

3. Forbidden Pleasure

Kate and Frederick married and had their only child, Sophia, late in life. Frederick died when Sophia was eight. When Sophia was fourteen, Kate, who was in failing health, worried about what would happen to Sophia. Sophia was mentally handicapped. She had never been institutionalized but always lovingly cared for at home. Sophia began staying a couple of nights a week in a group home, in preparation for the future, as no family members were willing to take responsibility for Sophia when Kate could no longer care for her. Although it was difficult at first for Sophia to adjust to being away from home, she soon began to enjoy spending time with her housemates.

Kate was also concerned about Sophia's sexual and reproductive autonomy. Sophia loved playing with her dolls and pretending to be a mommy, and said she wanted to be a real mommy with a real baby. However, Sophia was not able to care for herself and Kate was certain that she would be incapable of raising a child. Sophia, an affectionate young woman, had a natural interest in sex. Kate was concerned that a pregnancy and termination or birth of a child, particularly if Sophia were not allowed to raise the child, would be extremely traumatic. Yet, she did not want Sophia to be denied sexual intimacy and pleasure. Kate believed that sterilization was in Sophia's best interests.

Forced sterilization has a shameful history in the United States. The 1927 Supreme Court decision, *Buck v. Bell* (274 U.S. 200), upheld the right of states to forcibly sterilize individuals determined to be unfit to reproduce. By 1930, over half of U. S. states had laws allowing forced sterilization of individuals identified as feeble-minded. These victims were in reality often intelligent but poor, uneducated, non-English speakers, or a financial burden on the state. One of the most notorious programs was Virginia's Lynchburg Colony for the Epileptic and Feebleminded, where over 8000 young people were sterilized between 1927 and 1972. U.S. law and eugenic sterilization programs inspired Hitler's social hygiene experiment that began as forced sterilization and ended with the Nazi death camps.

The United States Supreme Court declared reproduction to be a fundamental human right (*Skinner v. Oklahoma* 1942), and subsequent law upheld and strengthened this ruling. Federal guidelines forbid the use of federal funds for sterilizing incompetent or institutionalized women (42 CFR § 441: 201-206). These safeguards protect individuals with limited decisional capacity from forced sterilization, allowing sterilization only in strictly limited situations, usually for medical necessity. Kate understood that these laws were established to safeguard against the cruel and arbitrary practices of the past, and protect the reproductive rights of mentally challenged women. She recognized that sterilization would permanently deprive Sophia of these rights. She also believed the laws could be every bit as dehumanizing as the practices they prohibited, and that denying sterilization deprived Sophia of the right to exercise sexual autonomy and experience sexual intimacy without the continual threat of grievous emotional harm.

Dr. Burns was a family practitioner who had cared for Kate for many years and for Sophia all her life. On several occasions as Sophia approached puberty, Kate and Dr. Burns had discussed Kate's concerns about Sophia's sexual autonomy. Dr. Burns did not believe birth control devices or pills were appropriate for Sophia. She and Kate agreed that Sophia was not able to take responsibility for her own protection or for the consequences of her sexual actions. They were certain that Sophia was unlikely to be as closely supervised in the future as she had been while living at home.

Dr. Burns understood Kate's reasons for requesting that Sophia be sterilized, but was ambivalent about supporting her request. Sterilization would be permanent and would forever deprive Sophia of

the right to reproduce. Dr. Burns did not believe that Sophia could give legitimate informed consent, either to agree to or refuse sterilization: as Sophia could not envision consequences, she was unable to understand and weigh the risks and benefits of various alternatives.

On the other hand, Dr. Burns believed that nobody was as capable of making decisions on Sophia's behalf as Kate. Having tended Sophia all her life, Dr. Burns knew that Sophia was not capable of caring for a child. Further, she knew that according to the National Resource Center on Child Sexual Abuse, Sophia was up to ten times more likely to be sexually abused than a child who was not mentally challenged, and that Chamberlain et al. in *Pediatrics* (73:445-450, 1984) reported that 50% of mentally challenged female adolescents have had sexual intercourse. Dr. Burns was absolutely convinced that Kate was motivated only by what she believed was in Sophia's best interest and would contribute to the best possible quality of Sophia's life.