

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

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

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

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

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

Reasons for providing the treatment

The "Ashley Treatment"

- Preventative medical care

Remarks on the "Ashley Treatment"

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

- Primary benefit to Ashley

- Improves Ashley's quality of life

- Additional benefit to Ashley

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

Ashley went through puberty by age nine

Side benefit

"Breast Bud Removal"

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

Hysterectomy

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

"Sizing for Wellness"

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

Appendectomy

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

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

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

Contact us by emailing pillowangel@hotmail.com

What the "Ashley Treatment" is?