

The Case  
Easy Read.

# TIME

Sunday, Jan. 07, 2007

## Pillow Angel Ethics

By Nancy Gibbs

What kind of doctors would agree to intentionally shorten and sterilize a disabled six-year-old girl to make it easier for her parents to take care of her? The question has had message boards steaming for days, but the answers are in no way easy.

Dr. Daniel Gunther and Dr. Douglas Diekema, who first revealed the details of "The Ashley Case" in the *Archives of Pediatric and Adolescent Medicine*, think that many of their critics don't understand the nature of this case. Talk to them, and you confront every modern challenge in weighing what medicine can do, versus what it should.

The case: Ashley is a brain-damaged girl whose parents feared that as she got bigger, it would be much harder to care for her; so they set out to keep her small. Through high-dose estrogen treatment over the past two years, her growth plates were closed and her prospective height reduced by about 13 inches, to 4'5". "Ashley's smaller and lighter size," her parents write on their [blog](#) "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." They stress that the treatment's goal was "to improve our daughter's quality of life and not to convenience her caregivers."

But the treatment went further: doctors removed her uterus to prevent potential discomfort from menstrual cramps or pregnancy in the event of rape; and also her breast tissue, because of a family history of cancer and fibrocystic disease. Not having breasts would also make the harness straps that hold her upright more comfortable. "Ashley has no need for developed breasts since she will not breast feed," her parents argue, "and their presence would only be a source of discomfort to her."

The parents say that the decision to proceed with "The Ashley Treatment" was not a hard one for them, but the same cannot be said for the doctors. "This was something people hadn't thought about being a possibility, much less being done," says Diekema, who chairs the bioethics committee of the American Academy of Pediatrics and was brought in to consult on this case. For the ethics committee of Seattle Children's Hospital, which reviewed the proposed treatment, "it took time to get past the initial response—'wow, this is bizarre'—and think seriously about the reasons for the parents' request," says Diekema.

First they had to be sure there would be no medical harm: removing breast buds, Gunther says, is a much

less invasive procedure than a mastectomy. The hormone treatment was commonly used 40 years ago on lanky teenage girls who didn't want to get any taller. "The main risk," Gunther says, "is of thrombosis or blood clot, which is a risk in anybody taking estrogen. It's hard to assess in a young child because no one this young has been treated with estrogen." There were very few reports of thrombosis among the teenage patients, he says, "So I suspect the risk is fairly low. After treatment is finished, I don't see any long-term risk, and we've eliminated the risk of uterine and breast cancer."


The ethics committee essentially did a cost-benefit analysis and concluded that the rewards outweighed the risks. Keeping Ashley smaller and more portable, the doctors argue, has medical as well as emotional benefits: more movement means better circulation, digestion and muscle condition, and fewer sores and infections. "If you're going to be against this," Gunther says, "you have to argue why the benefits are not worth pursuing."

They knew that the treatment would be controversial, though they did not quite foresee the media storm that would erupt when they decided to publish the case and invite their peers to weigh in. "I felt we were doing the right thing for this little girl—but that didn't keep me from feeling a bit of unease," admits Diekema. "And that's as it should be. Humility is important in a case like this."

Gunther also understands why the case has inspired such intense feelings—but notes that "visceral reactions are not an argument for or against." This was not a girl who was ever going to grow up, he says. She was only going to grow bigger. "Some disability advocates have suggested that this course of treatment is an abuse of Ashley's 'rights' and an affront to her 'dignity.' This is a mystery to me. Is there more dignity in having to hoist a full-grown body in harness and chains from bed to bath to wheelchair? Ashley will always have the mind of an infant, and now she will be able to stay where she belongs—in the arms of the family that loves her."

But how far would Drs. Gunther and Diekema take this argument? Would they agree to amputate a child's legs to keep her lighter and more portable? Hormone treatment is nowhere near as risky and disfiguring as amputation, Diekema retorts; it just accelerates a natural process by which the body stops growing. Parents of short children give them growth hormones for social more than medical reasons, he notes. How can it be O.K. to make someone "unnaturally" taller but not smaller? To warnings of a slippery slope, Gunther tilts the logic the other way: "The argument that a beneficial treatment should not be used because it might be misused is itself a slippery slope," he says. "If we did not use therapies available because they could be misused, we'd be practicing very little medicine."

*On Tuesday, Part 2, critics of Ashley's parents — and her doctors — have their say.*

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# TIME

Tuesday, Jan. 09, 2007

## Pillow Angel Ethics, Part 2

By Nancy Gibbs

The doctors who agreed to an experimental treatment for a severely disabled girl thought there were clear medical benefits to keeping her small. Autopsy the doctors' argument, and you find that they concluded they could remove Ashley's uterus and breast buds because she'd be better off without them; they could keep her short because, since she'll never have a job or a romance, she'd not suffer the social consequences of smallness. "To those who say she has a right to develop and grow," argues Dr. Daniel Gunther, "Ashley has no concept of these things." But he is talking as a scientist; the philosopher uses different tools. Just because autonomy doesn't show up on an X-ray doesn't mean it can't be harmed by a scalpel. And if rights are inalienable, they exist whether the patient is aware of them or not.

Looking back on the debate within the Seattle Children's Hospital ethics committee, the doctors admit that there was an instinctive, emotional ingredient in the decision to proceed with hormone treatments and surgery. "I think in the end it was the obvious bond and love that exists between Ashley and her parents," Gunther says, "that convinced them this was the right thing to do."

That argument sends disability rights advocates around the bend. "Benevolence and good intentions have been among the biggest enemies of disabled people over the course of history," says Arlene Mayerson, a leading expert in disability rights law, who like many critics feels intense sympathy for these parents. "Many things that were done under a theory of benevolence were later seen as wrongheaded violations of human rights." Medicine's role is to relieve pain and improve function, but Ashley was not sick, and the treatment was untested; do we really want to start bending the rules in the case of the disabled just for the promise of some benefit in the future, advocates ask? That's not healing, it's gambling.

Ashley may be an extreme case; but she is a terrifying precedent. Critics note that for brain-damaged children, development can come very, very slowly — so deciding when she's only six to change a child's body irreversibly can amount to a medical form of identity theft. Frequent touch is indeed important; but is it really so much harder to hug someone who is 5'6," or bring her to the table at dinnertime? Turning people into permanent children denies them whatever subtle therapeutic benefit comes from being seen as adults. "I know they love their daughter," says Julia Epstein, communications director for the Disability Rights Education and Defense Fund, ([www.dredf.org](http://www.dredf.org)) and the mother of a disabled child. "But they refer to her as the pillow angel. I know that's meant to be a sweet term, but it's terminally infantilizing." Her organization issued a statement affirming that "we hold as non-negotiable the principle that personal and physical

autonomy of all people with disabilities be regarded as sacrosanct." With the right information and support, disability rights advocates believe, there is no need for a medical solution to an essentially social problem.

Doctors watching it all from the sidelines note that there are serious medical questions at stake. For one thing, there is no way to know the effect of high-dose estrogen on such a young girl. "Before moving forward wholesale, we need to study it carefully," says Dr. Jeffrey Brosco, an associate Professor of Pediatrics at the University of Miami, who wrote a dissent in the journal where the case was published. "Right now it is truly an experimental treatment." But he is sure there will be more interest: just last week a family he treats had to put their 19-year-old son into a group home, because he had become too big and aggressive for them to care for anymore. "They don't have the money for a personal aide at home," he says, noting that in Florida alone there are 16,000 people on the waiting list for home services.

In fact one thing everyone could agree on was that the case highlights the lousy state of home care in this country. "The web of support for families who really want to care for their family member is uneven and sometimes tattered," says Thomas Murray, President of the Hasting Center, an independent bioethics research institute. "If there were abundant support to help care for a fully grown son or daughter, then people might not be pushed to a radical medical option like this."

Those troubled by the Ashley treatment as a medical fix for a larger social problem are watching the direction that Britain is taking. The Royal College of Obstetricians and Gynecology has proposed that doctors be allowed to kill the sickest infants — which is already legal in the Netherlands. "A very disabled child can mean a disabled family," the college wrote to the Nuffield Council on Bioethics, and urged that they "think more radically about non-resuscitation, withdrawal of treatment decisions... and active euthanasia, as they are ways of widening the management options available to the sickest of newborns." At least in Ashley's case, however much the doctors debated the proper "management options," they all agreed that her life had a value worth fighting to preserve. But as a standard, that's a pretty low bar to set.

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# The "Ashley Treatment" for the wellbeing of "Pillow Angels"®

**Ashley's Condition** - severe brain disorder since birth, remains undiagnosed:

- "Permanently Unabled": infant level mentally & physically, and will not improve
- Average adult size was expected (her body was growing normally)
- Average lifespan is expected (her condition is not terminal)

**"Permanently Unabled" children, who we affectionately call "Pillow Angels":**

- Form a new category of disability, survival was made possible through recent medical advancements
- Constitute less than 1% of children with disability, they are the most vulnerable of society
- Are profoundly dependent on their caregivers & profoundly precious to their families
- Their quality of life is much richer under their family's loving care, versus getting "warehoused in institutions"
- The overwhelming majority of their families & caregivers believe that increased weight & size is their worst enemy
- An extreme condition that calls for individualized options in the hands of parents to help their children

Reasons for providing the treatment

## The "Ashley Treatment"

- Preventative medical care

## Remarks on the "Ashley Treatment"

- Appropriate for children with similar condition to Ashley's
- Relatively safe and leads to significant, lifelong & direct benefits to these children, in the avoidance of pain and suffering & the improvement of their quality of life
- No amount of state funding or resources would replace these direct benefits
- We received 1,150 emails from parents & caregivers who have direct experience with Pillow Angels, & who expressed a strong support for the treatment
- Dozens of parents of Pillow Angels worldwide are evaluating the treatment for their children

- Primary benefit to Ashley

- Improves Ashley's quality of life

- Additional benefit to Ashley

- Makes it easier to care for Ashley (benefit through symbiosis with caregiver)

Ashley went through puberty by age nine

Side benefit

### "Breast Bud Removal"

- Removal of almond size glands that enlarge upon puberty
- Simple surgery if pre-puberty
- Eliminate discomfort caused from large breasts, laying down or in supportive harness
- Eliminate possibility of fibrocystic growth
- Eliminate possibility of breast cancer
- Avoid sexualization towards caregiver

### Hysterectomy

- Removal of tiny uterus
- Alternatives considered, not nearly as effective
- Eliminate menstrual pain & cramps
- Eliminate bleeding
- Eliminate possibility of pregnancy
- Eliminate chance of uterine cancer

### "Sizing for Wellness"

- Estrogen therapy (patches) for two yrs to speedup puberty/closure of growth plates
- 40%, 20% reduction in weight, height
- Increase mobility thru caregiver (more activities, circulation, stretching)
- Increase chance of living at home (versus institutionalization)
- Decrease chance of needing scoliosis surgery, by slowing its progression
- Decrease chance of bedridden induced infections
- Physical self closer to cognitive self
- A two hour surgery when Ashley was almost seven
- About as risky as a tonsillectomy
- Done before Estrogen therapy, since Estrogen causes:
  - 1) rapid growth of breasts & uterus, thus a future surgery becomes more involved & risky,
  - 2) increased chance of tumor in these organs &
  - 3) hard to control uteral bleeding

### Appendectomy

- Commonly done with abdominal surgeries
- Eliminate possibility of Appendicitis (5% chance)

**Prepared by Ashley's parents with input from "Friends of Pillow Angels"**

For more details see Ashley's blog by searching for "ashley treatment" or "pillow angel"

Contact us by emailing [pillowangel@hotmail.com](mailto:pillowangel@hotmail.com)