

'Pillow Angel' Ashley X

Ashley was 6½ years old when she was diagnosed with static encephalopathy, a condition in which her brain is in a permanent and unchanging state. Ashley's parents, who also have two other healthy children, had cared for Ashley in their home since birth, as Ashley's development equaled that of an infant. Ashley could not roll over, sit up or hold her head up, or use language.

Ashley's parents grew concerned over their abilities to continue to care for Ashley at home. With her continued growth and development, she would eventually become too large for them to manage her needs, including feeding her, changing her, bathing her, and positioning her during the night. Additionally, they were concerned at the prospects of her sexual development, including menstruation, breast development, and her fertility.

Ashley's parents made three requests of doctors at Children's Hospital and Regional Medical Center in Seattle, Washington. First, they wanted Ashley to have a hysterectomy — in which her uterus is removed — to prevent any risk of menstruation and/or pregnancy. Second, they requested the removal of her breast buds, which would eliminate the development of breasts altogether. Ashley's parents argued that her breasts would cause discomfort with the straps used to hold her in her chair, and that breast discomfort was a known problem for some adult women in the family. Finally, Ashley's parents requested medical treatment to limit her final adult (known as *height attenuation*) height and weight through hormone therapy.

The ethics committee noted that there was great need for caution for such a procedure, as there have been many documented cases of past abuses of people with physical and developmental disabilities. Dr. Doug Diekema (who, with Dr. Daniel Gunther, published their paper on Ashley in the *Archives of Pediatric and Adolescent Medicine*) noted that although there were few concerns regarding the hysterectomy and removal of breast buds, there was greater concern for the hormone therapy and resulting height attenuation.

Critics noted that the use of surgery and hormones to prevent a person from maturing into an adult was unprecedented in medical history. There were also worries about Ashley's rights as a patient, as her parents were making this decision without her ability to contribute. There was a general concern for the potential 'slippery slope' of adapting the bodies of the disabled to suit the needs of the caregivers, unless it could be justified that this change was also in the patient's (Ashley's) best interests. An ethics consultation involving about 20 individuals was performed prior to making the decision. The consultation included a developmental specialist, Ashley's primary care provider, and her hormone specialist. Although Ashley's parents attended the consultation, they were not a part of the deliberation.

After a lengthy consultation with parents, family, physicians, and the Seattle Children's ethics committee, a consensus was reached to perform the full treatment. A simple hysterectomy was performed on Ashley, although her ovaries were preserved in order to allow for normal hormonal production throughout her life. Her breast buds were removed without complication, and Ashley's height attenuation treatment included an estrogen skin patch applied daily for 2½ years without complication. Estrogen is the primary female hormone that, when used in high doses, shortens the amount of time that growth can occur.

One year after her treatments, at the age of 9, Ashley was 4'5", about 12 inches shorter than predicted without therapy. It was estimated that her weight — 65 pounds — was almost half of what it would be without the hormone treatments. She continues to live under the care of her family.

‘Pillow Angel’ Ashley X

To Think About

Do you think that the Review Board made the right decision about Ashley’s treatment? Why or why not?

Underlying all of the ethical debates is the question of who should be able make decisions regarding the welfare of a profoundly disabled child. How much freedom should parents have to make decisions for their children, and at what point should their choices require review by someone else (like a court)?

Some people have argued that permitting this kind of medical intervention in a patient with a profound and permanent developmental disability creates a slippery slope. They fear that even if these treatments were appropriate in this one case, they might be used inappropriately in others. Is there an answer to this slippery slope argument?

Some people have argued that this brings us back to the days of eugenics. Does it?

This case was met by the expression of great concern from some members of the disabilities community. They considered themselves to have a stake in this decision as well as the parents and Ashley. Are there other stakeholders in this situation? How do each of the stakeholders stand to be harmed or benefited? How does one resolve a conflict between stakeholders? Should an ethics committee weigh the claims of all stakeholders equally?

Selected References

Burkholder, Amy. “Disable girl’s parents defend growth-stunting decision.” CNN.com 13 March, 2008. <http://www.cnn.com/2008/HEALTH/conditions/03/12/pillow.angel/index.html>

Caplan, Arthur, Ph.D. “Commentary: Is ‘Peter Pan’ treatment right?” MSNBC.com 05 January, 2007. <http://www.msnbc.com/id/16472931/>

Dahlstrom, Linda. “Doctor at crux of stunting debate kills self.” MSNBC.com 11 October, 2007. <http://www.msnbc.com/id/21225569/>

Diekema, Doug, The Case of Ashley X, NWABR Ethics in Science Online Course, 2007.

Gibbs, Nancy. “Pillow Angel Ethics.” *Time* 07 January, 2007. <http://www.time.com/time/nation/article/0,8599,1574851,00.html>

Gibbs, Nancy. “Pillow Angel Ethics, Part 2.” *Time* 09 January, 2007. <http://www.time.com/time/nation/article/0,8599,1574851,00.html>

McDonald, Anne. “The other story from a ‘Pillow Angel.’” *Seattle Post-Intelligencer* 17 June, 2007. http://www.seattlepi.nwsourc.com/opinions/319702_noangel17.html

Contributed by Jacob Dahlke, Seattle Lutheran High School, based in part on materials by Doug Diekema, MD, Seattle Children’s Hospital Research Institute