

How Do YOU Decide Who Lives and Who Dies?

The genetic disorders a baby can be born with vary greatly in their severity, from simple cosmetic or minor structural differences (see polydactyly) to entirely hopeless problems (see acephaly). We now have the products and technology (DNA, RNA, and protein tests) to reveal, often in advance, a wide range of genetic disorders.

Through this exercise, you will learn about more than 20 human genetic disorders, including their causes, symptoms, and treatments. Most of these disorders can now be detected by prenatal tests, such as ultrasound and amniocentesis, allowing parents and doctors to know about the disorders a baby may have before it is born.

This knowledge raises difficult ethical questions that have not been solved to the satisfaction of our society. Many parents choose to terminate a pregnancy if the child will have a severe disorder when it is born. The main ethical question that arises is the following: When is it right to terminate a pregnancy because of a genetic disorder identified through a test?

Problem: If a test reveals a genetic defect, should a pregnancy be terminated?

Part I: How Serious Are the Disorders?

(Do this part with a partner.)

Using the Internet, go to the March of Dimes Web site (www.modimes.org). Find the list of birth defects/genetic disorders, and select 20 to study. Create a chart that lists each disorder and its symptoms. Rank the genetic disorders from least severe (1) to most severe (20). You should consider many things in making your list, including the medical, personal, social, and economic impacts of each disorder.

Part II: Where Do You Draw Your Line?

(Do this part individually.)

- A. Think of yourself as a pregnant woman, the husband of a pregnant woman, a friend of a pregnant woman, or a doctor. Ultrasound tests have shown mostly normal features on the fetus, but have also created some suspicion of a genetic disorder. Amniocentesis (genetic examination of fetal cells in the amnion) is being performed to test for genetic disorders. You are waiting for the results and thinking about what you might do.
- B. Examine your ranked list. Somewhere on this list is an imaginary line:
 1. Above this line are the disorders that are mild enough that you would personally support continuing the pregnancy.
 2. Below this line are the disorders that are so severe that you would not feel personally obligated to support the pregnancy.
- C. For you, this line could be any of the following:
 - anywhere on the list
 - above the first disorder on the list (meaning you would *not* support continuation of the pregnancy with *any* of the disorders)
 - below the last disorder on the list (meaning you would support continuation of the pregnancy with *any* of them)
- D. Give the line some deep thought. Then, draw this line on the ranking where you think you would place it. As with many decisions concerning ethics, drawing this line can be very uncomfortable. With increasingly sophisticated technology, it is a decision that has to be made with increasing frequency. Be able to give reasons for your placement of the line. Consider quality of life for parents and offspring, costs, treatment difficulties, and feelings about abortion.