

2015

Interview E Dad /
Dr.

Hi Ashley's dad,

...

We would like to use this story to engage viewers in a wider debate regarding the role of the family in making choices about disability vs. the government's role to safeguard individuals' rights. As such, the episode would likely focus not only on growth attenuation therapy, but also around other cases of parental choice with regards to disability. In other words, we are looking at bioethical decision-making in disability and asking who should get the final say on medical decisions over disabled family members - especially in cases when the disabled or 'unable' person cannot make that decision.

...

In this era we are coming more and more to this unexplored ethical territory where families and doctors make medical decisions that will be fiercely debated and openly criticised. It seems to me that while medicine is advancing, bioethics isn't; so we will continue to hear claims that people want to 'play God' or use medicine for 'unnatural purposes,' or to 'violate rights' - which to me all reveal this conflict with understanding the confines of parental choice. Through these multiple stories we will attempt to argue that family and parents should have a larger say in these matters, and that the government is often ill-equipped to make these decisions.

<AD> Dr. Diekema put it best in this speech: "when reasonable minds disagree, then the parents should decide"

<http://www.calvin.edu/january/2008/diekema.htm>

I think and hope that this is the best way to have an intelligent and (ideally perception-shifting) debate about the Ashely treatment and other similar treatments, but obviously I could be completely wrong, I'd really like to hear your opinions on the above.

<AD> When you have parents (know, love and care for the child), doctors, and ethics committees in the picture, I can't see how the government or government regulation could add value. So, I agree with your conclusion.

Questions:

The Ashely treatment is compromised of a series of operations and therapies - a hysterectomy, breast bud removal, hormone therapy, (appendectomy) - why was each deemed necessary - and were any additional medical operations considered and then dismissed?

<AD> check the one slide summary: <http://pillowangel.org/AT-Summary.pdf>

Some argue that precocious puberty, which is common in children with brain damage, is distressing to caretakers and family. Was this an issue with your family?

<AD> We had concerns/questions about Ashley's precocious puberty that led us to the idea of the Ashley treatment; see the details in the main article. Seeing it in a six year old was unusual, but not distressing.

How does GA treatment reduce seizure frequency within brain-damaged infants? Did Ashley have problems with seizures? (I don't believe she did, but just checking).

<AD> Ashley exhibited what some thought to be seizures but then it was determined to be something else. Charley's mother in NZ reported a dramatic reduction in seizures upon the estrogen therapy. You might want to discuss the details with her.

In your interview with Ed Pilkington you talk about the Seattle children's hospital that stopped providing the treatment, and how you set up an online community to help other families. Do you think there are instances when the medical establishment should be allowed to deny treatment to parents?

<AD> We encountered several cases where a hospital's ethics committee determined that GA is in the child's interest, yet the hospital refused to treat due to PR concerns. In a sense SCH is one of these cases. The SCH bioethicists have continued to highlight the potential benefits of the treatment, yet the hospital chooses to keep that door closed, to the detriment of a few families who have ended up having to seek out-of-state alternatives. Denying local treatment causes families the disruption of having to travel for care, and in some cases the child harm, if the family is not able to pursue the distant alternative. Harm by omission, in the sense of missing the benefits of the treatment and being inflicted what could have been avoided. Medical establishments should not be causing children harm due to PR concerns. Their first loyalty should be to the wellbeing of the child.

Arlene Mayerson, a disability rights advocate said of the case: "benevolence and good intentions have been among the biggest enemies of disabled people over the course of history" – When you first considered trying GA treatment were you worried about whether your intentions were skewing your perspective? What is it like for parents to make this kind of decision?

<AD> If you know Ashley, the answers to these questions would be obvious. Given her extreme and unique condition, the direct benefits to her were obvious and our decision (once all the information was available to us and discussed with excellent pediatric medical experts) was not difficult. At the time of the treatment, we were not thinking "disabled people". We were thinking of one deeply loved child, one very particular and medically established set of needs. Ashley's Mom and I can't speak for other parents, more of them are speaking out for themselves.

How much control should parents get over medical choices? Is the future of disability medicine based in individualized treatment like the Ashley treatment? Do we continue to judge on a case by case basis with ethical committees or do we need legislation reform?

<AD> Definitely case by case and individualized decisions. These kids have complex and unique conditions. Ashley's remain undiagnosed. Parents know their kids the most, love

them the most, and will deal with the consequences of these decision the most. I can't see how government involvement or legislation could help in this case.

Some of the resistance and criticism came from people with disability – people who claim Ashley was being robbed of womanhood and identity. Let's explore each individually: Does not having a uterus make Ashley not a girl? Would Ashley ever have become a woman?

<AD> When normal women go through a hysterectomy are they no longer female? Ashley is robbed of nothing. She has always been a female human being.

<AD> **"Woman" is a different issue. Physically, without GA, she would in all probability have matured into the typical body of a grown female human. However, her cognitive level would never enable her to become a woman. She profoundly and permanently lacks the intellect, agency, decision making, and all other mental aspects of womanhood due to her infant's brain and not to any bodily changes.**

<AD> **When actress Angelina Jolie got a double mastectomy and hysterectomy to prevent probable cancers due to genetic susceptibility, no one called her not a woman. What makes Jolie a woman is not her breasts or uterus/ovaries but her self awareness, skill, intelligence, decision making and manifesting ability, life experiences, developed identity through maturation and adult life. These are all things denied Ashley not because of GA but because of the static encephalopathy of unknown etiology.**

Has Ashley been deprived of an identity? Would Ashley have been able to develop an identity without the therapy? Does Ashley have an identity?

<AD> **Ashley is a much loved and valued member of the human race. A sense of self, identity in the psychological sense, is perhaps best summed up by reiterating that cognitively Ashley is approximately three months old. As such, her identity or self is a baby's needs for comfort, nurture, nourishment that she had and has and we hope will always have in abundance. So, no, the treatment does not take away from her identity, there is no relation between the two.**

What was the impact of Jenn Hooper 'going public' on your family? Were you in contact before?

<AD> **She is a member of our support group. We were glad that she did share Charley's story. We hope more parents will share theirs.**

Why do you think the government in the UK has denied Alison Thorpe's request to give her daughter Katie a hysterectomy? – do you think anyone should be allowed to give children with severe brain disorders hysterectomies/GA treatment?

<AD> **I am not familiar with the specifics of Katie's case. However, there are cases, like Ashley's, where a hysterectomy is appropriate, where it clearly brings direct, long-term benefits, removes a cause of recurrent suffering, and causes no harm. It should be a decision focused on individual needs and individual circumstances, free of politics, ideology**

or philosophy. The aim was to spare Ashley pain, suffering, and other complications. It is a preventative measure. All other considerations take a back seat to what is in Ashley's interest to live as physically comfortable as possible given her unique challenges and infant's inability to understand or endure and rationalize pain as temporary.

How has the media attention shaped your life? Will there always be controversy around the Ashley treatment? Will you ever reveal your names?

<AD> It is certainly an interesting chapter of our family's life. Our daughter's (known as Ashley X) story has become an important case study in bioethics, law, medicine, and philosophy. The interesting part for us is that other families were able to help their unique and precious children after learning from Ashley's story.

<AD> We hope the controversy will subside as there is more clarity about the treatment and its benefits. We do not feel there is a need to reveal our names. We have been able to get our message across and help other families through the support group, and are assured with the results so far.

Is Ashley still listening to Andrea Bocelli?

<AD> Ashley is still enchanted by good music. Lately we discovered the ARTS channel on satellite TV, which broadcasts music & art gems all the time, no commercials or fundraisers to disturb her.

You'll have to forgive me if some of these questions are blunt, they are thought out to solicit a direct response. Obviously you don't have to answer the ones you feel are misaligned or inconclusive to the argument. I also just want to be extremely clear that nothing you say can be used in our documentary without your specified consent, it simply goes towards shaping our argument for the episode.

<AD> We appreciate what you are tackling. It is a timely and challenging subject. Good luck with it.

I am incredibly appreciative of any time you may dedicate to helping us. If you can think else that is relevant, interesting or that I may have missed completely, I would love to hear about it.

Thank you so much and sorry for the really, really long email.

Best wishes