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for Rare Disorders



ON RARE DISEASE DAY®
FEBRUARY 29, 2024

HIGH SCHOOL CLASS CURRICULUM

Activity D: Big Challenges, Tough Decisions

Overview: This activity engages students in small group discussions about the ethical and psychosocial issues around rare diseases.

Main concept: Individuals with rare diseases face many challenges, such as discrimination, isolation, and bullying. They often need to make tough decisions regarding their health, relationships, work, finances, and even life and death decisions.

Material and supplies: Student handout for the class

Time required: 30-minute classroom activity

Procedure:

1. If this is the first classroom activity, spend a few minutes to talk to students about Rare Disease Day® and rare diseases (for information, refer to **Teacher's Fact Sheet**).
2. Divide the class into two to five groups.
3. Give students their discussion handouts and assign them to groups A to E. Allow 10-15 minutes for students to read over the case their group is assigned to and discuss the questions. During student discussions, visit each group to answer any questions the students may have.
4. After small group discussions. Invite students to present to the class what their group has discussed. Depending on how much time you have, invite just a few groups or all the groups to present, giving about five minutes for each group's presentation.
5. Wrap up the activity by saying something like, "These are just some examples of the difficult decisions someone with a rare disease may face. As you've learned from the group discussion, there are a lot of things that need to be considered when making a decision related to a rare disease. And they are not just medical decisions; these decisions may also affect someone's social life, family relationships, dreams and self-esteem. There is no right or wrong answers to these cases. People simply do the best they can at the time."
6. If this is the last classroom activity, thank the students for their participation. Distribute the **student take-home handout** and wrap up the period (for information, see the Student take-home handout file).

Questions? Write to NORD at education@rarediseases.org.

Potential Extension:

- In the **Teacher’s Resources** file for this Activity, there is extra information about each discussion case. Please be sure to read it over. There are also quotes from individuals with rare diseases, which you can share with your students.
- If you have more time in the period, ask some groups to act out the scenario in their case when presenting to the class, allowing each group to have a five-minute skit and a five-minute verbal presentation of their discussion points.
- Encourage students to read over the other cases on the handout that their group did not discuss after the period. Ask them to think about what they would do in each scenario.

ACTIVITY D. BIG CHALLENGES, TOUGH DECISIONS

Case A. The doctor said nothing’s wrong

Please read over the case your group is assigned to and discuss your thoughts with your groupmates. Spend a few minutes to think about the decisions you would make. These are all difficult, but very real and not uncommon decisions a person living with a rare disease has to make.

You are a senior in high school. Growing up, you had been hospitalized multiple times for problems like bleeding stomach ulcers, severe bruising, and lung infections. You are also known in your school for having a special “talent” --- you can do the extremely difficult yoga positions, even though you’ve never been trained in yoga. You are so flexible that you can even do poses like reverse Namaste (praying with hands behind your back) and twisting your thumb down to your wrist.

Over the years, you had always wondered if there’s something wrong with your body – including the fact that you had been extremely flexible and have had numerous health problems. However, your family doctor kept telling you that you were just over-worried and that there’s nothing wrong with you. He even thought that it’s a good thing to be so flexible.

Last week, you had another episode of bleeding ulcer. You became even more convinced that something bigger was wrong with you. However, none of the doctors in your town could figure out what was wrong. The nurse in the emergency room told your family that if you are worried, you can go to a big medical center in Boston to see some specialists.

Boston is far away from the town you live in. Traveling there would mean having to take time off school, having to figure out travel and accommodations, and adding extra expenses to your family.

Questions to consider:

1. With all of these concerns in mind, would you go to Boston? What are the pros and cons of going to Boston?
2. What do you think would happen if you decide to go/not to go? What might be some of the long-term outcomes?
3. What kind of information would you want to get from the specialists in Boston, if you decide to go?

ACTIVITY D. BIG CHALLENGES, TOUGH DECISIONS

Case B. Being the guinea pig

Please read over the case your group is assigned to and discuss your thoughts with your groupmates. Spend a few minutes to think about the decisions you would make. These are all difficult, but very real and not uncommon decisions a person living with a rare disease has to make.

You are a young mother. Your daughter, Lisa, was born with a rare disease, called Canavan disease. Children with this condition are missing one enzyme in their body, causing the buildup of a waste product in their brain. Their brain, and ultimately to its deterioration. There is currently no available treatment for this condition.

Lisa is three now. She has seizures, doesn't feed well, and cannot control her head. She has the brain capacity of a one year-old and is expected to have severe intellectual disability. Most of the children with Canavan disease do not live past age 2. Now that Lisa is three, you don't know how much time she has left.

A drug called lithium has been shown to slow the progression of Canavan disease in animals, but there have been no studies in humans yet. A research group is conducting a clinical trial to learn if lithium works in humans and is recruiting children with Canavan disease.

Questions to consider:

1. Would you enroll your daughter, Lisa, to the clinical trial? What are the pros and cons?
2. What information would you want to know about the clinical trial before deciding whether to enroll Lisa?
3. What are the pros and cons with enrolling Lisa? What if enrolling in the clinical trial involves frequent trips to a big hospital that is a long distance away?

ACTIVITY D. BIG CHALLENGES, TOUGH DECISIONS

Case C. To tell or not to tell?

Please read over the case your group is assigned to and discuss your thoughts with your groupmates. Spend a few minutes to think about the decisions you would make. These are all difficult, but very real and not uncommon decisions a person living with a rare disease has to make.

You are a high school student. You have a rare disease called Sjogren's (pronounced like "sho'grenz") syndrome, an autoimmune disorder characterized by degeneration of the mucus-producing glands. This has caused your eyes and mouth to be very dry. You've recently transferred to a new high school. Your classmates teased you and laughed at you for having to apply eye drops every half an hour.

You wonder if you should tell your classmates about your rare disease. Would telling them stop their teasing? Or would it make it worse? You wonder if your classmates would believe you, since you don't look sick at all. You wonder if your classmates would isolate you once they know you have a "disease." You are afraid that they may become scared of you or have misconceptions about you or your disease, since this condition is so rare.

Questions to consider:

1. Would you tell your classmates about your rare disease? Why or why not?
2. What else might you do in this situation? With each of your actions, how do you think your classmates would react?
3. What do you think could stop the teasing?

ACTIVITY D. BIG CHALLENGES, TOUGH DECISIONS

Case D. Can I still dream?

Please read over the case your group is assigned to and discuss your thoughts with your groupmates. Spend a few minutes to think about the decisions you would make. These are all difficult, but very real and not uncommon decisions a person living with a rare disease has to make.

You are a senior in high school. You want to become an architect, and you have been accepted to your dream program in a prestigious university in another part of the country. You are really looking forward to studying there next year.

However, in the last couple of years, you've been experiencing headaches in the mornings on most days of the week. At first you didn't pay much attention to your headaches, but they seemed to get worse over time. Sometimes it would hurt so much that you could hardly get out of bed to go to school. Your family was very concerned and has consulted many doctors over the years.

Recently, you were given the diagnosis of idiopathic intracranial hypertension. In this condition, the pressure inside your brain builds up for an unknown reason, giving you the headaches. There is not much known about this disease. The doctor cannot tell you what would happen to you. The condition could disappear by itself without any medication. Or it could get worse, leading to the loss of vision and hearing.

You and your family have been discussing if you should move out of home to attend your dream university. You want to seize this precious opportunity to attend the prestigious school. However, you know you will have the best care if you stay at home, as your parents can look after you on the days that you have bad headaches. You are also worried that if your headaches get so bad, you would eventually become too sick to attend any school.

Questions to consider:

1. Will you attend the prestigious university that is far from home or a smaller and less famous school that allows you to live at home?
2. What are some of the things you need to consider when making this decision?
3. If your headaches never go away and keep getting worse, at what point would you decide to drop out of school and give up the dream of being an architect, or would you never give up your dream?

ACTIVITY D. BIG CHALLENGES, TOUGH DECISIONS

Case E. It's not covered

Please read over the case your group is assigned to and discuss your thoughts with your groupmates. Spend a few minutes to think about the decisions you would make. These are all difficult, but very real and not uncommon decisions a person living with a rare disease has to make.

You have been diagnosed with amyloidosis (am-uh-loi-DO-sis), a rare disorder associated with abnormal protein deposits. You have heart problems (irregular heart beat) and digestive problems, because a protein called amyloid is abnormally deposited to your heart and digestive organs.

Since amyloidosis is rare, the doctors in your local hospital are not experienced with treating this condition. You want to go to the Amyloid Center at Stanford Hospital where they have state-of-the-art treatments for patients like you. However, the health insurance company that pays for your medical care is not in network with the Stanford Amyloid Center. It refuses to pay for your care there and insists that you can receive the same care at your local hospital.

Questions to consider:

1. What would you do in this situation? Would you go to your local hospital for treatment, or would you appeal to the insurance company to cover your care at Stanford?
2. Do you think the policy at your health insurance company is reasonable? Why or why not?
3. What if the insurance company refuses your appeal? What other resources or help would you seek? At what point would you give up, or would you never give up?