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# The Ashley Treatment: An Ethical Analysis

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## Abstract

Is it medically and ethically appropriate to shorten and sterilize a six-year old girl to make it easier for her parents to properly care for her now and in the future? This is the question that confronted Seattle's Children's Hospital when the parents of a six-year old girl named Ashley approached the Ethics Committee requesting approval for various procedures that would improve the quality of life of their daughter. Ashley, called the "pillow angel" by her parents, suffers from a developmental brain condition known as static encephalopathy. Her profound developmental disabilities and her inability to ambulate, provide numerous challenges for her parents and caregivers. If her growth could be permanently arrested while she was still small in stature, then according to her parents, the benefits would give Ashley a better quality of life and allow her parents to continue to care for her at home. The Ethics Committee recommended the procedure to keep Ashley small. High-dose estrogen treatments over the last two years both inhibited growth and rapidly advances maturation of the epiphyseal growth plates, bringing about permanent attenuation in size after a relatively short period of treatment. In addition to the high-dose estrogen treatment, physicians removed Ashley's uterus, to prevent potential discomfort from menstrual cramps and pregnancy in the event of rape, and removed her breast buds because of a family history of cancer and fibrocystic disease. Ashley also had an appendectomy for preventative reasons. This treatment has now been named the "Ashley Treatment." The debate surrounding this treatment contrasts those who argue that the Ashley Treatment violates the child's human rights and is for the sake of convenience for the parents versus those who argue that this treatment is not only in the best interest of the child because it will provide a better quality of life but is also in the best interest of the parents and society as a whole. Determining whether this treatment is in the best interest of the child is both a medical and ethical issue because substantive questions have arisen about this procedure. Are there uses of medical technology that are inconsistent with respect for the human person? If the Ashley Treatment becomes widely accepted, could this lead to the use of more controversial procedures that might reduce the size or reproductive capacity of other vulnerable people? If this treatment becomes a part of standard medical practice, could it affect insurance coverage and rates? These questions are important because other families are contemplating the same procedure for their children.

## INTRODUCTION

Is it medically and ethically appropriate to shorten and sterilize a six-year old girl to make it easier for her parents to properly care for her now and in the future? This is the question that confronted Seattle's Children's Hospital when the parents of a six-year old girl named Ashley approached the Ethics Committee requesting approval for various procedures that would improve the quality of life of their daughter. Ashley, called the "pillow angel" by her parents, suffers from a developmental brain condition known as static encephalopathy. "She had a normal birth, but failed to develop, mentally and physically, for reasons doctors could not ascertain. . . The diagnosis means that her brain has been damaged and the addition of the term 'static' means that her condition will not improve. She will remain for the rest of her life with the mind of a baby"<sup>1</sup>. Her profound developmental disabilities and her inability to ambulate,

provide numerous challenges for her parents and caregivers. If her growth could be permanently arrested while she was still small in stature, then according to her parents the benefits would give Ashley a better quality of life and allow her parents to continue to care for her at home. The Ethics Committee recommended the procedure to keep Ashley small. High-dose estrogen treatments over the last two years "both inhibited growth and rapidly advanced maturation of the epiphyseal growth plates, bringing about permanent attenuation in size after a relatively short period of treatment"<sup>2</sup>. Ashley's prospective height was reduced about 13 inches to 4 feet 5 inches. Ashley's parents argue that "this 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."<sup>3</sup>. However, besides the high-dose estrogen treatment, physicians removed Ashley's uterus, to prevent

potential discomfort from menstrual cramps and pregnancy in the event of rape, and removed her breast buds because of a family history of cancer and fibrocystic disease. Ashley also had an appendectomy for preventative reasons.<sup>4</sup> This treatment has now been named the “Ashley Treatment.”

The debate surrounding this treatment contrasts those who argue that the Ashley Treatment is for “creating a 21<sup>st</sup> century Frankenstein and for maiming a child for the sake of convenience” versus those who argue that this treatment is not only in the best interest of the child because it will provide a better quality of life but is also in the best interest of the parents and society as a whole.<sup>1</sup> Those advocating for the rights of the disabled see this treatment as potentially leading to the violation of human rights for the disabled. What can at first glance appear beneficial can in the long-run lead to harmful results. Disability-rights advocates argue that Ashley was not suffering and that the treatment was untested.<sup>4</sup> In an editorial regarding the Ashley Treatment in Archives of Pediatric & Adolescent Medicine, the authors question whether the Ashley Treatment is a “simple technical fix”<sup>5</sup>. Determining whether this treatment is in the best interest of the child is both a medical and ethical issue because substantive questions have arisen about this procedure. Are there uses of medical technology that are inconsistent with respect for the human person? If the Ashley Treatment becomes widely accepted, could this lead to the use of more controversial procedures that might reduce the size or reproductive capacity of other vulnerable people? If this treatment becomes a part of standard medical practice, could it affect insurance coverage and rates?<sup>6</sup> These questions are important because other families are contemplating the same procedure for their children.

The purpose of this article is twofold: first, to examine the medical facts of Ashley's condition and to analyze the Ashley Treatment; and second, to give an ethical analysis of the Ashley Treatment.

### MEDICAL ANALYSIS

Since infancy, Ashley has been suffering from a developmental brain condition diagnosed as “static encephalopathy with marked global developmental deficits”<sup>2</sup>. Encephalopathy, literally meaning “brain damage,” can stem from a variety of causes such as head trauma, brain tumor, exposure to toxic chemicals, pressure within the cranium, lack of oxygen or nutrition, bleeding in the brain, premature birth, birth defect, complications in labor and delivery and travel through the birth canal.<sup>7,8</sup>

Encephalopathy is generally characterized by an “altered mental state,” and specific symptoms include the loss of cognitive abilities, lapse in memory, problems with speech and hearing, loss of muscle control, learning and speech delays, tremors and seizures<sup>7,8</sup>. Encephalopathy generally is graded such that the symptoms can range from mild to severe, and each case is unique to the individual.<sup>8</sup>

Moreover, the cause of Ashley's condition is presently unidentifiable, which is sadly the etiology for many encephalopaths.<sup>3</sup> Ashley's brain stopped developing at around three months rendering her with the cognitive and mental abilities of an infant and her developmental progress is stagnant at that stage.<sup>2</sup> The defect in Ashley's brain has removed her ability to control her muscles, eliminating her ability to engage in even simple intentional movements or muscle manipulations. Specifically, Ashley “cannot keep her head up, roll or change her sleeping position, hold a toy or sit up by herself, let alone walk or talk,” according to Ashley's parents.<sup>3</sup> In addition, at nine years old, she lacks the capacity to express complex emotions or participate in complicated or even simple thought processes that would be expected from other children of her same age.<sup>3</sup> However, Ashley does exhibit an awareness of her own environment, expressing elation over music, lights and sounds, and appears to be soothed by personal contact., especially that of her parents, younger siblings and grandparents.<sup>3</sup>

Given Ashley's limited mental capacity and mobility, she is absolutely dependent on her caregivers in every way, including, changing her position, transportation, entertainment and feeding.<sup>3</sup> Ashley is fed through a percutaneous endoscopic gastrostomy (PEG) tube that has been inserted into her stomach during a surgical gastrostomy.<sup>9</sup> The tube allows Ashley to obtain nutritionally balanced liquid products without oral ingestion to ensure she receives the proper balance of fats, proteins, carbohydrates, vitamins and minerals.<sup>9</sup> The risks associated with this method of nutrition include aspiration, pneumonia from food traveling up into the esophagus, nausea, vomiting, cramping, diarrhea, infection and constipation as a result of improper food consistency.<sup>9</sup> As a result, the peg tube must be constantly monitored and kept clean to prevent any complications or aspirations.<sup>9</sup>

In early 2004, at 6 years and 7 months old, Ashley exhibited signs of puberty including the growth of her breasts and observable pubic hair.<sup>2</sup> Consequently, her parents began to seek surgical and medical options available to Ashley with

respect to menstruation, breast development and changes in height and weight<sup>2</sup>. Ashley's parents, along with the help of Dr. Douglass Gunther, Associate Professor of Pediatrics in Endocrinology at Seattle's Children's Hospital, designed the following course of action that has since been entitled the "Ashley Treatment": high-dose estrogen therapy to limit height and weight, hysterectomy to remove the uterus and prevent menstruation, breast bud removal to halt breast development, and an appendectomy<sup>3</sup>. While such drastic procedures have recently become a controversial topic for discussion especially within the medical and ethical communities, Ashley's parents maintain that all of the procedures were performed in Ashley's best interest, in the preservation of her dignity as an individual, and with the goal of improving her quality of life (i.e. reduced chances of skin sores due to her sedentary nature, bladder infections and pneumonia)<sup>10</sup>. Dr. Douglass Diekema, a physician on the Seattle Children's Hospital Ethics Committee that evaluated Ashley's case, also alludes to the fact that with her smaller size she will be able to participate in more family events, receive more personal contact and affection and no longer would experience the trauma of menstruation for which Ashley would have little comprehension<sup>11</sup>.

Initially, physicians implemented the use of high-dose estrogen therapy to slow and halt the growth of Ashley's bones, limiting her size<sup>2</sup>. Ashley is prescribed 400 µg of transdermal estradiol daily, using up to six transdermal patches at one time<sup>2,10</sup>. This prescription is eleven times greater than the standard prescribed oral contraceptive dosage of 20-35 µg<sup>12</sup>. Every three months, Ashley is monitored for growth, bone age, insulin-like growth factor I, estrogen and prolactin levels, and thrombotic factors<sup>2</sup>. Presently, Ashley has a bone age of 15 years old and her growth plates are 99% closed<sup>10</sup>.

Estrogen plays a key role in the growth, differentiation and function of many tissues within the body. In particular, research has proven that estrogen helps to regulate the fusion of the epiphyseal disks, or growth plates, in the long bones of the body<sup>13</sup>. During development, endochondral growth stimulates bone formation at the epiphyseal disks of the long bones<sup>14</sup>. This process involves cartilage formation followed by the migration of osteoblasts, bone forming cells, into the epiphyseal space, ultimately concluding in bone mineralization and ossification<sup>14</sup>. As an individual ages, there is a gradual decline in the proliferation of chondrocytes (cartilage forming cells) which slows bone formation in these areas, ultimately leading to the fusion of the epiphyseal

disks and the cessation of the growth process<sup>14</sup>. However, with the introduction of exogenous estrogen, the rate of proliferation slows much faster, inducing the termination of endochondral growth much earlier than without the estrogen<sup>13</sup>. Research reveals that estrogen appears to be involved indirectly in the premature fusion of the epiphyseal disks, such that it "exhausts the proliferative potential of the growth plate chondrocytes, consequently triggering earlier epiphyseal fusion"<sup>13</sup>.

In addition, research has proven that estrogen induces the apoptosis of osteoclasts, cells responsible for bone resorption and bone remodeling<sup>14,15</sup>. Following the addition of estrogen, osteoclasts display identifiable signs of apoptosis, or programmed cell death, including chromatin condensation and altered nuclear morphology<sup>15</sup>. Cells that are in the stages of apoptosis have a distinct morphology and have unique biochemical features, which are easily identifiable under a microscope<sup>15</sup>. During apoptosis the DNA with the nucleus of the cell is degraded by nuclear enzymes resulting in the appearance of multiple collections of chromatin around the edge of the nucleus<sup>14</sup>. In addition, the cell volume decreases, proteolytic enzymes begin to degrade the vital organelles such as mitochondria, and finally the membrane begins to fall apart<sup>14</sup>.

Moreover, estrogen also grossly affects osteoblasts, the bone cells directly responsible for bone formation<sup>16</sup>. Researchers assert that after the introduction of estrogen, there is a decline in cell proliferation and a decrease in osteoblast number<sup>16</sup>. Inactivating both osteoclasts and osteoblasts, prevents any form of bone remodeling and significantly decreases the rate of bone synthesis within the body. As a result of the high-dose estrogen therapy, Ashley will reach a final height of 4'6" and weight of approximately 70 pounds rather than an anticipated height of 5'6" and about 120 pounds<sup>10</sup>. While Ashley has a normal life expectancy, most likely comparable to that of an individual with cerebral palsy, she will permanently live in the body of a 9-year-old girl<sup>3</sup>.

The notion of growth attenuation through high-dose estrogen therapy was first implemented in the 1950s in an effort to reduce the height of taller adolescent females<sup>17</sup>. In the 1960s and 1970s researchers began to examine the potential side effects of high-dose estrogen therapy on females' health<sup>18</sup>. It was concluded that side effects such as nausea, headaches, weight gain, mild hypertension, benign breast disease and ovarian cysts were reported<sup>18</sup>. In addition, such a significant

dose of estrogen could also lead to two other major side effects: endometrial cancer and breast cancer. While Ashley's parents claim they chose the hysterectomy and breast bud excision for alternative reasons, the removal of these two organs relieves the high risk of cancer from the high-estrogen therapy. While it was formerly believed that estrogen had positive effects on cardiovascular function, recent studies indicate that there is no significant increase or decrease on the rate of cardiovascular disease<sup>19</sup>. Further risks include venous thromboembolism, gallstones and/or cholecystectomy, complications with lipid metabolism and cholesterol, stroke and myocardial infarction, endometrial and breast cancer, uterine bleeding, hypercalcemia in patients with breast cancer, and visual abnormalities in the form of vascular thrombosis<sup>20</sup>.

While Ashley will not develop endometrial or breast cancer, or suffer from uterine bleeding, the risk of venous thromboembolism, via deep vein thrombosis, is truly a significant risk for Ashley. Deep vein thrombosis is caused by the formation of blood clots in the deep veins and appears to cause mild inflammation in the vein<sup>21</sup>. This mild inflammation increases the chance that the clot will disengage from the vein wall, travel through the blood stream, and form a blockage in a major artery leading to the heart or lung, known medically as a pulmonary embolism<sup>20</sup>. Such a condition can be potentially fatal in a matter of hours and is virtually asymptomatic<sup>21</sup>. About one half of individuals experiencing vein thrombosis have no symptoms<sup>20</sup>. Individuals experiencing typical estrogen therapy are at a two fold greater risk for venous thromboembolism from 9 in 100,000 users to 18 in 100,000 or even as high as 34 in 10,000 users<sup>12,20</sup>. This risk for Ashley is even greater considering that she is receiving eleven times the normal dosage. Estrogen directly inhibits anticoagulants within the blood from preventing the formation of clots, affects the synthesis coagulation factors in the blood and causes blood thickening, which allows clotting factors to associate more frequently, enhancing clot formation<sup>12,22,23</sup>. Moreover, Ashley's sedentary condition puts her at even greater risk for venous thromboembolism as she has no mobility or means of circulating blood by movement<sup>21</sup>.

In addition, estrogen therapy also has been shown to affect lipid metabolism and cholesterol by decreasing HDL cholesterol and increasing LDL cholesterol<sup>12</sup>. Within the body, there are two types of carrier proteins that transport cholesterol, high-density lipoproteins (HDL) and low-

density lipoproteins (LDL)<sup>23</sup>. The HDL cholesterol, or "good" cholesterol, removes cholesterol from cells to the liver to be eliminated from the body, while LDL cholesterol, or "bad" cholesterol, directs cholesterol to be transported from the liver to cells within the body<sup>23</sup>. LDL cholesterol is often oxidized within cells and eventually leads to the development of atherosclerosis and plaque formation<sup>23</sup>.

Moreover, any increase in the amount of cholesterol within the systemic system ultimately leads to an increase in cholesterol in bile composition<sup>12</sup>. Even small increases in the amount of bile can cause precipitation and the formation of gallstones within the gallbladder<sup>12</sup>. With extended exposure, there is a two to four fold increase in gallbladder disease, possibly resulting in a cholecystectomy as an additional surgical procedure<sup>20</sup>. One final notion to take into consideration is that these risks are based on a daily estrogen dose of 20-35 µg. In Ashley's case, the risks are magnified greatly as she receiving a daily estrogen dose of 400 µg.

The second component of the treatment process is a hysterectomy, which is the complete removal of the uterus<sup>25</sup>. However, the ovaries were still kept in order to provide Ashley with natural hormones. By leaving the ovaries still within the body, Ashley will continue to experience the normal hormonal fluctuation, including estrogen and testosterone associated with menstruation until menopause without the associated shedding of uterine lining and bleeding<sup>23</sup>. The ovaries produce estrogen, progesterone and female androgens<sup>24</sup>. Estrogen is necessary for the maintenance of the female reproductive system and secondary sex characteristics<sup>24</sup>. Non-reproductively, estrogen promotes fat deposition, increases bone density and stimulates the closure of the epiphyseal disk, or growth plates, at the ends of long bones<sup>24</sup>. It has also been asserted that leaving the ovaries intact actually decreases the risk of ovarian cancer by almost 50%<sup>23</sup>. The ligation of the fallopian tubes prevents foreign agents, such as talc found in feminine hygiene products, from compromising the sterile ovarian environment and inducing the development of cancer<sup>23</sup>. The ovaries will continue to release one egg monthly, yet the egg will simply be absorbed by the body<sup>25</sup>. However, it has been cited that the ovaries may not function properly post-operatively as a result of altered blood supply<sup>26</sup>. Such a malfunction results in a decrease in the natural hormones production which are also responsible for imparting protection against osteoporosis and heart disease<sup>26</sup>.

Each year in the United States, there are 600,000

hysterectomies performed, making this type of surgery second only to cesarean sections<sup>23</sup>. A hysterectomy can be surgically performed in one of three ways: vaginally, abdominally or laproscopically<sup>23</sup>. Ashley underwent an abdominal hysterectomy enabling the surgeon to view all of the pelvic organs and access the appendix<sup>2,23</sup>. An abdominal hysterectomy is performed through a 13 cm incision in the abdomen, either vertically or horizontally, and the 1-3 hour procedure standardly necessitates general anesthesia, 3-5 days of hospitalization and 4-8 weeks recovery time<sup>25,27</sup>. An abdominal hysterectomy is performed as follows:

1. An incision is made through fat, muscle, fascia and peritoneal layers of tissue.
2. Fallopian tubes and ligaments are cut inside.
3. Uterine blood vessels are cut and tied.
4. Uterus is removed through the incision<sup>25</sup>.

Typically, pain killers are prescribed to alleviate any discomfort after the surgery and strenuous exercise or movement should be avoided<sup>27</sup>.

In 25 – 50% of abdominal hysterectomies, women experience at least one complication, which can include: post-operative bleeding (1 in 10 women), the formation of a blood-clot in the lungs, damage the ureter, bowel or bladder (1 in 300 women), infections of wound (1 in 20 women) and urinary tract, weight gain, abdominal or back pain, constipation, fatigue or frequent urination<sup>27</sup>. Some women also suffer from psychological side-effects such as depression, anxiety, mood change and irritability<sup>27</sup>. In addition, even if the ovaries are not removed during the procedure, there is a chance that the individual may experience symptoms of early menopause such as hot flashes and vaginal dryness<sup>27</sup>. Lastly, hysterectomies have a rather low mortality rate of between one in 2000 and one in 5000 women die as a result of the procedure<sup>27</sup>.

Extracting Ashley's uterus consequently prevents menstruation and the painful cramps and bleeding that are associated with the cycle. During menstruation many women experience back abdominal cramps, headaches and nausea which illicit extreme discomfort. For Ashley, such an experience could be terrifying especially with her limited capacity for understanding the changes that are occurring within her body<sup>3</sup>. Her only source of communication of pain and discomfort is crying, which is non-specific and can be

attributed to any number of reasons<sup>3</sup>. In addition, her parents contend that the removal of her uterus prevents any possibly pregnancy if she were ever sexually abused and also the removes any chance of uterine cancer, uterine fibroid tumors, cervical cancer, endometriosis, or other complications<sup>3,28</sup>.

In the same operation, physicians also performed an appendectomy on Ashley to remove her appendix and prevent the possibility of appendicitis<sup>3</sup>. Harvard medical specialists assert that the simultaneous appendectomy is a common procedure as it only takes a few extra minutes during the actual surgery<sup>25</sup>. There are approximately 250,000 appendectomies performed each year and about 7% of people in Western nations experience appendicitis<sup>29</sup>. This type of appendectomy is known as an appendectomy-en-passant, referring to the removal of a healthy appendix during a procedure of alternative intention<sup>30</sup>. Commonly, individuals suffer from wound infection following the surgery and antibiotics are typically prescribed both pre and post-operatively to help eliminate the chance of infection by a gut organism<sup>30</sup>. Likewise, abscesses may also form in the pelvis, abdomen, and less commonly, the liver<sup>30</sup>. Ashley's parents contend that the appendectomy is a preventative measure because the symptoms of appendicitis including, abdominal pain in the lower right quadrant, nausea, vomiting, high fever, and tenderness, are non-specific with the potential to be attributed to any number of ailments<sup>3,29</sup>.

Lastly, the treatment includes the removal of Ashley's breast buds, almond shaped centers of tissue that induce breast development and contribute to lactation<sup>3,31</sup>. While the actual breast buds were surgically removed, the areolas were not<sup>3</sup>. The areolas are largely comprised of small nodules, below which are the sebaceous glands and sweat glands<sup>14</sup>. These glands secrete oils that lubricate the skin and prevent cracking and drying<sup>12</sup>. In addition, there are many sensory nerve endings located within the nipple and areola<sup>12</sup>.

The breast buds begin to form during the sixth week of fetal development and are the source of all further breast growth and development<sup>31</sup>. From each breast buds stems a column of cells that becomes part of the sweat and milk duct system<sup>14</sup>. Removal of these tissue areas would halt progression of breast development and the underlying tissues.

This component of the treatment has multiple functions: prevention of breast cancer and fibrotic cysts that run in Ashley's family, removal of the chance for Ashley to

develop large breasts that could impart a significant amount of discomfort when she is lying down, and helps to mitigate her sexual appeal to possible predators<sup>3</sup>. Researchers assert that a female with disabilities is twice as likely to be a target of sexual abuse than a female without disabilities, and the risk increases with the more caregivers, attendants or physicians who are involved in treatment and care<sup>32</sup>. The fear of sexual or physical assault becomes especially prevalent with the possibility that Ashley may one day have to be placed in a long-term facility. The perpetrators of these crimes include strangers 28% of the time and service providers 7% of the time<sup>32</sup>. An additional study conducted in 1991 by the University of Alberta's Sexual Abuse and Disability Project revealed that of the 93 disabled women who reported cases of abuse, 44% of the perpetrators were service providers<sup>33</sup>. Researchers further claim that 90% - 99% of children with disabilities report being sexually abused by the age of 18, which is four times the rate of children without disabilities<sup>33</sup>. The rates of abuse are even higher for institutionalized individuals and highest for persons with combined mental retardation and physical disability<sup>33</sup>. While these statistics may appear significant, "Ashley would get pregnant only through sexual abuse, but surely action should be taken against the offenders rather than Ashley," asserts Liao et al in a recent Hastings report<sup>26</sup>. Is it appropriate to punish Ashley, as a possible victim, in this scenario? The public should be focusing on the perpetrators not the innocent victims.

While it is abundantly clear Ashley's parents love her dearly and are devoted to her care, it is obvious that there are also ramifications of the Ashley Treatment that offer significant benefits for the caregivers. Ashley's size will allow her to be moved easier so that she can participate in more family events and will also be easier to move in general. Her smaller stature and weight will prevent the development of bed sores and skin infections from her sedentary lifestyle, but will also reduce the attention required from her parents to treat those ailments. In addition, the hysterectomy relieves Ashley of the pain and emotional trauma of menstruation, but also removes her caregivers from attending to those needs each month. This is not to say that there are not benefits of the treatment that do enhance Ashley's quality of life, but it is important to recognize that they also have direct advantages for the caregivers as well.

For a 6<sup>1/2</sup> year old female with very limited cognitive function, the treatment components appear to be very serious and highly invasive. At such a young age, a hysterectomy

and breast bud removal surgery could be considered even radical and traumatic. There are a number of very serious risks when implementing estrogen therapy, which are consequently elevated considering the high level of estrogen that Ashley is receiving on a daily basis, compounded significantly by her immobility and low cognitive function. One of the most serious side effects of the estrogen therapy is the risk of deep vein thrombosis (DVT) and pulmonary embolism. Pulmonary embolism has the potential to be a fatal condition if not diagnosed early. The risk for DVT is elevated due to the estrogen therapy, but further increased due to Ashley's sedentary condition; her blood is not circulating as efficiently. While there are observable benefits to the Ashley Treatment, they do not appear to outweigh the risks. Furthermore, none of the procedures are medically necessary for Ashley's survival. Thousands of disabled individuals, from those with cerebral palsy to multiple sclerosis, live each an every day without this extreme type of medical intervention. To further determine if the Ashley Treatment is appropriate, an ethical analysis will be done to determine if the benefits outweigh the burdens at the present time.

### ETHICAL ANALYSIS

The issue of the Ashley Treatment has raised serious interdisciplinary concerns. There has been a call for a public debate on this issue that would examine all aspects of this treatment including the medical and ethical implications. Since the revelation of the Ashley Treatment, the public debate has ranged from support of her parents to accusations that this is a form of eugenics and even a violation of the basic human rights of the disabled. To determine if the Ashley Treatment is ethical, the principles of respect for persons, beneficence, nonmaleficence and justice will be applied to this treatment and its consequences.

### RESPECT FOR PERSONS

This principle incorporates two ethical convictions: first, that persons should be treated as autonomous agents; and second, that persons with diminished autonomy are entitled to protection. The principle of respect for persons thus is divided into two separate moral requirements: the requirement to acknowledge autonomy and the requirement to protect those with diminished autonomy<sup>34</sup>. Respect for human persons refers to the right of a person to exercise self-determination and to be treated with dignity and respect. All people deserve autonomy and to be treated with dignity and respect. Failure to provide any person with adequate health care, regardless of their race, creed, color, national origin,

sexual orientation, disability, etc., violates this basic right of respect for persons. Proponents of the Ashley Treatment, and in particular Ashley's parents, argue that this treatment is in Ashley's best interest because it will allow her to have a better quality of life and will assist them as caregivers in being able to give her the best possible care. Ashley is completely dependent on her parents for all aspects of her care which includes physical challenges such as lifting, turning, bathing, prevention of skin breakdown, exercises to preserve joint mobility, etc. Reducing Ashley's size and weight not only reduces the demands and stress on the caregivers but also allows this child to be given the best possible care.<sup>35</sup> Ethicist Joel Frader argues that "our society generally provides insufficient support for persons with disabilities and those who devote time, effort, and resources to caring for the patient. A more generous society would make sure caregivers have assistance devices and other help necessary so that the physical, social, and emotional work of providing care does not become overwhelming"<sup>35</sup>. Since society does not always fulfill its duty in this area, the Ashley Treatment will assist both the disabled person and the family. The parents also argue that having Ashley be a size that is more appropriate to her developmental level makes her less of an anomaly to society and might assure her of the basic dignity and respect all persons deserve.

Opponents argue that forcing Ashley to be a permanent child, or what some refer to as "terminal infantilizing," denies her the basic dignity and respect she deserves as a person. Does Ashley have the right to develop naturally? Do all people have the right to develop naturally? Bioethicist Arthur Caplan argues that "we should put greater focus on providing appropriately sized wheelchairs, and bathtubs and home-health assistance rather than on pharmacological remedies. This solution allows Ashley to be cared for without interfering with her natural developmental patterns. This reflects a moral tradition that dates back to Aristotle. It suggests that looking after Ashley's best interest might involve more than just making her as comfortable as possible. We must also allow her to develop naturally"<sup>6</sup>. Some may argue that this decision is a personal decision that Ashley's parents are making based on their right of autonomy that focuses on what is in the best interest of their child. Therefore, this is a private matter between the parents and the physicians at Seattle Children's Hospital. This is true but it could also have far reaching public consequences. Those who are advocates for the rights of the disabled fear the slippery slope. Could this technology be used on other children with similar conditions—cerebral palsy, spina

bifida and those with other serious brain injuries? Could we use other procedures to reduce the size and reproductive capacity of severely demented adult patients at risk of receiving sub-standard care because of his or her size or vulnerability?<sup>6</sup> Can medical technology have benefits but in the long-run diminish a person's basic dignity and respect?

The removal of Ashley's uterus raises real ethical concerns about sterilization. Directly sterilizing Ashley by removing her uterus because she does not need it can have wide-ranging consequences. The United States has a history of not always protecting the rights of the most vulnerable. "The eugenics movement of the first half of the 20<sup>th</sup> century, although now routinely castigated, was at the time championed by mainstream scholars and societal leaders across the political spectrum. Well-meaning eugenic advocates hoped to eliminate pain from disease and inequity in US society by allowing 'defective' infants to die, encouraging certain couples to marry, and discouraging others from parenthood. Because they believed that persons with mental retardation could not be trusted to understand the wisdom of eugenics, many states passed laws that led to the involuntary sterilization of adults with mental retardation. Upheld by the U. S. Supreme Court in their 1927 *Buck v. Bell* decision, such laws resulted in more than 60,000 individuals being sterilized. Although eugenics was viewed with mounting disdain after World War II, sterilizations of persons with mental retardation continued in the United States through the 1960s, and it was still routine practice in the 1970s to allow a child with Down syndrome to die of lack of surgical correction of duodenal atresia"<sup>5</sup>. We have mistreated vulnerable patients in the past—minorities, disabled persons, children, prisoners, etc. The most vulnerable have been denied their basic human rights by forced sterilizations, medical experimentation, and other eugenic experiments, etc. Those who advocate for the disabled believe we need a public debate on the Ashley Treatment because if safeguards are not put in place now, the consequences could be devastating for many vulnerable people both young and old in the future. Proponents for the Ashley Treatment argue that the slippery slope argument is a "red herring" because in the vast majority of cases, we have not descended down the feared slippery slope into moral degradation. When practices deviate too far from the norm, the public, when informed, will speak out<sup>6</sup>. This may be true, but until we have an open, honest and comprehensive debate on whether attempts to attenuate growth run with or against our fundamental values in caring for children with profound developmental disabilities, any further requests for this

treatment should be denied. To treat the disabled with dignity and respect means society needs to provide the necessary resources to assist disabled children and their families. What has to be determined is whether the Ashley Treatment is just “a pharmacological solution for a social failure”<sup>36</sup>. If it is then this treatment violates the principle of respect for persons.

A basic tenet of the principle of respect for persons is that one may never be used as a means to an end or in a manner inconsistent with the person's interests or wishes. It appears that there are still too many unknowns about this experimental treatment. Bioethicist Arthur Caplan argues that Ashley's case “should be considered research, and be subject to the same ethical scrutiny as any other scientific study. But partly because no new drugs or procedures are being tested, the Seattle doctors have been afforded more latitude than they should have been”<sup>37</sup>. Proponents argue that Ashley's breasts and uterus are not necessary organs because she will never utilize them. Because a person is unaware and will remain unaware does this mean they lose their inalienable rights? Opponents of this treatment argue that it was done to benefit the caregivers more than Ashley. Even if Ashley were larger there are other, less invasive and safer ways that would allow her mobility and family engagement. There are potential adverse effects with the high-dose estrogen treatments. “While there are data that high-dose estrogen treatment will make extremely tall-for-age (but otherwise normal) girls shorter as adults, this effect may be different in the population of children with severe disabilities. More needs to be known”<sup>5</sup>. In addition, the surgical procedures were non-therapeutic, and also have serious side-effects. Ashley's uterus was removed to avoid the possibility of uterine and cervical cancer. Ashley's appendix was removed for preventative measures. Could arguments be made to remove other additional organs to prevent future diseases? Where will we draw the line? To consent to this treatment with all the unknowns when Ashley is not suffering and the treatment is untested could be viewed as using her as a means to an end. The Ashley Treatment could also be looked upon as a medical experiment. Medical advances are necessary for society, and experimental surgeries and treatments are important tools to bring about these advances. But these advances can never be at the expense of denying individuals their basic dignity and respect.

### **BENEFICENCE**

Beneficence involves the obligation to prevent and remove

harm and to promote the good of the person by minimizing the possible harms or risks and maximizing the potential benefits. Beneficence includes nonmaleficence, which prohibits the infliction of harm, injury, or death upon others. In medical ethics this principle has been closely associated with the maxim *Primum non nocere*: “Above all do no harm.” Proponents argue that the Ashley Treatment is in her best interest for a number of reasons. First, being a smaller child it will be easier for her caregivers to lift her and care for her general hygiene, which should reduce the risk of bedsores, pneumonia and bladder infection that plague patients like Ashley. Second, the removal of the uterus will eliminate any possibility of Ashley being traumatized by menstruation, will prevent pregnancy and prevent cervical cancer. Third, her breast buds were removed to avoid the discomfort of large breasts which are common in Ashley's family and to prevent breast cancer. Fourth, the appendix was removed to prevent an appendicitis which occurs in 7% of the population and which would be difficult to diagnose in Ashley because she is unable to communicate the symptoms. Lastly, Ashley's parents believe that without developing secondary sexual characteristics, their daughter will be less vulnerable to sexual abuse<sup>3</sup>. In the eyes of Ashley's parents all of these procedures are increasing Ashley's quality of life and therefore are in her best interest. Opponents argue that the treatment and surgery are nonbeneficial because Ashley is not suffering, the treatment is untested and has potential adverse effects, and the surgery is unnecessary because there are viable options. Physicians are ethically bound to do no harm to a patient. Ashley had a surgical procedure that involves pain and risks and was nontherapeutic. The risks of high-dose estrogen therapy include blood clots, deep vein thrombosis and it affects lipid metabolism. Finally, opponents argue that this treatment is setting a dangerous precedent for society as a whole, especially for the disabled. If the principle of beneficence promotes the good of the person by minimizing possible harms and maximizing possible benefits, then we must examine other viable options. First, there are appropriate resources that would allow a larger person to maintain mobility and family engagement. Caplan argues that “appropriately sized wheelchairs, and bathtubs and home-health assistance” can provide a good quality of life without pharmacological remedies<sup>6</sup>. Second, removing Ashley's uterus “may cause her ovaries not to function normally as a result of a compromised supply of blood. This may result in Ashley's ovaries not producing enough of the hormones that would otherwise protect her against serious common



diseases such as heart disease and osteoporosis”<sup>26</sup>. Regarding menstruation, it would seem to be less traumatizing for Ashley and more reasonable to see if menstruation represented either a psychological or hygienic difficulty for her. If it did present problems then the physicians could respond medically to minimize the frequency and amount of bleeding, give pain killers for cramps or decide on a hysterectomy after puberty<sup>35</sup>. Third, Ashley's risk of becoming pregnant is small, even if she is placed in an institution. It also appears that her risk of cervical cancer and even breast cancer are small. The risks resulting from the surgery and the high-dose estrogen treatments seem to outweigh the benefits. Fourth, the rationale for the appendix removal is that there is a 7% chance of appendicitis. This procedure may be preventative but the benefits seem minimal. Besides, could this not open the slippery slope to other procedures? Why not perform a tonsillectomy or a fundoplication or some other simple surgery that would also be preventative. What criteria do we use for determining if the surgery is beneficial? Finally, there is the potential for future abuses with other disabled or demented individuals. Ashley's case may be extreme but it does set a medical precedent that could open up the slippery slope. Proponents for the treatment argue that every treatment has the possibility of abuse and if this is taken seriously we would stifle the practice of medicine and medical research. This is true but the track record in the United States for mistreatment of the most vulnerable in society is not good. What might stop parents petitioning an ethics committee to use growth attenuation therapy on a child with Down syndrome, or severe spina bifida? What might stop parents from requesting sterilization of their cognitively impaired child because it is in her best interests? Ashley's treatment is being justified because she is profoundly developmentally delayed and is unlikely ever to go beyond the capacity of an infant mentality. The problem is that there are others who fit this category. Is this the future treatment of choice? Ashley's case is centered on management options but it is not a stretch to imagine the debate moving to whether her quality of life is even worth preserving. All one has to do is look to the Netherlands and their Groningen Protocol to see in what direction some are moving in regards to the most vulnerable in society<sup>38</sup>.

No one will dispute that balancing benefits and burdens is difficult. Some will say that the benefits clearly outweigh the burdens with the Ashley Treatment. However, after reviewing the facts concerning the state of our knowledge regarding the treatment, the risks and potential adverse

effects and the possible viable options available, it is clear that the Ashley Treatment does not minimize the risks incurred by this patient, but exposes her to unnecessary risks that have the potential for injury, harm, and even death. This is an experimental, non-lifesaving treatment with serious and even deadly unknowns. Arguably, this treatment not only fails the test of beneficence, but also fails the test of nonmaleficence.

### JUSTICE

Finally, justice recognizes that each person should be treated fairly and equitably, and be given his or her due. The principle of justice can be applied to this situation in two ways. First, questions of justice have been raised about whether Ashley and others with similar medical conditions who are severely cognitively impaired might be classified as vulnerable individuals and whether this type of experimental treatment is a form of exploitation. There is no doubt that Ashley and others with her condition are vulnerable individuals. They are incompetent and are at the mercy of their surrogate decision makers. Even though many argue that the treatment and surgery is in the best interest of Ashley, because her quality of life will be better in numerous ways, others will argue that in reality it is primarily in the best interest of the caregivers. There are viable options regarding treatment and care that will allow Ashley to be cared for without interfering with her natural developmental patterns. To perform this treatment and surgery on Ashley that is experimental and has potential risks and burdens when there are other viable options available that are less harmful can be viewed as a form of exploitation. It is unjust to place vulnerable individuals like Ashley in this position when other less invasive options give these individuals a comparable quality of life.

Second, the issue of justice pertains to the Ashley Treatment specifically in regards to distributive justice, which concerns the fair and equitable allocation of medical resources. The main issue here is research priorities. Should funds be used to support this experimental treatment when the risks seem unreasonable and possibly harmful? The amount of money spent on these surgeries and treatment could certainly be invested in new ways to help severely disabled children and their families live a better quality of life. This would help to minimize the risks and maximize the benefits, not only for the disabled person, but also for families and society as a whole. Also, if the Ashley Treatment becomes a part of standard medical practice, it could affect insurance coverage and rates. Since all Americans have an interest in access to

affordable insurance, we should be very concerned about the relative value of this treatment as a matter of distributive justice. If this treatment is designed to prevent out-of-home placement, then one might think a cost-benefit analysis should be initiated to determine whether medication and surgery or more funds for home-based services would be more equitable and just. In general, pharmacological remedies do not usually trump adequate social support. As a matter of social justice, "when the parents' resources are limited, the state, with its greater resources, should not resort to biological modification, when the patient's quality of life can be preserved through social services"<sup>26</sup>. Who should receive medical resources and whether the Ashley Treatment is a fair and equitable allocation of medical resources is an important ethical issue. Medical professionals have an ethical obligation to use available resources fairly and to distribute them fairly and equitably. Failure to do so violates the principle of justice.

## CONCLUSION

The Ashley Treatment is experimental, non-therapeutic, and controversial and has the potential to set a dangerous precedent for society. The Seattle Children's Ethics Committee weighed the benefits and burdens of this treatment and recommended that it would be in the best interest of Ashley. Proponents of the treatment argue that the process of decision-making "increases the likelihood that a decision will withstand scrutiny, reduces the likelihood that participants will later realize they left out some important consideration, and should reassure the public, including advocates for handicapped children, that the child's interest is the focus of the decision"<sup>34</sup>. Unfortunately, most advocates for the disabled do not support the Ashley Treatment. The public reaction has been one of skepticism, and many within both the medical and ethical communities have serious concerns. Until more research is done on this treatment and there can be a thorough examination of its benefits and burdens versus the reasonable and accepted non-pharmacological remedies, the Ashley Treatment should not be given to other disabled children. When solutions exist that allow individuals with severe brain impairments to be cared for without interfering with their natural developmental patterns, then these solutions should always take priority. To permit this treatment, when there are so many unknown dangers would be medically irresponsible and ethically objectionable.

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