philosophical and ethical issues in medicine, health care, technology, medical research, the use of human subjects, and the environment; **reports or reviews** of empirical studies that implicate relevant philosophical and ethical questions; short, provocative **essays**; **case studies** (which may be accompanied by commentary on the case); **personal narratives** about receiving or providing health care; and **brief commentary** on relevant events in the news.

Most articles and empirical reviews accepted for publication are no longer than 6,000 words, and short essays no longer than 2,400 words. Shorter work is encouraged. For case studies, descriptions should be about 400 words, and commentaries should be no more than 650 words. Brief commentary should be no more than 800 words.

All feature articles, all reports and reviews of empirical work, and many short essays are reviewed blind. Authors' names and identifying information should appear only on a separate cover page. In matters of grammar and usage, the *Report* refers to the *Chicago Manual of Style*, although for purposes of review, submissions need not conform to Chicago. Authors' instructions for formatting endnotes are available at www.thehastingscenter.org.

The *Report* requires authors to disclose all financial relationships that might have biased their judgment, including:

- sources of funding for the item submitted
- financial or other significant relationships (including, for example, consulting, speakers' fees, membership on corporate advisory committees, and expert legal testimony) of the author and the author's immediate family in the last five years with companies, trade associations, unions, litigants, or groups that may gain or lose financially from the conclusions the author presents

Please complete a Conflict of Interest form for each author when submitting. This form is available at www.thehastingscenter.org.

To facilitate review, please submit electronic copies in *.rtf format to editorial@thehastingscenter.org.