

Mother seeks girl's womb removal

LONDON, England— A mother is seeking to have the womb of her severely disabled daughter removed to prevent the 15-year-old from feeling the pain and discomfort of menstruation.

Doctors in Britain are now taking legal advice to see if they are permitted to carry out the hysterectomy on Katie Thorpe, who suffers from cerebral palsy.

But a charity campaigning for the disabled said on Monday the move could infringe human rights and would set a “disturbing precedent.”

Andy Rickell, executive director of disability charity Scope, told the Press Association: “It is very difficult to see how this kind of invasive surgery, which is not medically necessary and which will be very painful and traumatic, can be in Katie’s best interests.

“This case raises fundamental ethical issues about the way our society treats disabled people and the respect we have for disabled people’s human and reproductive rights.

“If this enforced sterilization is approved, it will have disturbing implications for young disabled girls across Britain.”

Katie’s mother Alison Thorpe, who lives in Billericay, southern England, said the operation was in her daughter’s best interests.

“First of all, this is not about me. If it was about me, I would have given up caring for Katie a long, long while ago,” she told GMTV.

“It is about quality of life and for Katie to not have the associated problems of menstruation adds to her quality of life. It means she can continue with the quality of life we can give her now.

“Katie wouldn’t understand menstruation at all. She has no comprehension about what will be happening to her body. All she would feel is the discomfort, the stomach cramps and the headaches, the mood swings, the tears, and wonder what is going on.”

Thorpe said an operation would be best for Katie, despite the initial pain it would cause.

She added: “The short-term pain and discomfort we can manage with painkillers. We will be able to manage that pain much better than menstruation once a month, when Katie cannot tell us ‘I’m in pain.’”

Surgery to stunt girl's growth sparks debate

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In a case fraught with ethical questions, the parents of a severely mentally and physically disabled child have stunted her growth to keep their little “pillow angel” a manageable and more portable size.

The bedridden 9-year-old girl had her uterus and breast tissue removed at a Seattle hospital and received large doses of hormones to halt her growth. She is now 4-foot-5; her parents say she would otherwise probably reach a normal 5-foot-6.

Some ethicists question the parents’ claim that the drastic treatment will benefit their daughter and allow them to continue caring for her at home.

The case has captured attention nationwide and abroad. “Offensive if not perverse,” wrote one person on MSNBC.com’s bulletin board. “This smacks of eugenics, but I understand the parents thought process,” another wrote.

Right or wrong, the couple’s decision highlights a dilemma thousands of parents face in struggling to care for severely disabled children as they grow up.

“This particular treatment, even if it’s OK in this situation, and I think it probably is, is not a widespread solution and ignores the large social issues about caring for people with disabilities,” Dr. Joel Frader, a medical ethicist at Chicago’s Children’s Memorial Hospital, said Thursday. “As a society, we do a pretty rotten job of helping caregivers provide what’s necessary for these patients.”

The case involves a girl identified only as Ashley on a blog her parents created after her doctors wrote about her treatment in October’s Archives of Pediatrics and Adolescent Medicine. The journal did not

disclose the parents' names or where they live; the couple do not identify themselves on their blog, either.

Left in an infant state

Shortly after birth, Ashley had feeding problems and showed severe developmental delays. Her doctors diagnosed static encephalopathy, which means severe brain damage. They do not know what caused it.

Her condition has left her in an infant state, unable to sit up, roll over, hold a toy or walk or talk. Her parents say she will never get better. She is alert, startles easily, and smiles, but does not maintain eye contact, according to her parents, who call the brown-haired little girl their "pillow angel."

She goes to school for disabled children, but her parents care for her at home and say they have been unable to find suitable outside help.

An editorial in the medical journal called "the Ashley treatment" ill-advised and questioned whether it will even work. But her parents says it has succeeded so far.

She had surgery in July 2004 and recently completed the hormone treatment. She weighs about 65 pounds, and is about 13 inches shorter and 50 pounds lighter than she would be as an adult, according to her parents' blog.

"Ashley's smaller and lighter size makes it more possible to include her in the typical family life and activities that provide her with needed comfort, closeness, security and love: meal time, car trips, touch, snuggles, etc.," her parents wrote.

University of Pennsylvania bioethicist and MSNBC.com columnist Art Caplan said the case is troubling and questioned how preventing normal growth could benefit the patient. Treatment that is not for a patient's direct benefit "only seems wrong to me," Caplan said.

But Dr. Benjamin Wilfond, a pediatric bioethicist at Children's Hospital, said that while he "was a little startled" when he first learned of Ashley's case, he understood the parents' decision.

"In this case, being short is a benefit to the child," Wilfond told NBC affiliate KING-TV of Seattle. "There are other parents that make decisions to make their children taller because that may be a benefit to the child. And so I think what all these cases have in common is an intention to help the child."

Comfort and convenience cited

Ashley's parents say keeping her small will help reduce risks for bedsores and other conditions that can afflict bedridden patients. Also, they say preventing her from going through puberty means she won't experience the discomfort of having periods or growing breasts that might develop breast cancer, which runs in the family.

"Even though caring for Ashley involves hard and continual work, she is a blessing and not a burden," her parents' blog says. Still, they wrote, "Unless you are living the experience . . . you have no clue what it is like to be the bedridden child or their caregivers."

Deborah Feldman of KING-TV contributed to this report.

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