

## Ethics and Bioethics - Assessing Prior Knowledge

### *Family Secrets: Part 3* Assessing Prior Knowledge

**Team Members' Names:** \_\_\_\_\_

**Take 5 minutes to jot down some ideas that come to mind, either from your research so far in your teams, or from your personal background, when you hear the following terms: Ethics and Bioethics**

**Ethics:**

**Bioethics:**

## Major Ethical Principles Chart

Individual Rank	Ethical Principles	Example	Example
	Right to decide - <b>Autonomy</b>	Choosing a career or college that's different from one that your family or your friends recommend.	
	Doing what is best - <b>Beneficence</b>	Deciding to exercise on a regular basis.	
	Being fair - <b>Justice</b>	Deciding to give everyone on the team a chance to play.	
	Do no harm - <b>Nonmaleficence</b>	Deciding not to eat junk food that could be harmful for you?	

## Ethical Values Chart

**Rank only the top 3 values**

<b>Rank</b>	<b>Values</b>	<b>Example</b>	<b>Example</b>
	Relieving the other's suffering <b>(Compassion)</b>	Providing food for the hungry	
	Keeping a secret <b>(Confidentiality)</b>	Not telling others that a friend has cheated	
	Keeping a promise <b>(Fidelity)</b>	Remaining faithful to a spouse	
	Treating others as you would like to be treated <b>(Golden Rule)</b>	Holding the door open for an elderly person	
	Telling the truth <b>(Honesty)</b>	Admitting that you were speeding	
	Conforming to your principles/values <b>(Integrity)</b>	Not copying answers to the homework	
	Keeping from public view <b>(Privacy)</b>	Asking that a bank not release your financial information to others	
	Preserving the dignity of self and others <b>(Respect)</b>	Speaking without profanity or ethic slurs	

# ***Family Secrets***

## **Part 3 A Difficult Choice**

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*Narrator: It's now 5 years later. Jenny meets her dad to celebrate her 21<sup>st</sup> birthday. She finally feels confident enough to ask her Dad the question that's been on her mind for a long time.*

Dad: I'm glad we could meet for lunch. Twenty-first birthdays call for a special celebration.

Jenny: Dad, turning twenty-one is really special for me, but it's also scary. Mom's having a family party for me tonight, but tomorrow I have my first appointment with a genetic counselor. And I think Jeremy made an appointment too.

Dad: Does that mean you decided to get tested?

Jenny: I don't know. I've been doing a lot of reading about Huntington's. It's really scary, and there's a lot I still don't understand. Now that Jeremy and I are both old enough to get tested, Mom is really pressuring us.

Dad: Remember it's not her choice.....It's one you and Jeremy need to make.

Jenny: Dad, I don't want to upset you, but I really need to understand why you never got tested. It's important to hear your side of things before I make my decision.

Dad: It's tough to explain. At first they didn't really know why your grandmother's personality was changing. When the doctors finally figured out she had Huntington's, there wasn't any test for the gene. Once they had the test, I'm not sure why I didn't get tested. Your mother used to tell me I hid from the problem, hoping it would go away. She wanted me to face the future and plan for it. But I didn't think I could handle knowing. Your grandma needed me, and I couldn't imagine taking care of her if I knew that I would suffer like she did. Even worse, I couldn't bear thinking I might have passed the gene to you or to Jeremy. I wish I'd known about Grandma's illness before we had you and Jeremy.

Jenny: But you could have gotten tested and found out that you didn't have the gene. Wasn't it worse to live with the uncertainty—to not know?

Dad: Maybe, but there was the possibility that I did have the gene and there were other reasons why I didn't want the test.

Jenny: Like what?

Dad: I couldn't be sure that other people won't find out about my test results. Imagine what the airline I work for would do if they found out one of their pilots had the gene? What would my health insurance company do? There are some laws about privacy and discrimination but I wasn't sure they would really protect me.

Jenny: One article I read said that people could avoid that kind of problem by paying for their genetic testing by themselves so their insurance company and employer wouldn't find out the results.

Dad: But even if you do that, it would still be a risk to tell anyone the results of the test. Think about who you should tell, and then who they might tell. Your mother? Jeremy? Your friends? Keeping all this as a family secret was the safest thing for me to do.

Jenny: I know about family secrets. You and Mom raised us to say that Grandma had mental problems. We weren't supposed to talk about Huntington's. Now I understand that you and mom did that to protect us. But it would have been nice to ask my friends for their advice.

Dad: And speaking of friends. What are you going to do if you start dating someone seriously? When should you tell him? Or even should you tell him? Getting tested doesn't stop the questions; it simply changes the questions that you need to deal with.

Jenny: Maybe I should wait until I've found a boyfriend that I'm really serious about. Or maybe I should even wait until after I'm married and want to have children. Then my husband could help me decide. Maybe by then they'll have a cure. .

Dad: Would that be fair to him?

Jenny: No. I guess not. Talking to you has just made this more complicated. But I guess that's good. It makes me realize that I really need to think about the pluses and minuses for all my options.

Dad: Jenny, there is something else you and Jeremy need to know. I have been having some problems lately. I'm getting angry and depressed more often. and I've been noticing these small muscle twitches. I finally went to Dr. Day, and she told me that these might be early signs of Huntington disease. I'm getting tested to be sure. I mailed the Informed Consent Form back to the genetic counselor today. But I think I know what the results will be.

Jenny: I'm so sorry. I hope you're wrong. I hope you'll let us know the results.

Dad: I'm really glad you and Jeremy are seeing a genetic counselor. The counselor will probably add a few more things for you to think about. Make sure you read the informed consent form carefully and ask all your questions before you make your decision.

Jenny: I hope the genetic counselor will help me make a list of the pros and cons for having a genetic test.

# Ethical Decision-Making Process

1. What is the ethical problem or dilemma?

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2. Identify the stakeholders who may be affected by the problem.

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3. List others who could assist or influence the stakeholders in making the decision?

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4. Describe at least three possible courses of action and record these on the attached Ethical Decision-Making Process Chart on the next page.

5. Describe the benefits (pros) and risks (cons) of each course of action on the Ethical Decision-Making Process Chart on the next page.

6. Identify the ethical principles and values which support each course of action on the Ethical Decision-Making Process Chart on the next page.. Refer to the Principles and Values Charts.

**Ethical Decision-Making Process Chart**

<b>Course of Action</b>	<b>Pros (benefits)</b>	<b>Cons (risks)</b>	<b>Principles</b>	<b>Values</b>

