

The Ashley Treatment: Best Interests, Convenience, and Parental Decision-making

Forthcoming in the Hastings Center Report

Who's best interest?

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I.

The story of Ashley, a nine-year-old from Seattle, has caused a good deal of controversy since it appeared in the *Los Angeles Times* on January 3, 2007.¹ Ashley was born with a condition called static encephalopathy, a severe brain impairment that leaves her unable to walk, talk, eat, sit up, or roll over. According to her doctors, Ashley has reached, and will remain at, the developmental level of a three-month-old.²

In 2004, Ashley's parents and the doctors at Seattle's Children's Hospital devised what they called the "Ashley Treatment," which included high-dose estrogen therapy to stunt Ashley's growth, the removal of her uterus via hysterectomy to prevent menstrual discomfort, and the removal of her breast buds to limit the growth of her breasts. Ashley's parents argue that the Ashley Treatment was intended "to improve our daughter's quality of life and not to convenience her caregivers."³ They also "decided to share our thoughts and experience . . . to help families who might bring similar benefits to their bedridden 'Pillow Angels,'" which means that this treatment has public policy implications.

In the case of incompetent children like Ashley, parents are the custodians of the child's interests and are required to make decisions that protect or promote those interests. Doctors should also offer treatments that are in Ashley's best interests. It would be wrong to offer a treatment that was against the interests of the child but in the parents' (or others') interests. The central questions in medical ethics in relation to this case are: Were these treatments in Ashley's best interests? Do they treat her as a person with dignity and respect, and were they likely to make her life go better?

II.

Ashley's parents argue that they sought the Ashley treatment in order to alleviate Ashley's "discomfort and boredom." Their contention that stunting Ashley's growth was done for sake of improving "our daughter's quality of life and not to convenience her caregivers" is controversial.

According to her parents, keeping Ashley small—at around seventy-five pounds and four feet, five inches tall—means that Ashley can be moved considerably more often, held in their arms, be taken "on trips more frequently," "have more exposure to activities and social gatherings," and "continue to fit in and be bathed in a standard size bathtub." All this serves Ashley's health and well-being because, so the parents argue, "the increase in Ashley's movement results in better blood circulation, GI functioning (including digestion, passing gas), stretching, and motion of her joints," which means that Ashley will be less prone to infections.

Undoubtedly, the parents are right that Ashley will benefit in the manner they have proposed if they can do all these things for her. The claim about the value of small

size in a particular social circumstance is certainly not unique. Dwarves have given the same argument as a justification for preferring to have short children. They have argued that parenting dwarves is desirable for them because of their own size and because they have made modifications to their homes and their surroundings to take into account their short stature.⁴

As a general point, it is entirely conceivable that in some natural, social, or psychological circumstances, having a normal body may be a disadvantage. In H.G. Wells' short story "The Country of the Blind," Nunez, a mountaineer in the Andes, falls and comes upon the Country of the Blind. Nunez has normal vision, but in this society of blind people, he is disadvantaged, and he eventually consents to have his eyes removed. Similarly, in a world of loud noise, being able to hear could be a disadvantage. In the case of apotemnophilia—a body dysmorphic disorder in which the patient feels incomplete possessing all four limbs—doctors justify amputation by reasoning that the patient's psychology demands it. In Ashley's case, having a normal sized body could be a disadvantage. Stunting Ashley's growth may then be in her overall interest, given her likely natural and social circumstances.

Of course, Ashley's parents may have had other motives besides her benefit. Many critics have claimed that what her parents were really after was to make things easier or more convenient for themselves. Convenience may have been at least *part* of their motivation. Her parents could have found ways to take care of Ashley even if she had grown to her normal size of five feet, six inches. They argue that they were already near their limits when lifting Ashley; but if their own convenience was no consideration, they could have augmented their strength by hiring people to help them, or by going to

the gym, or by taking steroids, and so on. We are not advocating any of these things; we are asserting only that since the parents *could* have taken these measures, part of the rationale for making Ashley smaller may have been their own convenience.

This said, acting out of the motive to convenience the caregivers or otherwise promote their interests is not necessarily wrong, for two reasons. First, motives may only form part of the justification of the treatment of children. Whether the treatment will benefit or harm them is just as important, and sometimes even more so. Imagine a parent who takes a child with appendicitis to a hospital merely hoping that the child will get admitted so that the parent can get some badly needed sleep. Does this make it wrong to perform an appendectomy? Obviously not. In such a case, the justification of the procedure depends on the interests of the child and not on the motives of the parents (though of course the two can be related).

Second, in any plausible moral theory, moral obligations should typically not be so demanding that one must make enormous sacrifices in order to fulfil them. As Judith Jarvis Thomson observes, “nobody is morally *required* to make large sacrifices, of health, of all other interests and concerns, of all other duties and commitments . . . in order to keep another person alive.”⁵ Exactly where the demands of morality stop, especially in the case of parents, is not easy to say. But, arguably, if Ashley’s parents have to take steroids, which may have side effects, in order to move Ashley around, or if they will have to impoverish themselves in order to hire additional caregivers, then these alternatives might just be too demanding, and Ashley’s parents would not be obligated to pursue them.

Of course, someone might accept that the demands of morality have limits but still question whether stunting Ashley's growth for her caregivers' convenience is justified. Indeed, many are worried that the Ashley Treatment might represent a return to the practices of the eugenics movement and be an affront to human dignity.⁶ In particular, it has been asked whether, if it is permissible to stunt Ashley's growth to keep her small, why it is not also permissible surgically to remove her legs to keep her small. Needless to say, it is disturbing to think of a scenario in which severely disabled institutionalized children are subjected to mass surgery and growth-stunting to make the staff's work easier.

These questions raise issues concerning the ethics of body modification. Some forms of plastic surgery are performed on children: "bat ears" are sometimes corrected to prevent a child's being teased, and growth hormone or estrogen treatment is sometimes provided to children predicted to have short or tall stature.⁷ However, other forms of body modification that might be allowed in adults are not permitted in children. A Scottish surgeon, Robert Smith, amputated the healthy legs of two patients suffering from apotemnophilia. The patients had received psychiatric and psychological treatment prior to the operation, but did not respond. Both operations were carried out with private funding, and the patients said they were satisfied with the results.⁸ But this kind of surgery could not be ethically performed on healthy children because it is not plausibly in their interests, given the risks to, and the stress such an operation would impose on, their bodies. For this reason, surgically removing Ashley's legs just so she would be easier to care for would be unethical.

Giving Ashley estrogen to stunt her growth is obviously controversial but may be justifiable in this circumstance. Imagine that as a part of Ashley's condition, her body would grow to five times the size of other people. She would be enormous. In such a case, it does not seem too objectionable to arrest this kind of development through pharmacological means to allow her to be nursed and cared for, even if this is done partly for the caregivers' convenience. That is, suppose that if her development was not arrested, providing her with decent care would eventually require twenty people. If this is right, the question is not whether development *may* be arrested, but only *when* it may be arrested.

Here it is important to point out that decisions of this kind should be made on a case by case basis, with independent ethical review, such as occurred in this case through a hospital's clinical ethics committee. In general, it is inappropriate for institutions to biologically modify their patients to make them easier to manage, though clearly many demented people are sedated for this purpose. The benefits of being cared for at home by one's family may warrant imposing some burdens on incompetent dependants to enable them to remain at home and to make it possible for care to be delivered there. 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.

III.

The removal of Ashley's uterus and her breast buds is another matter. Ashley's parents argue that a hysterectomy will allow her to avoid the menstrual cycle and the discomforts commonly associated with it, eliminate "any possibility of pregnancy," and also eliminate

the possibility “of uterine cancer and other common and often painful complications that cause women later in life to undergo the procedure.” We find these arguments debatable.

For starters, it is unclear how much discomfort women suffer from the menstrual cycle, and whether the level of discomfort justifies hysterectomy. Also, even if Ashley will experience some discomfort, it is unclear why less invasive methods— such as giving Ashley pain killers whenever she experiences cramps—are not sufficient. Furthermore, removing Ashley’s uterus may cause her ovaries not to function normally as a result of a compromised supply of blood.⁹ 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.

Regarding unwanted pregnancies, while this does occur sometimes, the parents’ statement gives the impression that sexual abuse is a given to one in Ashley’s situation. Also, the parents may be in danger of blaming the victim. Ashley would get pregnant only through sexual abuse, but surely action should be taken against the offenders rather than Ashley. In any case, there are less invasive ways of avoiding pregnancy, such as putting Ashley on birth control pills.

Finally, regarding the possibility of uterine cancer and other painful complications, it seems premature to undertake a preventive measure when no one knows whether the symptoms will ever manifest. Giving Ashley regular health checkups seems to be much more appropriate and less invasive.

According to Ashley’s parents, surgically removing Ashley’s breast buds is justified because Ashley will not be breastfeeding. In addition, their presence “would only be a source of discomfort to her” because Ashley is likely to have large breasts, and

“large breasts are uncomfortable lying down with a bra and even less comfortable without a bra.” Moreover, they “impede securing Ashley in her wheelchair, stander, or bath chair, where straps across her chest are needed to support her body weight.” Furthermore, removing her breasts also means that she can avoid the possibility of painful fibrocystic growth and breast cancer, which runs in Ashley’s family. Finally, according to the parents, large breasts “could ‘sexualize’ Ashley towards her caregiver, especially when they are touched while she is being moved or handled, inviting the possibility of abuse.” Again, we find these arguments problematic. We shall start with the ones that have been addressed previously.

In arguing that the breasts could “sexualize” Ashley, the parents are again in danger of blaming the victim for possible abuse. Moreover, someone might sexually abuse Ashley whether she has breasts or not. The focus should be on the potential sex offenders.

The argument that breasts would make securing Ashley in her wheelchair difficult, and so on, is an argument from convenience. Like the previous argument about size, it depends on how likely the harm to Ashley would be and how great the sacrifice of coping with management would be. Unlike Ashley’s height and weight, in this case, it does not seem too demanding to require the parents to look for straps that would be more suitable for a larger breast size. Even if Ashley had been allowed to grow her breasts to their full potential, surely there are disabled persons with similar breast sizes, and their caregivers have apparently been able to use straps that are suitable for them (although the situation may be different when the patient’s disability is as grave as Ashley’s).

The possibility of painful fibrocystic growth and breast cancer is similar to the risk of uterine cancer; here, too, undertaking a preventive measure when the symptoms have not manifested seems premature. Even in the case of familial breast cancer, such as cancer linked to the genes BRCA 1 and 2, it is still not standard medical practice to offer prophylactic mastectomy to children, even those with a permanent intellectual disability that renders them incompetent. Many would argue that screening is preferable until there is more debate on the justification of prophylactic surgery in incompetent people.

The argument that Ashley does not need her breasts because she will not breastfeed (making her breasts only a “source of discomfort”) assumes that the sole function of having breasts is for breastfeeding. Allowing Ashley to develop breasts may enable her to form and complete her gender identity. It is true that gender assignment surgery has been performed on children at birth in cases of intersex conditions,¹⁰ but there is a growing consensus that surgery should be delayed until the child can make his or her own decision about it.¹¹ Ashley will never (on the evidence provided) be able to decide for herself. But there is a difference between gender assignment and gender *elimination*. Ashley’s parents argue that since Ashley has the mental state of a three-month-old, it is more fitting for her to have the body of an infant. They cite the statement of George Dvorsky, a member of the board of directors for the Institute for Ethics and Emerging Technologies, approvingly:

If the concern has something to do with the girl’s dignity being violated, then I have to protest by arguing that the girl lacks the cognitive capacity to experience any sense of indignity. Nor do I believe this is somehow demeaning or

undignified to humanity in general; the treatments will endow her with a body that more closely matches her cognitive state— both in terms of her physical size and bodily functioning. The estrogen treatment is not what is grotesque here. Rather, it is the prospect of having a full-grown and fertile woman endowed with the mind of a baby.

This argument implies that anyone with the mind of a baby should have the body of a baby, but there's no reason to think this is true. Indeed, suppose a woman in her forties has such severe dementia that her mental state is reduced to that of a baby; to hold that she should no longer have breasts is absurd.

It is important to remember that surgical procedures like hysterectomy are not without risks. Anaesthetics are occasionally lethal, and the surgical complications can include perforation of the bowel, infection, and occasionally death. All told, drug treatment to stunt growth seems more justifiable than the surgical modifications.

IV.

Ashley's case calls to attention the fact that every able person in our society has at least a prima facie duty to provide support and assistance to those who are providing care, not just for the likes of Ashley, but also for all normal children, the elderly, and others in care. Because of their basic, biological need for love, children have a human right to be loved.¹² Successfully discharging the duty to love children requires considerable time and resources. Possibly some parents can successfully discharge this duty using their own resources. But for many others, it can be quite difficult, owing perhaps to the demands of employment or of other family members. However, if the right of children to be loved is

a human right, and if the duties that stem from such a human right are applicable to all able persons in appropriate circumstances, then all other able persons in appropriate circumstances have associated duties to help parents discharge their duties to love their children. Such help might mean supporting better child care programs or advocating flexible workplace policies that would make it easier for parents to care for their children. It might also mean paying taxes and voting for policies that would help parents discharge their duties.¹³

This argument can be extended to the case of Ashley and others who require care, such as the elderly. Those who require care, like Ashley, have a fundamental need—and, therefore, a human right—to be cared for; and we, as members of society, have an associated duty to support policies that help their families care for them.

One of the main objections to the Ashley Treatment is that Ashley's disadvantage is socially constructed. If more resources were available for her care, then she could be nursed and cared for in a normal adult size. Those who defend the Ashley Treatment are right to respond that because these resources are not now adequately provided, Ashley's parents may be taking the only option open to them. Indeed, to deny her both the necessary social resources and medical treatment is to doubly harm her. If we as a society believe that it is undignified, as a matter of human rights, for Ashley to undergo these treatments, then we must be prepared to provide her caregivers with enough assistance and support that they would not have to resort to these means. Upholding human dignity comes with a price, and if it is what we should value as a society, then we must be prepared to pay to uphold it.

Acknowledgments

We thank Wibke Gruetjen for helpful discussions and comments on earlier versions of this paper.

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13. Strictly, these are prima facie duties: it is an open question whether justice requires this use of limited health resources or some other use that may more efficiently and effectively promote health.