

2012 Interview  
w/ Ashley's Dad.

# The Ashley treatment: 'Her life is as good as we can possibly make it'

In an exclusive email exchange, Ashley's father talks to Ed Pilkington about his daughter's condition, her growth attenuation treatment - and the criticism his family has faced

**Ed Pilkington in New York**

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Towards the end of 2006 an endocrinologist in Seattle called Dr Daniel Gunther published an article in the Archives of Pediatrics in which he described a series of medical interventions he had given to a severely disabled child called Ashley.

Together with Ashley's parents, he devised a course of therapy designed to keep the child permanently small. For three years from the age of six, Ashley was administered high doses of the hormone estrogen to bring to a close her growth, effectively freeze-framing her body at the size of a child's. She was also given a hysterectomy so that she would avoid menstruation, and had her nascent breast buds removed to escape the discomfort of fully grown breasts.

The aim of it all, Ashley's parents insisted, was to give their daughter the best life possible despite a condition from birth which left her unable to talk or walk, and with the cognitive ability of an infant. News broke around the world of the pioneering treatment in January 2007, igniting a global debate about the acceptable limits of medical intervention for the most severely disabled children.

Five years on, Ashley's dad (AD) agreed to talk to the Guardian's Ed Pilkington (EP) in an email conversation that was carried out over several weeks. Here he brings us up to date with the story of his daughter, his "pillow angel" as he calls her, reveals how several other families have followed his example, and gives his response to the fierce criticism that was levelled against his family for what they had done.

*EP: It has been five years since you went public with what you called the "Ashley treatment", the use of medical procedures to attenuate your daughter's growth and inhibit the onset of puberty. The treatment was, unsurprisingly, massively controversial. Very important ethical debates have flowed from your pioneering treatment which I want to explore with you as we get into this dialogue.*

*But to start with, can we please focus on Ashley herself. She was six when you began the treatment, nine when you announced it to the world in January 2007, and now she is 14. How*

would you describe her today - as she approaches her 15th birthday - to someone like me who has never met her?

**AD:** We didn't exactly announce the treatment. Ashley's endocrinologist, Dr Gunther, wrote about her in the Journal of Pediatrics in October 2006. The media picked up the story, and the controversy exploded, which motivated us to tell Ashley's story in January 2007 through a blog, now at [pillowangel.org](http://pillowangel.org).

The treatment accelerated Ashley's puberty rather than inhibit it. In girls, puberty is caused by a surge of estrogen; the Ashley treatment added estrogen so that Ashley's growth would conclude at an earlier age and a smaller size.

Today at 14, Ashley is still an infant cognitively, as she was at birth and five years ago. She is completely loved, and a source of joy and a delight to our family.

Ashley is very pretty, like her mom. She has soft dark brown hair, beautiful blue eyes, long eyelashes, and is at a stable height and weight, that of an average nine-year-old, her age upon conclusion of the treatment.

No parent ever wants a child to be unhappy, uncomfortable, or ill. The Ashley treatment made her far more likely to be comfortable, healthy, and happy. Given the limitations imposed by her medical condition, her life is as good as we can possibly make it.

**EP:** *AD, before we go further into the discussion, it might be worth you telling us - as I'm sure some readers might be wondering by now - why you go just by your initials. You live in the Seattle area, that much we know, but beyond that you have been careful to preserve the anonymity of your family. Can you explain why?*

**AD:** AD stands for Ashley's dad. When the story first broke in the pediatrics journal and sparked media controversy, we - Ashley's mom and I - realized that it was potentially a deeply controversial story. So, with three small children to care for, we chose the surest way to safeguard our family and decided to stay anonymous. Our youngest is still a child (nine years old) and not yet able to deal with some of the potential blowback. For example, we received many hate emails. Kids shouldn't ever have to deal with that.

The press has been wonderful in helping us keep our privacy to be parents, caregivers, and just to be a family. We may be a news story from time to time, but we are always parents and always a family.

**EP:** *In 2007, when news of the Ashley treatment emerged, Ashley was 53in (135cm) tall and 65lbs (30kg) in weight. At that time, your calculations based on analysis of her bone mass and other tests, was that as a result of the treatment she had already reached 99% of her final height and she would forever remain the size of a nine year old. Instead of continuing to grow, as she would normally have done, to about 66in (168cm) and 125lbs (57kg), you anticipated that she would remain pretty much the size she was in 2007.*

*So let's jump five years to the present. What height and weight is Ashley today, and were your predictions accurate?*

**AD:** Ashley is at a stable 54in (137cm) tall and 75lbs (34kg). As a contrast, Ashley's 12-year-old sister is 66in (168cm) tall and 120 lbs (55kg) and still growing. Ashley's health is also stable, she is on a single prescription drug for reflux.

So, with respect to the treatment, the predictions are proving accurate and every intended benefit to Ashley is realized: smaller size, no menstrual discomfort, and no breast issues.

Ashley has scoliosis, a frequent co-condition in children with similar brain injury. Before the treatment, the scoliosis bent her spine a few more degrees each year. The scoliosis has been stable throughout the last five years, since the Ashley treatment was completed. Time will tell if it remains stable and she will be able to avoid a scoliosis surgery, which is possibly another significant benefit of the Ashley treatment and one we did not anticipate at the beginning, but are very hopeful about.

In addition, the six other families who concluded the treatment for their pillow angels (some are boys) in the last couple of years and are in contact with us, also reported smooth going with the treatment and successful results. Also, some of these parents reported additional benefits to the treatment, including reduction in seizures and in dystonia. Unfortunately, because of the controversy, many doctors and hospitals will not provide the treatment, so it is currently exclusive to families with means, and a lost opportunity for other children who could benefit.

**EP:** *In 2007, you said that the objective of the Ashley treatment, which you devised together with specialist doctors from Seattle's children's hospital, was to improve Ashley's own quality of life, with no consideration paid to your own needs as her parents caring for her. You believed that by attenuating her growth, avoiding the onset of puberty and removing her breast buds she would be physically more comfortable.*

*She would be free of menstrual cramps, the discomfort associated with breasts, and have reduced risk of bed sores and the other side effects of constantly lying down. She would also be happier because she would be more mobile and thus more included within day-to-day family life. Again, let's leap five years to the present day. Do you think the experience of the past five years has proven you right, and if so why?*

**AD:** Being right was never the goal. We worked hard, along with Ashley's doctors, to give Ashley the best quality of life for someone in her condition. To clarify though, Ashley is not mobile. She cannot walk, crawl, or scoot. Her smaller size allows her caregivers, mostly her parents and her grandparents, to move her frequently throughout the day, repositioning her to prevent bedsores and to aid circulation. We carry her or wheel her to keep her with us in the house, go on walks, get fresh air, and so on.

Ashley's life may be very limited, but like any baby, novelty attracts her attention. We do all we can to provide her with experiences that seem to make her happy, give her a good life,

and cheer her into expressing delight through vocalization and kicking.

Every child should get the stimulation, education and love that help them grow, develop, and reach full potential. Our son and younger daughter get books, sports activities, education appropriate to their needs and what is suitable for them. We do the same for Ashley, recognizing that her needs are very special and different; we do our best to meet them.

*EP: Also in 2007, you were convinced that Ashley would never develop cognitively beyond the level she had reached then, which you likened to the developmental level of a three-month-old baby. Has there been any sign of development since then? And in case anyone is wondering why Ashley is not answering these questions for herself, can you tell us whether she has attained in the last five years any powers of speech?*

**AD:** We look for signs from Ashley all the time. Her Mom and I, and her brother and sister all talk to her. Ashley is still an infant cognitively. She cannot talk, although she vocalizes, as she did five years ago. She does not track and follow with her eyes, point at or grip a toy. Her capability level is essentially that of a newborn's. In all medical probability, Ashley will never develop beyond early infancy level.

We'd love for Ashley to be able to do more. The kind of developments that we've observed with her along the years include: being able to hold her head up, stick her thumb in her mouth, and touch her hair behind her ear. These were big milestones for her and very exciting developments for us.

*EP: You mentioned that there have been six other families who have concluded a similar combination of medical procedures that you have called the Ashley treatment over the past couple of years. Up to now, as far as I'm aware, it was assumed that your family was the only one in America - even the world - to have carried out this treatment for a severely disabled child.*

*But we now learn that there have been six others, which is fascinating. Have they all followed in your footsteps - by that I mean, have they learned from Ashley's example, been inspired by it, and emulated it?*

**AD:** As far as we know, Ashley was the first in the world to receive this treatment. These other families learned about the treatment through Ashley's story and got in touch with us for help.

After the story came out in 2007, more than a thousand families and caregivers reached out to us in support of the treatment, based on their direct experience in caring for "pillow angels". Many families who heard Ashley's story and were still early in this journey of caring for their special children, realized that this treatment significantly improves their children's quality of life.

Because of the controversy and that Seattle children's hospital was no longer providing the

treatment, some of these families reached out to us for help. Given our limited means of helping them, we set up a private discussion group for them to meet and help one another, which worked out.

At this point, we're in contact with six families who concluded the treatment successfully and at least as many who are in progress. There are other families in contact who are still searching for providers.

We estimate that we're in contact with less than 10% of the families who are successful in providing the treatment to their children. Families who have found doctors that are willing to help their children have no need to contact us.

*EP: I imagine that this is a sensitive area, and that you will only want to say as much as the other families are themselves comfortable with revealing. But the knowledge that there is a group of families like yourself that have used medical techniques to attenuate the growth of their disabled children raises lots of interesting questions.*

*You mention that some of the six are boys - can you say precisely how many are boys and how many girls? What ages are they, can we know any names, and what procedures were carried out? Are they all in the US, or are their families in other countries? And when you say you are in contact with them, have you developed a network of supportive families facing the same issues, a sort of Ashley treatment club, if that's not too silly a way of putting it?*

**AD:** This private discussion group became a "pillow angels quality of life support group". The Ashley treatment is part of what we discuss; we also share other helpful ideas from our direct experiences.

Two of the six are outside the US, two are boys, and half of them received surgeries while the other half only the estrogen therapy, which is the part that causes an earlier end to growth and therefore shorter stature and lower weight.

*EP: You mention you have learned from these other families other aspects and benefits of the Ashley treatment for disabled children. Can you give me more detail about what precisely the families have told you, and what you have learned from their additional experiences?*

**AD:** One mother reported a halt to her daughter's prior frequent seizures, and a reduction in her hypertonia (tenseness in her neck, arms and legs) upon the estrogen therapy.

Another mother reported that her son's orthopedic surgeon told her that the estrogen therapy increases bone density, which ultimately helps with the prevention of bone fractures.

In addition, it is possible that growth attenuation stopped or slowed down the progression of Ashley's scoliosis (curving of her spine), reducing the risk of needing surgery. This could be an additional significant benefit of the treatment that we were not aware of initially.

*EP: You also mention that because of the controversy surrounding the Ashley treatment -*

*which I want to come onto shortly – such treatment has been blocked in many hospitals and is only open to "families with means". Your family spend thousands of dollars on the original Ashley treatment, can you remind me how much? And the other six families, have they had to spend similar amounts? Have they been able to find private medical institutions willing to carry out the procedures within the US, or have they been forced to travel abroad to receive the treatment?*

**AD:** There are some institutions and doctors both inside and outside the US that are providing the treatment. There are cases where families had to go to other countries and to other states.

Ashley's treatment cost under \$40k, which was mostly due to the surgery and was fully covered by our insurance. As far as we know the other treatments are covered by insurance as well.

*EP: Let's get back to your family's experience with the Ashley treatment. When it first became public in 2007 you must have been aware that it would be controversial, but were you prepared for just how explosive it was?*

**AD:** Initially we did not imagine a reaction at all, let alone an explosive one. Remember, the original publication was in a medical journal. You do not expect a lot of controversy when you know the treatment is clearly the right thing for your special child and when we took care that the treatment was medically, legally, and ethically vetted before it was begun. The benefits to Ashley are significant and life lasting. The same sentiment about the treatment and surprise to the reaction was shared by many other parents who wrote us. So, no, we weren't prepared for the explosion.

*EP: Have there been some dark moments over the past five years, when you have felt particularly beleaguered?*

**AD:** In the first couple of weeks in January '07 we were overwhelmed by how the story went viral and spread worldwide. That made us uneasy, especially the negative reactions and inaccurate coverage. At the same time 95% of the thousands of emails that we received provided incredible support.

*EP: Several disability groups have been critical of the treatment. The harshest accusation was that it violated Ashley's dignity and her rights as a human being, on a par with forced sterilizations of disabled people in past decades. What do you think of that argument, and of the demand made by these groups that the Ashley treatment be banned?*

**AD:** Ashley does not have the concept of dignity but she does have a very real experience with pain and discomfort. What is meaningful to her is to be as pain free and physically comfortable as possible. What is meaningful to her is to be able to enjoy those things she can enjoy: being with family, hearing music, cuddling. Ashley shows enjoyment for being included in family activities. She kicks her legs and orchestrates her arms, she makes little happy sounds, her face radiates with smiles. We however care a great deal about our

daughter's human dignity and feel that the treatment makes Ashley more dignified by providing her with a better quality of life.

Ashley's most important human right is not to be blocked from receiving a treatment that her parents, doctors and ethics committee all agreed is of benefit to her. Depriving her of the treatment's benefits, thus causing her preventable pain and suffering, would be taking away from her human rights.

We find the suggested analogy to the forced sterilization of individuals with disability (eugenics) to be a shallow one. We see a deeper analogy that leads to the opposite conclusion: a collective policy to block the Ashley treatment from children independent of their individual needs has a deeper similarity to Eugenics. Both are misguided collective policies that harm the individual.

*EP: Other groups sympathized with your desire to make Ashley more comfortable, but questioned whether invasive medical techniques were necessary. Again, any thoughts?*

**AD:** No amount of resources can replace the direct benefits to Ashley that the treatment provides. For example, how would additional resources compensate for discomfort caused by large breasts or menstrual cramps? Also, those that think a lift will do, simply have no clue. Any caregiver with direct experience can understand these points. We could have all the help and assistive technology in the world and if Ashley was still physically uncomfortable or in chronic pain that was preventable by a simple medical procedure, wouldn't we be cruel to not provide that?

*EP: After the treatment was completed, the local disability authorities in Washington state reviewed it and concluded that it shouldn't have been carried out without a prior court order. What is your reaction to that decision?*

**AD:** Our attorney, who is specialized with and has extensive experience with disability law, studied Washington's law carefully in this area (his report, made in preparation for Ashley's surgery, was made publicly available by the authority you reference); his conclusions disagree with those of the authority. Sterilization is a side effect of the treatment, not its intent. Also, Ashley is not capable of intentional procreation.

*EP: Why in your view have so many disability groups including several disabled people themselves been opposed to the Ashley treatment?*

**AD:** The groups reacted to how inappropriate the treatment would be for them as individuals. We completely agree, the huge majority of disabled people and especially individuals who can read about and object to the Ashley Treatment would not be candidates. Ashley's level of disability is extremely rare; we estimate that it affects much less than 1% of children with disability. From reviewing the reaction of the disabled community in detail, it is clear to us that not enough attention was given to Ashley's unique condition and needs, and how the treatment brings her significant and direct benefits.

Also, the disabled community objected to changing the individual rather than focusing on changing society so that disabled people could function more easily in society: accommodations such as curb cuts for wheel chairs, mainstreaming in school, and beeping crosswalks. These are all great things and we support them. Society needs to provide for everyone, especially those with special needs, paying attention to the specifics of the need and the person.

*EP: The key ethical question, it seems to me, relates to the meeting point between two potentially conflicting responsibilities. On the one hand, parents of severely disabled children must make difficult decisions on behalf of their loved-ones who cannot decide for themselves. On the other hand, government is charged with protecting vulnerable children from possible abuses. Where in your view does the onus lie between these two duties?*

**AD:** Parents have always had to make tough decisions for their children. When it comes to medical issues, ethics committees at leading children's hospitals exist to scrutinize issues like the Ashley treatment. The ethics committees have medical and ethical training and must uphold the child's interest and wellbeing in their decision. Their decisions are particular to each specific case. We can't see how government could add value given this existing mechanism.

*EP: In addition to the criticism you faced, there has also been a huge outpouring of support for what you have done. Your website carries just some of the hundreds of positive messages you've received. How many do you think there have been over the past five years, and how do they compare proportionately with the more critical comments?*

**AD:** We published these statistics on the blog a while ago. Out of the five thousand emails that we received, more than 95% were supportive. More than 1,100 supportive emails came from parents or caregivers with the direct experience. Many supportive emails indicated a reversal of position upon visiting the blog and seeing Ashley's photos.

*EP: Many of the letters and emails came from other families with severely disabled "pillow angels". Has this positive feedback from families in similar situations been important in helping you cope with the attacks?*

**AD:** All the supportive emails helped, especially those that shared experiences with their "pillow angels" that elaborated the benefits of the treatment.

*EP: Reading through the testimonies, many families talk of their grief at having to put their grown-up children into a disabled people's institution after it became physically untenable to care for them at home. That strikes me as another kind of violation of human rights.*

**AD:** We believe that the main value that Ashley's life has is in the context of being part of her family and her family's love, so we feel strongly about her continuing to be an integral part of our family. We do understand when families reach the point of having no choice but to give their growing child away, and we sympathize with how difficult that must be.



We hope that the treatment will increase the chances for "pillow angels" to stay at home surrounded in the loving care of their families. Institutionalization is no way to live, for many it is the only alternative and yes, you're right, institutionalization is a form of human rights violation, especially when treatments exist to make institutionalization less likely.

**EP:** *Earlier in this conversation you said that as a side effect of the controversy many hospitals and doctors had decided not to offer the Ashley Treatment for other severely disabled children. What is the impact, in your view, of this practical opposition?*

**AD:** The impact is that many families are not able to provide the treatment; so severely disabled children are deprived of the benefit. The treatment becomes exclusive to the wealthy and powerful.

**EP:** *As we wrap up this email conversation, a couple of final thoughts: First, knowing what you now know about how the treatment would pan out - both in terms of Ashley's well-being and in terms of the ethical debate around it - would you have done anything differently? Do you have any regrets?*

**AD:** We would have liked to avoid the controversy, but it is the broad media coverage that informed other families of the treatment and in some cases ended up helping their children; so, we can't think of things that we would do differently.

**EP:** *Finally, what matters overwhelmingly in all this is Ashley herself. So we should end with her. What has she taught you over the past five years, and what are your hopes for her in the five years that lie ahead?*

**AD:** You are absolutely right, Ashley is the center of this whole journey! We hope she will continue to be well and happy. We hope she lives in comfort and health. We deeply hope the scoliosis is completely stopped. We know she lives surrounded by love.

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