

The “Ashley Treatment”, Towards a Better Quality of Life for “Pillow Angels”[©]

By Ashley’s Mom and Dad
PillowAngel@hotmail.com

Original version was posted on January 2nd, 2007 - Last update on March 25th, 2007

The March 25th update addresses many questions and miss-understandings that we encountered both in the media coverage and in private email to us. It also discusses additional benefits to the Ashley Treatment, which other parents brought to our attention.

[The related blog](#) (Google “ashley treatment”) includes additional support material

Ashley’s Story

Our daughter Ashley had a normal birth, but her mental and motor faculties did not develop. Over the years, neurologists, geneticists, and other specialists conducted every known traditional and experimental test, but still could not determine a diagnosis or a cause. Doctor’s call her condition “static encephalopathy of unknown etiology”, which means an insult to the brain of unknown origin or cause, and one that will not improve.

Now nine years old, Ashley cannot keep her head up, roll or change her sleeping position, hold a toy, or sit up by herself, let alone walk or talk. She is tube fed and depends on her caregivers in every way. We call her our Pillow Angel since she is so sweet and stays right where we place her—usually on a pillow.

Ashley is a beautiful girl whose body is developing normally with no external deformities; see [photos](#). She is expected to live a full life and was expected to attain a normal adult height and weight. Ashley being in a stable condition is a blessing because many kids with similarly severe disabilities tend to deteriorate and not survive beyond five years of age.

Ashley is alert and aware of her environment; she startles easily. She constantly moves her arms and kicks her legs. Sometimes she seems to be watching TV intently. She loves music and often gets in celebration mode of vocalizing, kicking, and choreographing/conducting with her hands when she really likes a song (Andrea Bocelli is her favorite – we call him her boyfriend). She rarely makes eye-contact even when it is clear that she is aware of a person’s presence next to her. Ashley goes to school in a classroom for special needs children, which provides her with daily bus trips, activities customized for her, and a high level of attention by her teachers and therapists.

[©] This blog article is copyrighted. We hereby grant permission to quote from it as long as our blog is clearly credited and the following Web link is clearly listed: <http://ashleytreatment.spaces.live.com/blog>. Printing copies for personal use or educational purposes is permitted, we ask for \$1 per copy contribution to The Smile Train per instructions at: <http://www.smiletrain.org/>.

The Ashley Treatment



Figure 1 – Ashley along the years, from her first Christmas to age nine.

Ashley brings a lot of love to our family and is a bonding factor in our relationship; we can't imagine life without her. She has a sweet demeanor and often smiles and expresses delight when we visit with her, we think she recognizes us but can't be sure. She has a younger healthy sister and brother. We constantly feel the desire to visit her room (her favorite place with special lights and colorful displays) or have her with us wanting to be in her aura of positive energy. We're often gathered around her holding her hand, thus sensing a powerful connection with her pure, innocent and angelic spirit. As often as we can we give her position changes and back rubs, sweet talk her, move her to social and engaging places, and manage her entertainment setting (music or TV). In return she inspires abundant love in our hearts, so effortlessly; she is such a blessing in our life!

To express how intensely we feel about providing Ashley with the best care possible, we would like to quote from a private email that we received from a loving mother with her own 6 year old Pillow Angel: “In my mind, I have to be immortal because I have to always be here on Earth to take care of my precious child. Taking care of him is difficult, but it is never a burden. I am [his] eyes, ears and voice. He is my best friend, and I have dedicated my life to providing joy and comfort to him. To my last breath, everything I will ever do will be for him or because of him. I cannot adequately put into words the amount of love and devotion I have for my child. I am sure that you feel the same way about Ashley.”

The chance of Ashley having significant improvement, such as being able to change her position in bed, let alone walk, is non-existent. She has been at the same level of cognitive, mental and physical developmental ability since about three months of age. Ashley has aged and grown in size but her mental and physical abilities have remained and will remain those of an infant.

Faced with Ashley's medical reality, as her deeply loving parents, we worked with her doctors to do all we could to provide Ashley with the best possible quality of life. The result is the “Ashley Treatment.”

Summary

The Ashley Treatment is the name we have given to a collection of medical procedures for the improvement of Ashley's quality of life. The treatment includes growth attenuation through high-dose estrogen therapy, hysterectomy to eliminate the menstrual cycle and associated discomfort to Ashley, and breast bud removal to avoid the development of large breasts and the associated discomfort to Ashley. We pursued this treatment after much thought, research, and discussions with doctors.

Nearly three years after we started this process, and after the treatment was published in October, 2006 by Dr. Gunther and Dr. Diekema in a [medical journal](#)¹ that resulted in an extensive and worldwide coverage by the press² and dozens of public discussions³, we decided to share our thoughts and experience for two purposes: first, to help families who might bring similar benefits to their bedridden Pillow Angels; second, to address some misconceptions about the treatment and our motives for undertaking it.

A fundamental and universal misconception about the treatment is that it is intended to convenience the caregiver; rather, the central purpose is to improve Ashley's quality of life. Ashley's biggest challenges are discomfort and boredom; all other considerations in this discussion take a back seat to these central challenges. The Ashley Treatment goes right to the heart of these challenges and we strongly believe that it will mitigate them in a significant way and provide Ashley with lifelong benefits.

Unlike what most people thought, the decision to pursue the Ashley Treatment was not a difficult one. Once we understood the options, problems, and benefits, the right course was clear to us. Ashley will be a lot more physically comfortable free of menstrual cramps, free of the discomfort associated with large and fully-developed breasts, and with a smaller, lighter body that is better suited to constant lying down and is easier to be moved around.

Ashley's smaller and lighter size 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. Typically, when awake, babies are in the same room as other family members, the sights and sounds of family life engaging the baby's attention, entertaining the baby. Likewise, Ashley has all of a baby's needs, including being entertained and engaged, and she calms at the sounds of family voices. Furthermore, given Ashley's mental age, a nine and a half year old body is more appropriate and provides her more dignity and integrity than a fully grown female body.

We call it Ashley Treatment because:

- 1- As far as we know Ashley is the first child to receive this treatment,
- 2- We wanted a name that is easy to remember and search for,
- 3- The name applies to a collection of procedures that together have the purpose of improving Ashley's quality of life and well-being. Growth attenuation is only one aspect of the treatment.

The Ashley Treatment

In early 2004 when Ashley was six and a half years old, we observed signs of early puberty. In a related conversation with Ashley's doctor, Ashley's Mom came upon the idea of accelerating her already precocious puberty to minimize her adult height and weight. We scheduled time with Dr. Daniel F. Gunther, Associate Professor of Pediatrics in Endocrinology at Seattle's Children's Hospital, and discussed our options. We learned that attenuating growth is feasible through high-dose estrogen therapy. This treatment was performed on teenage girls starting in the 60's and 70's, when it wasn't desirable for girls to be tall, with no negative or long-term side effects.

The Ashley Treatment

The fact that there is experience with administering high-dose estrogen to limit height in teen-age girls gave us the peace of mind that it was safe—no surprise side effects. Furthermore, people found justification in applying this treatment for cosmetic reasons while we were seeking a much more important purpose, as will be detailed below.

In addition to height and weight issues, we had concerns about Ashley's menstrual cycle and its associated cramps and discomfort. We also had concerns about Ashley's breasts developing and becoming a source of discomfort in her lying down position and while strapped across the chest area in her wheelchair, particularly since there is a family history of large breasts and other related issues that we discuss below. The estrogen treatment would hasten both the onset of the menstrual cycle and breast growth. Bleeding during the treatment would likely be very difficult to control.

It was obvious to us that we could significantly elevate Ashley's adult quality of life by pursuing the following three goals:

- 1- Limiting final height using high-dose estrogen therapy.
- 2- Avoiding menstruation and cramps by removing the uterus (hysterectomy).
- 3- Limiting growth of the breasts by removing the early breast buds.

The surgeon also performed an appendectomy during the surgery, since there is a chance of 5% of developing appendicitis in the general population, and this additional procedure presented no additional risk. If Ashley's appendix acts up, she would not be able to communicate the resulting pain. An inflamed appendix could rupture before we would know what was going on, causing significant complication.

Ashley was dealt a challenging life and the least that we can do as her loving parents and caregivers is to be diligent about maximizing her quality of life. The decision to move forward with the Ashley Treatment was not a difficult one for us as many seem to think. It was obvious to us that a reduction in Ashley's height (and therefore weight), elimination of the menstrual cycle, and avoidance of large breasts would bring significant benefits to her health and comfort. The only downside that we could think of was the surgery itself; however, the involved surgery is commonly done and is not complicated. Hysterectomy is a 1.5 hour surgery of less involvement and risk than a Fundoplication (wrapping and sewing the upper part of the stomach around the esophagus), which is commonly provided to children like Ashley to mitigate reflux and vomiting. The breast bud removal is a minor surgery with minimal risk. Furthermore, we're fortunate to have access to one of the best surgical facilities and teams at Seattle Children's Hospital. If we were in a less developed locale or country with higher risk of surgery, we would have looked at this part of the analysis differently.

Since the Ashley Treatment was new and unusual, Dr. Gunther scheduled us to present our case to the ethics committee at Seattle Children's Hospital, which we did on May 5th 2004. The committee includes about 40 individuals from different disciplines and is evenly composed of men and women. After we presented our case we waited outside while the committee deliberated the issue. The committee chairman along with Doctor

The Ashley Treatment

Diekema, ethics consultant, conveyed the committee's decision to us, which was to entrust us with doing the right thing for Ashley. There was one legal issue that we needed to investigate related to "sterilization" of a disabled person. Upon consultation with a lawyer specializing in disability law, we found out that the law does not apply to Ashley's case due to the severity of her disability, which makes voluntary reproduction impossible. The law is intended to protect women with mild disability who might chose to become pregnant at some future point, and should have the right to do so. Furthermore, sterilization is a side effect of the Ashley Treatment and not its intent.

The combined hysterectomy, breast bud removal, and appendectomy surgery was performed without complications in July 2004. Ashley spent four days in the hospital under close supervision, and thanks to aggressive pain control her discomfort appeared minimal. In less than one month, Ashley's incisions healed and she was back to normal; it's remarkable how kids heal so much quicker than adults. Ashley's Mom had had a C-section and knew first hand how Ashley would feel after surgery; thankfully, the recovery went much better than Mom anticipated.

Shortly after the surgery and recovery, we started the high-dose estrogen therapy. We completed this treatment in December 2006 after two and a half years. During this whole period, we have observed no adverse consequences.

Expenses of the surgery and of the therapy that followed, which we estimate to be about \$30,000, was fully covered by insurance.

Following we provide more details about the different aspects of the treatment and the related benefits.

Limiting Final Height Using High-Dose Estrogen

After the surgery, we started Ashley on a high-dose estrogen therapy using derma-patches that we changed every three days. Estrogen accelerates puberty and advances bone age until separate growth plates in the bones fuse together, see hand X-ray [photos](#), halting growth and determining the extent of height. This occurs in both boys and girls. Therefore, Ashley did go through puberty; however, sooner than she would have.

Dr. Gunther sees Ashley every three months to monitor:

- Weight and height
- Bone age, by comparing her hand X-ray to a set of reference photos
- Estrogen level, and other tests, through blood work

Based on Dr. Gunther's analysis, predictions, and estimates, this treatment is expected to reduce Ashley's untreated height by 20% and weight by 40%. If we had started the treatment at a younger age, the benefits to Ashley would have been greater.

The Ashley Treatment

More specifically, at this point Ashley is 53" (4' 5"), (average for a nine and a half year old girl), and has a bone age of 15 years (see [photos](#)), which implies that she is about 99% of her height. When Ashley was 6 years and 6 months old she was 48" (4' 0"), (75th percentile for her age at the time). Normal growth would have resulted in an adult height in the neighborhood of 66" (5' 6"), (Ashley's Mom and Dad, are 5' 9" and 6' 1", respectively). Therefore, the treatment is expected to produce a height reduction of 13 inches (or 20%). Average weight of a 4' 5" woman is 75 lbs, while the average weight of a 5' 6" woman is around 125 lbs, so the treatment is expected to produce a weight reduction of 50 pounds (or 40%).

We are currently near the limits of our ability to lift Ashley at 65 pounds. Therefore, an additional 50 pounds would make all the difference in our capacity to move her. Furthermore, other than her Mom and Dad the only additional care givers entrusted to Ashley's care are her two Grandmothers, who find Ashley's weight even more difficult to manage. We tried hard and found it impossible to find qualified, trustworthy, and affordable care providers.

The main benefit of the height and weight reduction is that Ashley can be moved considerably more often, which is extremely beneficial to her health and well being. Currently, one person can carry Ashley, versus requiring two people or a hoisting harness and ropes, should she have grown larger. As a result, Ashley can continue to delight in being held in our arms and will be moved and taken on trips more frequently and will have more exposure to activities and social gatherings (for example, in the family room, backyard, swing, walks, bathtub, etc.) instead of lying down in her bed staring at TV (or the ceiling) all day long. In addition, the increase in Ashley's movement results in better blood circulation, GI functioning (including digestion, passing gas), stretching, and motion of her joints.

From the hundreds of emails that we received from families that had or have their own Pillow Angels, a significant benefit to the size reduction is the ability of families to keep caring for their loved ones at home. We read one testimony after another about how heart breaking it was for certain families to reach a point of inability to care for their Pillow Angels at home, and hence end up with no choice but to place them in an institution. This consideration was not a factor for us pursuing the Ashley Treatment, since the possibility of reaching the point of not being able to care for Ashley at home never crossed our minds (we're still young and able and perhaps naïve about the future). **However, with the extensive input that we've received from other families, it is now abundantly clear to us that keeping Pillow Angels under the care of their families at home throughout their lives, is a very important benefit that the Ashley Treatment brings to Pillow Angels and their families. Furthermore, we strongly believe that the comfort and quality of life benefits of the Ashley Treatment are even more relevant if Pillow Angels end up in institutions, which was indicated to us in emails from many care givers.**

The Ashley Treatment

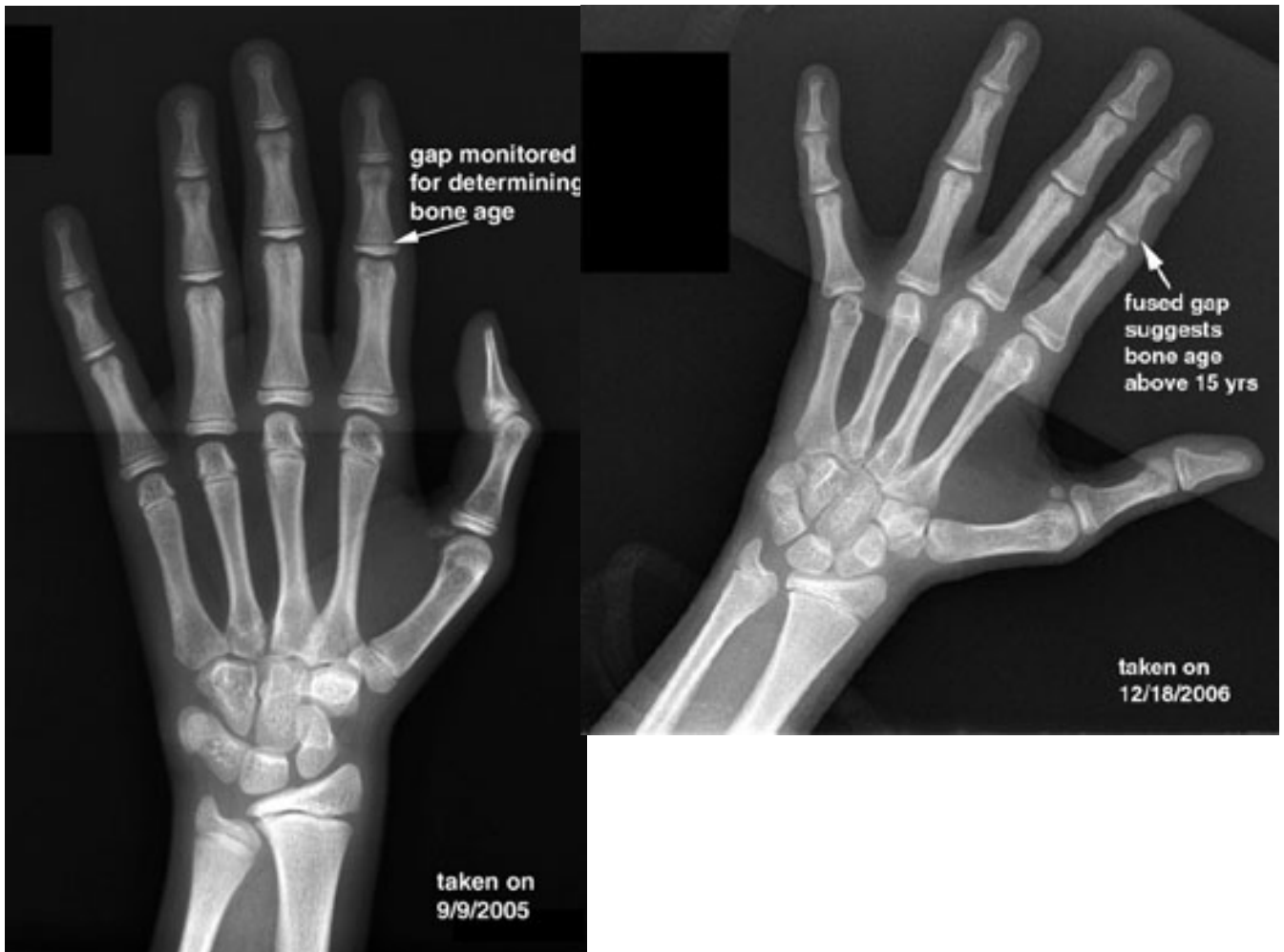


Figure 2 – Hand X-rays as indicators of bone age.

A doctor suggested that Ashley will be less prone to infections as a result of her smaller size. Bedridden individuals are more susceptible to potentially fatal infections. Both the reduction in size in itself, and the increased movement and resulting blood circulation are expected to reduce the occurrence and magnitude of such infections including:

- 1- **Skin sores:** larger body weight leads to pressure skin ulceration or bed sores, providing an inlet for deadly bacterial infections (another way to look at this is that adults are more susceptible to bed sores than children).
- 2- **Pneumonia:** increased body weight increases the pressure on the chest and reduces the lungs' ability to expand, causing fluid build up in the lungs that increases the chance for pneumonia and breathing complications.
- 3- **Bladder infection:** similarly, increased body weight causes increased pressure on the bladder outlet, resulting in urinary retention and an increased risk for bladder infections.

The Ashley Treatment

Parents of other Pillow Angels suggested additional benefits of the Ashley Treatment. Ashley, like many children in her condition, has a serious case of scoliosis (curvature of the spine), whose progression often reaches a point of requiring quite an involved [scoliosis surgery](#). Halting growth should slow down or may even halt the progression of scoliosis. We also learned of Pillow Angels with diseases that cause their bones to be brittle. An orthopedic surgeon suggested to a mother with one of these Pillow Angels that halting growth will reduce incidences of bone fractures and hence the need for his services.

These benefits make intuitive sense and so we decided to mention them; however, at this point we do not know of studies to reference that provide us with objective and quantitative understanding of them

Furthermore, Ashley remaining child sized has other practical ramifications such as:

- 1- She will continue to fit in and be bathed in a standard size bathtub. Since Ashley can't sit, she needs to lie down in the bathtub. Without the treatment eventually she would stop fitting in a standard size bathtub and would need a different arrangement for bathing.
- 2- Ashley is more comfortable lying down and does not like to sit in her wheelchair, she fusses and cries if she is in it for more than a short time. We move her around the house while lying down in a regular double-stroller (we face the chairs together, cover them with a thick double natural sheepskin and set the back of one to a reclining angle). The system works remarkably well; however, Ashley is already at the weight limit for which this stroller is designed (two babies).

Avoiding Menstrual Discomfort through a Hysterectomy

The Hysterectomy involved removing Ashley's uterus but keeping her ovaries to maintain her hormonal cycle and the generation of her natural hormones. Ashley has no need for her uterus since she will not be bearing children. Hysterectomy prevents the discomfort, pain, cramps and bleeding that are so commonly associated with the menstrual cycle. Many emails we received testify to how painful these symptoms are due to the cramping of the uterus and how hard they are on Pillow Angels.

Additional and incidental benefits to hysterectomy include avoiding any possibility of pregnancy, which to our astonishment does occur to disabled women who are abused. The hysterectomy also eliminates the possibility of uterine cancer and other common and often painful complications that cause women later in life to undergo the procedure.

Preventing Breast Growth by Removing the Early Breast Buds

Ashley has no need for developed breasts since she will not breast feed and their presence would only be a source of discomfort to her. This is especially true since Ashley is likely destined to have large breasts, given her maternal and paternal female lineage. Ashley's aunt had a breast reduction operation at age 19 and Ashley's Mom considered one at a

The Ashley Treatment

similar age, but opted against it so not to adversely affect future breast feeding. Large breasts are uncomfortable lying down with a bra and even less comfortable without a bra. Furthermore, breasts impede securing Ashley in her wheelchair, stander, or bath chair, where straps across her chest are needed to support her body weight. Before the surgery Ashley had already exhibited sensitivity in her breasts.

Though this step in the treatment might seem extreme to some, it is a simple procedure when the breasts are still undeveloped. This operation involved removing Ashley's subcutaneous, almond-sized breast buds, which contain the milk glands, while keeping the areolas and nipples intact. This surgery was done with small incisions below the areola, the slight scars almost disappeared a month after the surgery. This operation is akin to removing a birthmark and is a very different surgery from a mastectomy on an adult woman with developed breasts. Furthermore, when done in conjunction with the hysterectomy this step poses little to no additional recovery time or surgery risk (for example, anesthesia is done once).

Additional and incidental benefits to breast bud removal include:

- 1- Avoiding the possibility of painful fibrocystic growth and future related surgeries. Women in Ashley's lineage have a history of fibrocystic growth.
- 2- Avoiding the possibility of breast cancer. Ashley has breast cancer history in her family.
- 3- Large breasts could "sexualize" Ashley towards her caregiver, especially when they are touched while she is being moved or handled.

Of all the things we wanted to do to provide lasting physical comfort and quality of life to Ashley, the breast bud removal posed the biggest challenge to Ashley's doctors, and to the ethics committee. We overcame this reluctance by detailing the benefits above, recounting Ashley's family history of breast problems, and pointing out the fact that the same procedure is commonly provided to males for cosmetic reasons and to mitigate unwanted breast development (it is called Gynecomastia). In boys who might receive high-dose estrogen therapy in the future, breast growth will become an important consideration, and can be dealt with as in Ashley's case.

Addressing some Common Misconceptions

From observing early media coverage and visiting certain online discussion groups, it became clear to us that there are several misconceptions or misunderstandings about the treatment that we provided for our daughter and our motivation for pursuing it, which we address here.

We are thankful to the support and prayers from many, and we included some of the testimonies and supportive comments on [Ashley's blog](#). At the same time we're surprised at the volume and magnitude of the critical comments. We carefully reviewed these comments: they seemed to us to be gut reactions without depth or rational consideration

The Ashley Treatment

of the situation, the treatment, or the motivation behind it, which we hope this article sheds more light on. It seems that people are thinking of a child who is mostly normal or who might progress to approach normal. As we stated earlier, Ashley has not shown material progress in her mental ability since she was three months of age, she is dependent on us in every way (including position change), she can't hold a toy, and we're not sure she recognizes us.

To put our decision process in perspective, it is not uncommon for parents with children who have cancer or birth defects to pursue significantly more intrusive treatment (chemo or radiation therapy) or more involved surgery (extensive plastic surgery face reconstruction), than what the Ashley Treatment entails. We strongly believe that the benefits that we're seeking for Ashley are not any less worthy than these other unfortunate situations entail.

We hope that by now it is clear that the Ashley Treatment is about improving Ashley's quality of life and not about convenience to her caregivers. **Ashley's biggest challenge is discomfort and boredom and the Ashley Treatment goes straight to the heart of this challenge.** It is common for Ashley to be uncomfortable or to be bored. Even though Ashley's level of tolerance has increased along the years, she is helpless when bothered and her only recourse is to cry until someone comes to her rescue. These episodes are triggered by something as simple as sliding off the pillow, a sneeze, or a hair landing on her face and tickling/bothering her, let alone menstrual cramps, adult-level bed sores, and discomfort caused by large breasts and a constricting bra. Also, without the treatment, Ashley could not be moved as frequently or be as included in family life, and we would not experience the joy of being an intact family as often.

If people have concerns about Ashley's dignity, **she will retain more dignity in a body that is healthier, more of a comfort to her, and more suited to her state of development** as [George Dvorsky](#), a member of the Board of Directors for the Institute for Ethics and Emerging Technologies, alludes to in a related article⁴: "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."

Even though caring for Ashley involves hard and continual work, **she is a blessing and not a burden.** She brings a lot of love to our hearts as we're sure all Pillow Angels bring their families. In the words of a mother who lost her Pillow Angel: "While I would never want her to go through the discomfort she endured during her life, I would give all I have for one more snuggle, one more gaze from her radiant eyes." If there is a prize for those who have the record of how often they are told "I Love You", we're certain that these kids would win it effortlessly. Ashley's presence in our home kindles abundant feelings of love in all members of the family. It is a joy just being with her, she brings nourishment to our souls; it is a pleasure to visit with her and sweet talk her and observe

The Ashley Treatment

her innocent and genuine smile. Ashley sets the barometer in our home, when she is happy we're happy and when she is not we're not.

We are very fortunate that Ashley is a healthy child, outside her abnormal mental development, and is in a stable condition. We're describing our unique experience which is not universal in this regard, and most likely not even representative. We fully understand that different Pillow Angels have different problems and pose different challenges to their caregivers, and that different families have different abilities and resources to provide for their special needs children.

The decision to move forward with this treatment, unlike what most have thought, was not difficult. Ever since we researched the idea and with Ashley's doctor's confirmation that it could be done, we focused squarely on getting it done as quickly as we could to maximize the benefits. It was clear to us that the lifelong benefits to Ashley by far outweigh risk factors associated with the surgery. In contrast, the decision to insert the feeding tube into Ashley's stomach and associated surgery was a lot harder for us. Ashley's doctor suggested that we put the feeding tube in at 5 months of age because it was taking up to eight hours a day to get enough nutrition in her through a bottle. We delayed the tube insertion for years in order to spare Ashley the surgery. At five years of age we finally decided to go for the surgery, since almost every time Ashley would catch a cold she would completely refuse her bottle for days and end up dehydrated and in the emergency room.

Furthermore, **we did not pursue this treatment with the intention of prolonging Ashley's care at home.** We would never turn the care of Ashley over to strangers even if she had grown tall and heavy. In the extreme, even an Ashley at 300 pounds, would still be at home and we would figure out a way to take care of her.

The objection that this treatment interferes with nature is one of the most ridiculous objections of all; medicine is all about interfering with nature. Why not let cancer spread and nature takes its course. Why give antibiotics for infections? Even an act as basic as cutting hair or trimming nails is interfering with nature.

Some question how God might view this treatment. **The God we know wants Ashley to have a good quality of life and wants her parents to be diligent about using every resource at their disposal** (including the brains that He endowed them with) **to maximize her quality of life.** Knowingly allowing avoidable suffering for a helpless and disabled child can't be a good thing in the eyes of God. Furthermore, the God we know wants us to actively share our experience and learning with the rest of the world to help all Pillow Angels and other special need children in reaping the benefits of the Ashley Treatment.

We want to avoid sensationalism or philosophical debates about what we did and why we did it. We'd rather care for and enjoy Ashley than get into such endless debates. In our opinion, only parents with special-needs children are in a position to fully relate to this topic. Unless you are living the experience, you are speculating and you have no clue what it is like to be the bedridden child or their caregivers. Furthermore, in the case of the

female aspects of the treatment, women are in a better position to relate to these aspects and the benefits for which they are intended.

What this Means to Other Families with Pillow Angels

We've received hundreds of emails and there are hundreds of postings in dozens of blogs by parents with special need children, indicating that they wish they had the option of the Ashley Treatment before their kids reached their adult size and how this would have changed their lives significantly. You can see a sampling of these points of view in [the testimonies section](#) of Ashley's blog. One mother explained in graphic detail how heart breaking it was for her to have to let her daughter go to a care center since "I am tired, my body is breaking down rapidly, and emotionally drained" and she stopped being able to care for her daughter at home. It is this type of family that we hope our experience will help some day.

Clearly, the Ashley Treatment is not for all disabled kids. Our daughter's condition pointed to a clear decision where the benefits far outweigh the risks and short term discomfort associated with surgery. Families of other kids may likewise find the Ashley Treatment to be the right approach for them. It is our hope that this treatment becomes well-accepted and available to such families, so they can bring its benefits to their special needs child if appropriate and at an optimal age in order to obtain the most benefits.

Clearly, a decision on the applicability of the Ashley Treatment needs to be made upon careful evaluation of their child's unique condition, with help from their doctors, and careful evaluation of the benefits that might be obtained. We believe the parents are in the best position to make this evaluation and ultimately make this decision.

In addition, our understanding is that the growth limiting aspect of the Ashley Treatment is applicable to male children. It seems to us that it even makes more sense in their case, since boys tend to grow taller and bigger. In boys hysterectomy will not be an issue; however, since estrogen will result in breast growth, the breast bud removal surgery would still need to be considered.

Definitions

Since the two terms below that we introduced in this paper have become of common use, we offer the following definitions that reflect our original intentions behind them.

Pillow Angel: Affectionate nickname for Ashley X, now generally refers to people with a cognitive and mental developmental level that will never exceed that of a 6-month old child as well as associated extreme physical limitations, so they will never be able to walk or talk or in some cases even hold up their head or change position in bed. Pillow Angels are entirely dependent on their caregivers.

Ashley Treatment: A collection of medical procedures intended to enhance the quality of life of Pillow Angels. It includes limiting adult height through high-dose estrogen therapy, and for females it includes a hysterectomy and breast bud removal prior to the

The Ashley Treatment

estrogen therapy in order to prevent discomfort associated with menstrual cramps and developed breasts. It is generally acknowledged that Pillow Angels are most comfortable and attain the highest possible quality of life in the loving care of their own family. The Ashley Treatment improves the quality of life of Pillow Angels, including helping their families continue to care for them at home. The treatment was first applied to a Pillow Angel named Ashley at Seattle Children's Hospital, and was first discussed in a medical article published in October 2006 and in a blog by Ashley's parents published on January 2nd 2007. The treatment was widely publicized by the media worldwide in early January 2007 and was the subject of controversy.

Acknowledgment

Our sincerest thanks to Ashley's doctors and the surgery team at Seattle Children's for their world class expertise, competence and support throughout this pioneering treatment. Special thanks to Doctor Daniel F. Gunther, without whose courage, confidence, knowledge, open mindedness and unwavering support the treatment would not have been realized and the idea would have remained just an idea. We know that many endocrinologists would not have ventured into such new territory. It is our, and Ashley's luck, that we knocked on the right door.

We thank our good friend Margaret Russell for her tireless support in reviewing and editing many versions of this article, which helped clarify its message significantly. We thank our family and friends for their love and support throughout the Ashley journey including her treatment.

References

- [1] "[Attenuating Growth in Children with Profound Developmental Disability, A New Approach to an Old Dilemma](#)", Archives of Pediatrics & Adolescent Medicine, Vol. 160, No. 10, October 2006, Daniel F. Gunther, MD, MA; Douglas S. Diekema, MD, MPH.
- [2] This story topped the Health section of Google News between January 5th and January 8th – [there have been more than 600 related articles worldwide](#).
- [3] "[Pillow Angel Parents Deserve Credit, Not Blame](#)", BLOG: SCIAM OBSERVATIONS, Opinions, arguments and analyses from the editors of Scientific American, January 4th, 2007.
- [4] "[Helping families care for the helpless](#)", George Dvorsky, Sentient Developments, Institute for Ethics and Emerging Technologies, November 6th, 2006.