



Focus on Ethics

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| The Hippocratic oath | Le serment d'Hippocrate |
| The declaration of Helsinki | La déclaration d'Helsinki |
| Ethical values | Valeurs éthiques |
| Ethic committee | Comité d'éthique |
| Informed consent | Consentement éclairé |
| Confidentiality | Secret professionnel |
| Breach confidentiality | Rompres le secret professionnel |
| Good medical practice | Bonne pratique médicale |
| Medical malpractice | Faute professionnelle |
| Conflict of interest | Conflit d'intérêt |
| Heroic treatment | Acharnement thérapeutique |
| euthanasia | L'euthanasie |
| Medically-assisted suicide | Suicide médicalement assisté |
| Assisted reproductive technology (ART) | Procréation médicalement assistée(PMA) |
| surrogacy | Gestation pour autrui (GPA) |
| cloning | Le clonage |
| Genetics | La génétique |
| Genetic counselling | Conseil génétique |
| Embryonic stem cell research | La recherche sur les cellules souches embryonnaires |

Text:

A Question of Medical Ethics

1. On New Year's Day, the parents of a severely physically and mentally- disabled girl decided to explain in a blog their **rational behind** a decision to keep her small and childlike. Ashley, now nine years old with an estimated mental age of three months, **underwent** high-dose oestrogen treatment, **hysterectomy** and breast bud removal to **stunt** her **growth** and physical development when she showed the first signs of **puberty** at the age of six years. This treatment, argue the parents, makes it easier for them to care for her, which will mean a much better quality of life for Ashley.
2. At one month of age after a normal pregnancy and delivery, Ashley ha presented with signs of **Hypotonia**, spasms and **developmental delay**, and was subsequently diagnosed with static encephalopathy of unknown origin. She cannot **sit up** or change her position, does not speak, and is gastrostomy-tube fed, but reacts to her **surroundings** by vocalising and smiling. Her parents, who also have two healthy children, describe movingly how she is integral and very much loved part of their family.
3. Daniel Grassroot and Douglas Potter published her care in October, 2006, and explained that the Seattle children's Hospital's full ethics committee had **given the go-ahead** for this treatment, concluding that the benefits to the girl and her parents **outweighed** the risks.
4. In an accompanying comment, Jeffrey Williams and Chris Spector argue that the real tragedy about such cases is the underlying failure of society to provide adequate social support to carers in an extremely difficult situation. Ashley's father's blog contains one very telling sentence in this context: "We tried hard and found it impossible to find qualified trustworthy and **affordable health care providers**".
5. So, have these parents and doctors been courageous and compassionate to give this particular girl the best life possible? Or have they violated her human rights and dignity in a misguided attempt to make the best of bad circumstances? There are no easy answers to these questions. But at least this complex situation is now in the public domain to allow a considered debate on how to best help such families. What should not be questioned is the meticulous care Ashley's doctors have shown in trying to do the best for this young and much-loved daughter of devoted parents.

Vocabulary

| Word | Definition |
|---------------------|--|
| Rationale | The reasoning or principals that explain a course of action or a decision |
| Undergo | To endure or benefit from a medical or surgical treatment |
| hysterectomy | Surgical removal of the uterus |
| Stunt | To prevent someone or something from growing or developing. |
| Puberty | The time at which the onset of sexual maturity occurs and the reproductive organs become functional. |
| Hypotonia | Diminished tone of the skeletal muscles |
| Developmental delay | Marked absence of progress in the physical or mental development of children |
| Sit up | To remain in a seated position, to move from a lying |
| surroundings | Position to sitting position The immediate environment |
| Give the go-ahead | To give approval, green light |
| outweigh | To be greater or more important than |
| Carer | A person who looks after an old or sick person at home |
| Trustworthy | Reliable, that you can count/ rely on |
| Affordable | Not too expensive |
| Healthcare provider | A qualified health professional who gives medical attention to patients at home or in hospital. |

Word formation

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| - centesis | Paracentesis Amniocentesis | Puncture of a cavity to draw fluid Puncture of the uterus |
| -tomy | Thoracotomy Laryngotomy | Incision of the chest wall Incision of the larynx |
| -stomy | Gastrostomy Colostomy Cholecystostomy | Creation of an opening in the stomach Creation of an opening in the colon Creation of an opening into the gallbladder |
| -ectomy | Hysterectomy Lumpectomy | Removal of the uterus Removal of mass |
| -plasty | Angioplasty Stomatoplasty | Reconstitution of a blood vessel Plastic reconstruction of the mouth. |