

# Growth attenuation treatment: Tom, the first boy to undergo procedure

Tom is the first severely disabled boy known to have received growth attenuation treatment, keeping him forever small

Karen McVeigh in New York

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**W**hen Tom's parents first explored the idea of the so-called "Ashley treatment" for their son, who had severe cerebral palsy, they came upon a stumbling block. Ashley, the first disabled child to undergo a course of medical and surgical treatment designed to keep her forever small, was a girl. The cocktail of procedures had never been applied to a boy.

But Tom, their first child who they adopted as a baby from Vietnam, was growing bigger, stronger and heavier. He was becoming more difficult to carry around and care for.

With this thought in mind, they made a decision that would take them - and Tom - into uncharted medical and ethical territory.

Tom is believed to be the first disabled boy to undergo growth attenuation (GA) hormone treatment designed to keep him small for the rest of his life.

The Guardian has learned that there are at least 12 families worldwide - possibly more than 100 - who have undergone or are undergoing the treatment, which has become the subject of fierce debate over the acceptable limits of medical intervention in the care of severely disabled children.

Tom's mother, who is 50, agreed to talk to the Guardian on condition of anonymity. She said she first learned the extent of her son's disabilities when he was two: that he would never sit, walk, eat or talk and that his epileptic seizures could prove fatal. She vowed then she would do anything to help him. GA treatment, she feels, is part of that promise.

She said: "If you had an eight-year-old who had cancer, you wouldn't ask, do we give her chemotherapy? You just do it. Every medical treatment is playing God. It is interfering with nature. This is to do with respecting a human being who needs help."

Tom, who is 12 but has the cognitive capacity of a two-month-old baby and is totally dependent, according to his mother, is close to completing the treatment that began when

he was almost eight. He weighs 70 lbs (32kg), is 53in tall (134cm) and is likely to remain that size forever.

Tom lives with his parents and younger sister in Europe - his mother did not want to specify the country and declined to provide the Guardian with a photograph - and is happiest, she said, among his family when he is being cuddled. Because he cannot move independently, she has to carry him from his bed to a mat on the floor, or outside to the garden.

Children like Tom are difficult to carry around, she said because "they are so strong and the muscles are so tense. A child weighing 25kg seems to be the weight of three because of the muscle spasms."

Her first meeting with the endocrinologist who would treat Tom lasted an hour. The doctor had never given a disabled boy GA therapy before, although he had used similar treatment on children who had grown unusually tall. He said he would use estrogen to speed up the natural closure of Tom's growth plates and that, in turn, would stop the child growing.

Many of Tom's mother's questions to the doctor went unanswered.

"I asked him about the medication, will it cause more seizures, will it affect him falling asleep, will it affect his feeding issues? He had to repeat himself, saying, 'I don't know, I don't know!'"

But the endocrinologist assured her it was safe and, when he treated children who were too tall, he never had complications.

Her main worry, she said, was that Tom might develop breast buds, a potential side-effect of using estrogen. But the doctor said if that happened, they could operate to remove them. In the end, he never did develop breast buds. The physician told Tom's mother that her son would be carefully monitored, his growth, blood and liver function checked for any side effects.

"It worried me, but we had to find a balance about not knowing enough about the treatment and the doctor saying it was safe to give him estrogen" she said. "It wasn't like a new drug that we never tested before."

She said she asked the doctor why he would use estrogen, a female hormone, instead of the male corollary, testosterone. "He said if he gave him testosterone Tom would go into puberty and he would start to have facial hair and pubic hair and that it would affect the hormone levels in his body."

Tom's mother said that the potential sexuality of her son, who has a normal life expectancy, hadn't initially caused her concern, because at that time he was only eight. But, after discussing GA therapy with the doctor she felt that experiencing puberty might be too upsetting. As an infant, for example, Tom always became very agitated when having his hair cut; she worried trimming his beard may cause him similar distress.

The doctor told her that it was difficult to predict exactly what would happen, but that puberty - like bone growth - would be sped up before coming to a stop under the treatment. It is unlikely that he will ever show any signs of puberty.

In October 2008, Tom began receiving a small dose of estrogen to see how he would react. The dose was gradually increased.

The first few months of the treatment were very difficult, she said. "We were tense and anxious, looking for any change. But he didn't show any sign of pain or discomfort."

### 'No official protocol'

Tom's mother was told that the procedure would not normally be undertaken without approval by a hospital ethics committee, but she is unclear as to whether permission has been officially granted.

She said: "Our doctor told me that there is still no official protocol. Cases are assessed one by one."

Tom's mother knows of another mother from Ireland who has approached her doctor for treatment for her disabled son. Part of her desire for anonymity was to ensure that the doctor was not identified.

She said she was shocked at the level of criticism leveled at Ashley's family and suspects that it stems from a lack of understanding. "If the people who cried out the loudest in a negative way had any clue what it is to care for a child like Tom, like Ashley, they would not say the horrible things they have accused Ashley's family of," she said.

"I don't think they can accuse us of disrespecting our children. It's the opposite. It was difficult for Ashley's family because they were in the front line and they were really brave to fight for this therapy.

"It will help Tom a lot and I will be grateful for the rest of my life for what they did. Those people who reacted the most harshly were [self-aware] disabled people. They are aware of their rights. Tom isn't. Ashley isn't. Somebody has to make decisions for them and who better to make that decision than the parents who love the child."

*Tom is not his real name, and was changed to maintain his anonymity.*

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