# The Case of the Pillow Angel

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In January 1997 a pillow angel was born. Her parents named her Ashley. Three months later her brain stopped developing and she was diagnosed with static encephalopathy. She smiled and grew like any normal child but six years later she still could not talk, walk, or eat without assistance. Completely dependent on her parents, she is a pillow angel, a non-ambulatory child who sweetly and quietly rests when placed on any pillow.

Then, in 2004, Ashley began showing signs of puberty. Her parents presented her case to the Children's Hospital of the University of Washington, requesting a hysterectomy and oestrogen therapy to stunt her growth. The reasons were complicated, the precedents unset and after much consideration the hospital's institutional ethics committee authorized the performance of the procedures. For the remainder of her life Ashley will retain the appearance of being nine. She will never develop sexually and will forever have the mental capacity of a three month old *(1)*. In 2006 her parents wrote a blog in response to ethicists' criticisms of what is now termed the "Ashley Treatment." The world responded with a barrage of opinions, suggestions, congratulations, and fears. The controversy of Ashley's story revolves around questions; not of medicine but of morals. It has caused society to redefine specific rights for disabled persons, re-evaluate the perception of human dignity, and, ultimately, face the shortcomings of a societal system that fails to meet the needs of not only those who are disabled but also of those who seek to ensure health and happiness for the disabled.

Static encephalopathy is a non-degenerative condition encompassing a wide range of disabilities generally defined by brain damage that interferes with development and function. The symptoms can range from spastic movements and speech delay to mental retardation, with the type and extent of damage varying greatly *(2)*. Ashley is an extreme case with symptoms including an inability to sit up, ambulate, survive without a gastrotomy-tube, or use language. However, she is able to respond to others through smiling and vocalization, and prior to undergoing any treatment, experienced normal physical development *(1)*.

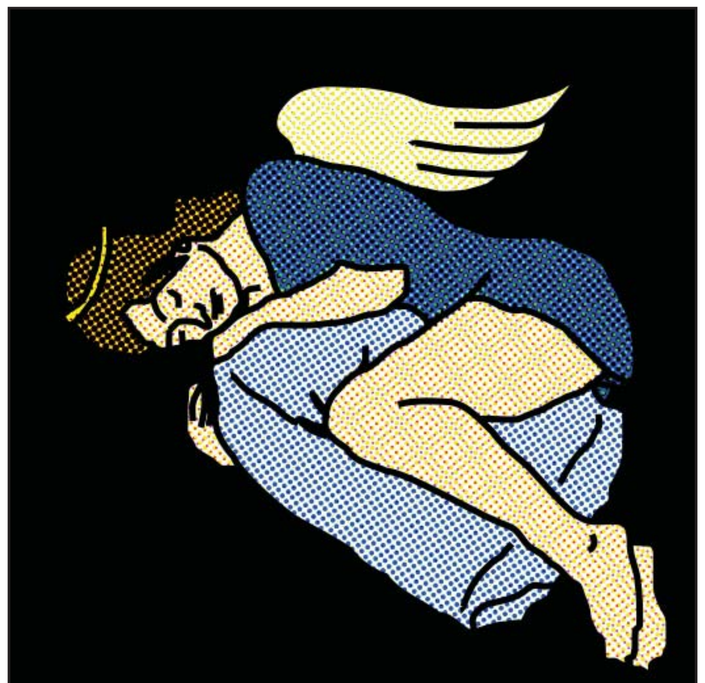
It was when Ashley first entered puberty that her parents approached the Children's Hospital in Seattle with a request for surgical procedures and hormone treatment. In conjunction with the hospital, Ashley's parents and a board of physicians and ethicists eventually developed a series of procedures that they felt would improve the condition of Ashley's life *(3)*. A hysterectomy was performed with the intent to alleviate monthly menstrual pains and bleeding that might frighten a disabled patient; Ashley's breast buds were removed to decrease the possibility of molestation by a caregiver; estrogen was administered to stunt her growth and her appendix was removed purely as a precaution. For Ashley, being small will help decrease bedsores – a major problem for non-ambulatory patients – and allow her to continue taking an active part of her family's life *(1)*. By ensuring that Ashley will never exceed the physical maturity of a nine year old, her parents have enabled themselves to continue caring for her without the need of impersonal moving apparatus or additional assistants.

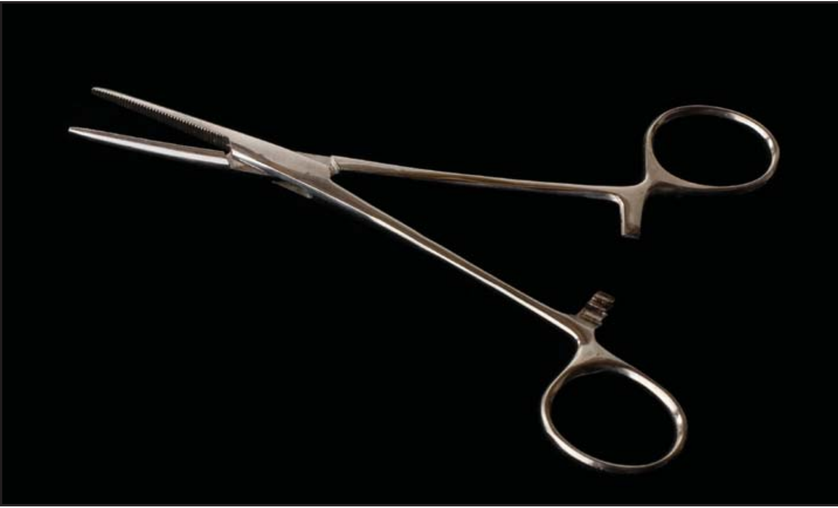
Because Ashley's treatment was the first of its kind to be publicly announced, her doctors, Dr. Gunther and Dr. Diekema, were careful to explain their justification for performing these controversial procedures. While they acknowledge the historical stigma around hysterectomies and their association with forced sterilization, they write that because Ashley has "no realistic reproductive aspirations", sterilization is irrelevant. They claim that the procedure has many advantages, including the possible reduction of the risk of thrombosis and uterine and cervical cancer, and minimal long-term complications. Although Dr. Gunther and Dr. Diekema attempt to introduce a new option for parents of disabled patients, they explicitly state that each case should be reviewed on an individual basis *(1)*.

**Ashley had "been denied her basic human rights through draconian interventions with her person"** *(4)*

With the publication of Dr. Gunther and Dr. Diekema's medical paper and Ashley's parents' blog, there came a wide array of responses, including much criticism regarding the rights of disabled people and the violation of human dignity. The Disability Rights Education and Defense Fund was one of the first to strongly comment against the procedure, stating that Ashley had "been denied her basic human rights through draconian interventions with her person" *(4)*.

In addition, 580 individuals and over 133 organizations signed an online document, entitled *A Statement of Solidarity for the Dignity of People with Disabilities,* stating that although Ashley's parents love her, the procedure is unethical because it strips Ashley of her dignity. Although this





document wields no legal power, it is indicative of a strong interest to ensure the well-being of the disabled, and the need for society to provide better support for the care of the disabled and stronger laws to ensure their dignity *(5)*.

When it became apparent that a societal whiplash against Ashley's treatment was occurring, many bioethicists responded by arguing in favour of the morality and the compassion of the treatment Ashley received. George Dvorsky of the Board of Directors for the Institute for Ethics and Emerging Technologies has been an adamant defender of Ashley's parents stating that, "the concept of 'human dignity' must be coupled with cognitive capacity if it is to have any meaning at all. Clearly this girl has dignity of some kind, but it does not diminish her dignity for decisions to be made on her behalf ... she will never regret those decisions, and her quality of life will be much better because of the decision of her parents *(6)*." Peter Singer, famed bioethicist and author of *Writings on an Ethical Life,* agrees with Dvorsky on this point and further argues that it is an illogical objection to say that the treatment is "unnatural," as all medical treatment is unnatural to some degree *(7)*.

Dr. Wilfond, Director of the Treuman Katz Centre for Paediatric Bioethics at Children's Hospital in Seattle, approaches Ashley's case of growth attenuation as a health care issue rather than one revolving around a question of dignity. He reminds us that paediatricians are responsible for constantly monitoring and manipulating all patients' growth. In Ashley's case this is particularly relevant as she is dependant on a feeding tube. Her parents and doctors have complete control over the amount of food and nutrients she intakes, and consequently they determine how much she can grow. Dr. Wilfond suggests that one of the main reasons Ashley's growth attenuation has been met with criticism is because, while it is normal for doctors and parents to control a large amount of their children's growth, the generally held perception is that more growth is better. Dr. Wilfond attests, however, that while this is usually the case, more growth would actually be worse for Ashley. He reiterates that a paediatrician's job is to do what is best for the child, whether it is more growth or less growth, and that due to the rarity of Ashley's case, usual approaches did not appropriately apply *(8)*.

While some believe that these procedures were beneficial in Ashley's case, many emphasize the possibility of misuse. Paediatricians Dr. Brosco and Dr. Feudtner warn that if this procedure is to be practised, it must be done with the strictest legal and ethical regulations. While they do not specify what these regulations should be, Dr Brosco and Dr Freudtner explicitly state that the "collective community response" ought to be the deciding voice *(9)*.

Generally, the objections and justifications for Ashley's treatment revolve around the concept of a loss versus a gain. Those in opposition tend to, though not universally, believe that by permanently altering Ashley's physical state without her consent there is a *loss* of dignity and therefore a violation of her human rights *(4)*. Those in support of the treatment tend to argue, though again not universally, that there is no loss of dignity, because she will mentally and emotionally *gain* happiness and comfort from the procedure. Despite the polarity of opinions most reasonable sources, regardless of their stance, agree with Arthur Caplan, director of the Centre for Bioethics at the University of Pennsylvania, when he states that "keeping Ashley small is a pharmacological solution for a social failure" (*10)*. From this acknowledgment of a fundamental societal failure there grows a real possibility for societal change, especially as more and more people pursue options similar to 'the Ashley Treatment'.

While the procedures Ashley's parents pursued have sparked heated controversy, such a strong response from all sides indicates that society cares and is invested in the ease and dignity of not only Ashley's existence but that of the entire disabled community. Whether society agrees on how to treat her or not, those who are voicing their opinions are united in their belief that they are speaking and working for the betterment of those who are disabled and defenceless. From these differences we can only hope that there will flourish a united effort at some point to bring societal, governmental, and medical benefits to those who require it most, to those most qualified for these medical treatments and least capable in deciding their futures, to Ashley and her fellow "angels".

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