

# APPENDIX

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### INTRODUCTION

The study of ethics involves consideration of conflicting moral choices and dilemmas about which reasonable people may disagree. Since a wide range of positions is likely to be found among students in most classrooms, it is especially important to foster a safe classroom atmosphere by creating some discussion ground rules. These ground rules are often referred to as “norms.” An agreed-upon set of ground rules should be in place before beginning the *Bioethics 101* curriculum.

### LEARNING OBJECTIVES

***Students will be able to:***

- Create and agree to classroom discussion norms.

### PROCEDURE

Ask the students, “What can we do to make this a safe and comfortable group for discussing issues that might be controversial or difficult? What ground rules should we set up?” Allow students some quiet reflection time, and then gather ideas from the group in a brainstorming session. One method is to ask students to generate a list of ground rules in small groups and then ask each group to share one rule until all have been listed. Clarify and consolidate the ground rules as necessary.

Post norms where they can be seen by all and revisit them often. If a discussion gets overly contentious at any time, it is helpful to stop and refer to the ground rules as a class to assess whether they have been upheld.

Some possible student ground rules/norms could include:

- A bioethics discussion is not a competition or a debate with a winner and a loser.
- Everyone will respect the different viewpoints expressed.
- If conflicts arise during discussion, they must be resolved in a manner that retains everyone’s dignity.
- Everyone has an equal voice.
- Interruptions are not allowed and no one person is allowed to dominate the discussion.
- All are responsible for following and enforcing the rules.
- Critique ideas, not people.
- Assume good intent.

# APPENDIX

## Student Handout—*Elements of a Strong Justification*

Name \_\_\_\_\_ Date \_\_\_\_\_ Period \_\_\_\_\_

A strong justification should have the following elements:

✓	A good justification includes:	Which means...
<input type="checkbox"/>	A DECISION	A position (claim) has been clearly stated. The decision relates directly to the ethical question.
<input type="checkbox"/>	FACTS	The facts and science content can be confirmed or refuted regardless of personal or cultural views. This can be used as evidence to support the claim.
<input type="checkbox"/>	ETHICAL CONSIDERATIONS	Ethical considerations may include Respect for Persons, Maximize Benefits/ Minimize Harm, and Justice, in addition to others. This can be used as evidence to support the claim.
<input type="checkbox"/>	STAKEHOLDER VIEWS	There are a variety of views and interests in the decision and more than one individual or group will be affected by the outcome.
<input type="checkbox"/>	ALTERNATIVE OPTIONS and REBUTTALS	No one decision will satisfy all parties. A thorough justification considers strengths and weaknesses of various positions.
<input type="checkbox"/>	REASONING and LOGIC	A logical explanation that connects the evidence to the claim is provided.

*For our purposes, the justification for the decision is more important than the position on the decision.*

# APPENDIX

## Ashley's Case Overview

The following case study and support materials were created as a pre-/post-test for a research study designed to investigate the relationship between explicit instruction in bioethical reasoning and resulting student outcomes.

*Lesson Five* of the curriculum is designed to assess students' ability to synthesize what they have learned throughout the curriculum module, and results in a written paragraph showing student reasoning. Teachers may use *Ashley's Case* as a pre-/post-test for the *Bioethics 101* curriculum, if desired. For the *Ashley's Case* assessment, students are not asked to integrate their justification into a final paragraph detailing how evidence from the case is used to support their claim, although elements of student reasoning will be apparent in the assessment questions.

Name \_\_\_\_\_ Date \_\_\_\_\_ Period \_\_\_\_\_

### Ashley's Case

Ashley, at age 6½, could not roll over, sit up or hold her head up, or use language. Developmentally, she was like an infant. Ashley's parents, who have two other healthy children, had cared for Ashley in their home since birth. Ashley was diagnosed with "static encephalopathy," meaning that her brain had stopped developing. Doctors determined that there was no chance of Ashley improving over time.

Ashley's parents grew concerned over their abilities to continue to care for Ashley at home. With continued growth and development, she would eventually become too large for them to manage her needs, including feeding her, changing her, bathing her, and positioning her during the night. Additionally, they were concerned at the prospects of her sexual development, including menstruation, breast development, and fertility.

Ashley's parents made three requests of doctors at Children's Hospital and Regional Medical Center in Seattle, Washington. First, they wanted Ashley to have a hysterectomy (removal of her uterus) to prevent any risk of menstruation and/or pregnancy. Although there are methods like birth control pills to address these issues, they are accompanied by the possibility of long-term side effects. One risk, blood clots, is considerable in a patient who is bed-bound and unable to move herself. Second, they requested the removal of her breast buds, which would eliminate the development of breasts altogether. Ashley's parents argued that her breasts would cause discomfort with the straps used to hold her in her chair, and that breast discomfort was a known problem for some adult women in the family. There was also a family history of fibrocystic breast disease and breast cancer. Without breasts, Ashley would be spared future mammograms and possible biopsies. Finally, Ashley's parents requested medical treatment to limit her final adult height and weight through hormone therapy. High dose hormone therapy to limit height was a common treatment for "tall girls" in the 1960s and 70s and the medical risks over the long term are known to be limited.

The ethics committee noted that there was great need for caution with such procedures, as there have been many documented cases of past abuses of people with physical and developmental disabilities. Dr. Doug Diekema (who, with Dr. Daniel Gunther, published their paper on Ashley in the *Archives of Pediatric and Adolescent Medicine*) acted as ethicist on this case, and was part of the group that decided the outcome of the parent's requests. Dr. Diekema noted that there were few medical risks involved with the hysterectomy and removal of breast buds (standard surgical procedural risks), and only slightly higher risks associated with the hormone therapy (such as blood clotting).

Critics noted that this combination of surgery and hormones to prevent a person from maturing into an adult was unprecedented in medical history. There were also worries about Ashley's rights as a patient, as her parents were making this decision without her ability to contribute. There was a general debate about the potential "slippery slope" of adapting the bodies of the disabled to suit the needs of the caregivers, unless it could be justified that this change was also in the patient's (Ashley's) best interests. An ethics consultation involving about 20 individuals was performed before making the decision. The consultation included a developmental specialist, Ashley's primary care provider, and her hormone specialist. Although Ashley's parents attended the consultation, they were not a part of the deliberation.

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Please see the Teacher Resource section for source information. Originally developed by Jacob Dahlke.

**Ethical Question:** Should one or more medical interventions be used to limit Ashley's growth and physical maturation? If so, which interventions should be used and why?

1. What is your position on this issue?

SCORE

2. What is the factual content to support your position that can be confirmed or refuted regardless of cultural or personal views?

SCORE

3. What are the views and interests of the individuals or groups affected by the decision that you think are most relevant to your position?

SCORE

4. What ethical considerations can be included to support the position? (Respect for Persons, Maximize Benefits/Minimize Harms, Justice)

SCORE

5. What are the alternative options and why are they not as strong as your position?

SCORE



# APPENDIX

## Scoring Rubric

### Ethical Question:

Should one or more medical interventions be used to limit Ashley's growth and physical maturation?  
If so, which interventions should be used and why?

Dimension	Exemplary (4 Points)	Proficient (3 Points)	Partially Proficient (2 Points)	Developing (1 Point)
1. What is your <b>decision</b> ? Why is that the best option? (A position that relates directly to the ethical question has been clearly stated and explained.)				
<b>Decision</b>	<p>Student states the best option and discusses all of the interventions with pros/cons, or student states the best option and uses ethical principles to support decision.</p> <p>Student shows thoughtful consideration and organized thinking. Student uses accurate information to support his/her decision.</p>	<p>The student's choice of best option is clearly stated, but may not mention all options. Student shows clear thinking.</p> <p>Student states the best option, and provides accurate information to support his/her decision, or student discusses other interventions.</p>	<p>Student does not clearly state the best option or does not state the best option as what should be done (e.g., "If I were Ashley, I would want the procedures," or "The procedures seem unnecessary."). Student does not give any reasons to support his/her decision.</p>	<p>Student states an option that is not one of the options for the case (e.g., assisted suicide) or student response shows no understanding of the situation or the question being asked.</p>
2. What <b>facts</b> support your decision? Is there information missing that could be used to make a better decision? (The facts and science content can be confirmed or refuted regardless of personal or cultural views.)				
<b>Facts</b>	<p>The justification <b>uses the relevant scientific reasons</b> to support student's answer to the ethical question. Student demonstrates a solid understanding of the context in which the case occurs, including a thoughtful description of important missing information. Student shows logical, organized thinking.</p> <p>Both facts supporting the decision and missing information are presented at levels exceeding standard (as described above).</p>	<p>The main relevant facts are identified. All scientific concepts are correctly presented. Student shows clear thinking. Information missing from the case that would influence decision-making is referenced.</p> <p>Both facts supporting the decision and missing information are presented at levels meeting standard (as described above).</p>	<p>Factual information relevant to the case is described but some key facts may be missing and some irrelevant information may also be included. Student may not have noted information missing from the case that would influence decision-making.</p> <p>Student presents only facts or missing information.</p>	<p>Factual information relevant to the case is incompletely described or is missing. Irrelevant information may be included and student demonstrates some confusion.</p>

Dimension	Exemplary (4 Points)	Proficient (3 Points)	Partially Proficient (2 Points)	Developing (1 Point)
3. Which <b>stakeholders</b> will be impacted by the decision and how will they be impacted? (There are a variety of views and interests in the decision, and more than one individual or group will be affected by the outcome.)				
<b>Stakeholder Views</b>	Three or more stakeholders, the ways in which they are impacted, and their values, interests, and/or concerns are identified OR four or more stakeholders and the ways in which they are impacted are identified.	Three stakeholders and the ways in which they are impacted are identified OR four stakeholders are identified without mention of impacts on them.	Two stakeholders and the ways in which they are impacted are identified OR three stakeholders are identified without mention of impacts on them.	Only one stakeholder and the way in which this stakeholder is impacted is identified OR two stakeholders are identified without mention of impacts on them.
4. What are the <b>main ethical considerations</b> ? (Ethical considerations may include Respect for Persons, Do Good/Do No Harm, Justice, and Care.)				
<b>Ethical Considerations</b>	The student <b>evaluates the case in depth using one or more ethical considerations</b> . The student shows exceptional understanding of how one or more ethical considerations relates to the case. The student's decision is supported by the thorough, thoughtful application of the consideration(s) to the case. The student demonstrates organized thinking, and his/her conclusions flow logically from premises.  Student response includes analysis/evaluation of the case with regard to issues of consent, best interest, and/or benefits/harms.	The student demonstrates an understanding of the ethical consideration(s) related to the case. The student provides clear explanation of how ethical considerations support his/her decision. Student response includes issues of consent, best interest, and/or benefits/harms.	The student demonstrates a general awareness of ethical considerations and how they relate to the case, but may not articulate the relationship clearly or provide enough explanation. The student demonstrates mostly clear and organized thinking, but portions of the answer may be unclear, disorganized, or incomplete.  Student response seems to refer to issues of consent, best interest, and/or benefits/harms.	The student lacks an awareness of ethical principles or does not properly relate them to the case. The student demonstrates some confused or disorganized thinking. Student response does not include ethical considerations (e.g., legal considerations).
5. What are the strengths and weaknesses of <b>alternate solutions</b> ? (No one decision will satisfy all parties. A thorough justification considers various positions.)				
<b>Alternate Solutions</b>	Provides a thorough analysis of the alternate solutions that includes multiple strengths and weaknesses and/or multiple alternate solutions. The writing is clear and organized.	Presents both the strengths and the weaknesses of the alternate solution(s).	Discusses only the strengths or the weaknesses of the alternate solution or contains either misconceptions or unrealistic strengths or weaknesses (e.g., Ashley's brain will start to develop or being able to mature normally is a strength for her).	No alternate solutions are discussed, or does not present strengths and/or weaknesses of alternate solutions or presents unrealistic alternatives (e.g., assisted suicide).

### Key Facts and Scientific Concepts

- Ashley was a 6.5-year-old girl with static encephalopathy which means she is developmentally like an infant with no chance of improvement in the future.
- Ashley's parents cared for her in their home since birth.
- As Ashley grows, she will become harder to move, change, bathe, and position at night.
- Ashley's parents asked her doctors to help them keep her at home under their care by performing three procedures:
  1. Hysterectomy to prevent menstruation and/or pregnancy.
  2. Removal of breast buds to prevent breast development (family history of breast discomfort and breasts get in the way of straps used to hold her in a sitting position).
  3. Hormone therapy to limit her final adult height and weight.
- Doctors note there are few risks involved with a hysterectomy and removal of breast buds besides standard surgical procedural risks and only slightly higher risks associated with hormone therapy. High-dose hormone therapy has a long history of use in children and risks (such as blood clotting) are known to be limited.
- This procedure to prevent a person from maturing into an adult is unprecedented in medical history.

Stakeholders Impacted by Decision	Interests/Values
<b>Ashley</b>	Since she is developmentally an infant, her interests are similar: comfort; the need for the familiar faces of those who love/care for her; family.
<b>Ashley's parents</b>	Want to keep their child in their home; concerned for her comfort, safety, and well being; concern for her future; they would like to care for her as long as possible.
<b>Advocates for the rights of disabled persons</b>	Concerned that this could become accepted practice in the care for disabled persons; focus of care should be on patient's needs, not those of caretakers, when considering medical treatments.
<b>Ashley's doctors and care team</b>	Concern for Ashley's health and future care; want to provide ethically sound treatments that benefit her without undue risk to her health.
<b>Families with similar situations</b>	If the treatment is successful, this could inform other families with disabled children about their choices for care; increases the options available to them for keeping children in the family home rather than in an institution.

**Main Ethical Considerations: Sample Student Responses**

Exemplary	Proficient	Partially Proficient	Developing
<p><b>Student chooses to proceed with only the least invasive treatment.</b></p> <p>The main ethical considerations are Do Good/Do No Harm and Respect for Persons. Hormone therapy has a slightly higher risk of complications (blood clots) than the surgeries but doesn't require her to be under anesthesia and is not invasive. The hormone therapy will keep her small so that her parents will be able to care for her more easily which will be the major benefit to her. In this way, the most good can be done for Ashley with the least amount of harm.</p> <p>The best people to care for her are those who love and know her the most. By keeping her body whole but limiting her growth, she is kept safe and secure in the family home while at the same time respecting Ashley as a person and allowing the natural path of her development into an adult female.</p>	<p><b>Student chooses the option to deny all treatments.</b></p> <p>We should respect Ashley as a person and not something to be changed surgically to make it easier on the caretakers. There are other ways they can take care of her like getting a home nurse to do all the difficult work. She could have serious complications with the surgeries and that wouldn't be worth it.</p> <p><b>Student chooses to proceed with all three treatments.</b></p> <p>Ashley can't decide so her parents who care for her should be able to make the decision they think will be best for her. They know her family history and how to make her comfortable. If breasts will make her uncomfortable in seat straps then they should prevent the pain by removing her breast buds. If they know menstruation will be hard on her, then she should have a hysterectomy. And if she is small, she will be at home with her loving family because they will be able to take care of her easily. This will be a benefit (doing good) for all involved and respect the family's wishes and needs.</p>	<p><b>Student chooses to proceed with all three treatments.</b></p> <p>We need to respect her parent's ability to make choices about Ashley since they have authority over her as a child.</p>	<p><b>Student chooses the option to deny all treatments.</b></p> <p>Ashley wouldn't be able to have babies otherwise. She should be able to have babies if she wants to. It's not fair.</p>

**Strengths and Weaknesses of Alternate Solutions**

Exemplary	Proficient	Partially Proficient	Developing
<p><b>Example:</b> Since she wears diapers anyway, menstruation shouldn't be too much of a problem to care for and if she stays in the family home, pregnancy shouldn't be a risk so there is no need for the hysterectomy. The family can't predict she will have the same discomfort with breasts as other females in the family so an invasive surgery like breast removal should wait until a real problem arises.</p>	<p><b>Example:</b> All of the procedures carry some risk to Ashley's health and none of them are medically necessary. The hormone therapies in particular, with their risk of clotting, are too dangerous.</p>	<p><b>Example:</b> The surgeries won't hurt her that much. She's never going to get pregnant anyway so she doesn't need her uterus and she won't need breasts either.</p>	<p>No alternate solutions are discussed.</p>

### Case Study Follow-up (to be related to students *after* the post-test)

After a lengthy consultation with parents, family, physicians, and the Seattle Children's ethics committee, a consensus was reached to perform the full treatment. (The parents contributed to the discussion, but were not a part of the decision-making process.) A simple hysterectomy was performed on Ashley, although her ovaries were preserved in order to allow for normal hormonal production throughout her life. Her breast buds were removed without complication, and Ashley's height-limiting treatment included an estrogen skin patch applied daily for 2.5 years without complication. Estrogen is the primary female hormone that, when used in high doses, shortens the amount of time that growth can occur.

One year after her treatments, at the age of 9, Ashley was 4'5", about 12 inches shorter than predicted without therapy. It is estimated that her weight—65 pounds—was almost half of what it would have been without the hormone treatments. She continues to live under the care of her family.

#### Sources:

"Disabled girl's parents defend growth-stunting decision." Burkholder, Amy. *CNN.com*, March 13, 2008. <http://www.cnn.com/2008/HEALTH/conditions/03/12/pillow.angel/index.html>

"Commentary: Is 'Peter Pan' treatment right?" Caplan, Arthur, PhD. *MSNBC.com*, January 5, 2007. <http://www.msnbc.com/id/16472931/>

"Doctor at crux of stunting debate kills self." Dahlstrom, Linda. *MSNBC.com*, October 11, 2007. <http://www.msnbc.com/id/21225569/>

Diekema, Doug. The Case of Ashley X. NWABR Ethics in Science Online Course. 2007.

"Pillow Angel Ethics." Gibbs, Nancy. *Time*, January 7, 2007. <http://www.time.com/time/nation/article/0,8599,1574851,00.html>

"Pillow Angel Ethics, Part 2." Gibbs, Nancy. *Time*, January 9, 2007. <http://www.time.com/time/nation/article/0,8599,1574851,00.html>

"The other story from a 'Pillow Angel'." McDonald, Anne. *Seattle Post-Intelligencer*, June 17, 2007. [http://www.seattlepi.nwsource.com/opinions/319702\\_noangel17.html](http://www.seattlepi.nwsource.com/opinions/319702_noangel17.html)