

Chronic Illness and Disability in the Classroom

Enduring Understandings:

- People who are chronically ill typically have no control over their illness.
- Most people with a chronic illness, especially adolescents, want to participate as much as possible in social interaction.
- For many people with chronic illness, the illness makes living an active life difficult.
- A person with a serious illness may find that other people shy away from being friends.

Essential Questions:

- What is a chronic illness?
- If you were told that a student with a chronic condition would be joining your class, what questions would you have?
- If you found out that a member of your family was diagnosed with a chronic illness, what questions would you have?
- How could you help a person with a chronic illness feel better about his or her life?

Note to the Teacher:

Students often have a difficult time dealing with the illnesses of others. Adolescents usually accept an illness that can't be seen better than one with visible symptoms; thus, they may handle a malady such as heart disease, which doesn't change the outside of the body, more easily than a disfiguring illness. Many young people will have to deal with illness of a classmate or a relative, and it is often necessary to do preliminary work with them to desensitize them to the less pleasant details of the illness.

ACTIVITY 1 helps students develop empathy for an ill person and recognize and articulate their own feelings about him or her.

ACTIVITY 2 helps students understand the difference between feelings and behavior. Students should realize that they do not have to act on a feeling just because they have it. The activity gives students a chance to discuss the issue of depression and understand something about its causes.

ACTIVITY 3 helps students develop a sensitivity to language issues around chronically ill people. The goal of this activity is to encourage students to develop an appreciation of the gifts that chronically ill people can bring us.

DURATION OF LESSON:

This lesson can be taught in three 45–50 minute periods. If the class is anticipating the addition of a chronically ill class member, the lesson can be extended as needed to include specifics about the student’s illness. The lesson can also be extended to include service-learning experiences at veterans hospitals or nursing homes.

STANDARDS

Indicators addressed by this lesson:

STANDARD 1. Contributes to the overall effort of a group.

LEVEL IV (GRADES K–12)

4. Demonstrates respect for others’ rights, feelings, and points of view in a group
9. Contributes to the development of a supportive climate in groups
11. Takes the initiative in interacting with others

STANDARD 4. Displays effective interpersonal communication skills.

LEVEL IV (GRADES K–12)

2. Demonstrates appropriate behaviors for relating well with others (e.g., empathy, caring, respect, helping, friendliness, politeness)
3. Exhibits positive character traits towards others, including honesty, fairness, dependability, and integrity

Materials needed:

- Cards or pieces of paper for grouping
- 4 pieces of chart paper and felt markers
- HANDOUTS 1 and 2**
- Book of poems by Mattie J. Stepanek

Procedure:

ACTIVITY 1: CHRONIC ILLNESS

1. As soon as the class is seated, tell them that the lesson is going to be about chronic illness and that they will begin by meeting in groups to answer some questions. Have them gather in groups of three to five, divided on a random basis.
2. Distribute **HANDOUT 1: WHAT DO YOU KNOW ABOUT CHRONIC ILLNESS?** to one person—the reader—in each group. Ask each group also to select a scribe and a reporter. Give them six or seven minutes to brainstorm answers to the questions on the handout without writing anything down.
3. At the end of that period, stop the groups. Tell them that you want them to think about their answers and take about three minutes to write answers to each question, using the ideas they had while brainstorming. While they are working, put four large pieces of paper up on the walls.
4. Bring the class back together. Appoint a student as a scribe to record the class’s answers, one answer to each piece of chart paper.

Suggested answers and follow-up questions:

a. What is a chronic illness? (How is it different from an acute illness? From a condition?) You may elicit answers like those below. Be certain that the difference is pointed out between an illness and a condition.

- A chronic illness is an illness that is ongoing but that a person can live with. Often the illness gets worse and then better and then worse again. In some cases, the person can predict when he or she is going to feel bad and when he or she will have a good day or week.
- An acute illness is an illness that is very serious and may end in death or the need for an immediate intervention of some sort, such as an organ transplant.
- A condition is a state of the body that is usually permanent but is not caused by a disease-causing organism. Having a badly deformed limb is a condition. Having a cataract or a speech impediment is a condition.

b. If you were told that a student with a chronic condition was to join your class, what questions would you have?

- Would this person be able to participate fully in our class activities?
- Would we have to make allowances for the way this person does physical things (wheelchair? Speech problems? Use of a computer to communicate? Easily tired?)

- Would this person have problems that I find disgusting? (Would he or she be incontinent? Drool? Have a bad odor? Have an IV?)
 - Should I talk to him or her about the illness or pretend the person is the same as everyone else?
 - Should I offer to help carry books, or open doors, or pick up things the person drops?
 - Should I try to be friends even if I don't want to be friends? (The next question is, Why don't I want to be friends? The usual answer is that "I don't have anything in common with that person." Students may feel that the ill person has such a different life that not many people have anything in common with him or her unless they are also ill or disabled. Remind students that such a person still needs friends and may have hidden assets that you don't find until friendship is attempted.)
- c.** If you found out that a member of your family was diagnosed with a chronic illness, what questions or worries would you have?
- Will he die from the illness? If so, how soon?
 - How will this person's illness affect my life?
 - Is this illness something he or she brought on himself or herself (by smoking, for example) and does that cause you to be angry? (Family members are sometimes angry over "lifestyle" diseases. These would include diabetes or heart disease brought on by obesity, or lung cancer for smokers.)

- Did the person involved know about the lifestyle dangers when he or she was young? (For issues of obesity, point out that it is a lot easier for a slender person to stay thin than it is for a heavy person to become thin. The same is true with the difficulties of stopping smoking.)
 - Was this disease a result of the person's employment (black lung disease in miners, joint degeneration as a result of heavy work) which was undertaken to support the person's family?
 - Was this disease or condition a result of going to war (to support his or her country)?
 - Would you (as a student) feel guilty about being angry about the illness of a parent or caregiver, even if the illness is not a lifestyle condition? (Such feelings are normal but need to be tempered with understanding.)
- d. How could you help a person with a chronic illness feel a little better about his or her life?
- Would acceptance of the whole person, including the disease, be a help? What would this entail?
 - There was a recent news report that a Japanese man carried a quadriplegic friend up a mountain on his back. Why would he do such a thing? Why would the quadriplegic want to do that? Do you think this was a strange thing to do?
 - How could you assist older people with chronic illness, such as those in nursing homes and veterans hospitals?
- How would you assist members of your own family? Frequently the whole family fabric is interwoven with issues about one person's illness.
 - Life with a disabled person is frequently a lot of work for family members who are not disabled. If you were one of the family members, how could you frame your own feelings so that they didn't interfere with your relationship with the person?
5. As the lesson ends, ask students to look at the charts and identify which of the questions or statements are things that they have no control over. On the chart paper, put big red dots by those. Then look for the questions or statements that the students do (or would) have control over and put green dots by those.
 6. Tell students that in the next class they are going to spend some more time thinking about how to handle the issues that we *can* control and how to accept those that we *can't* control.

ACTIVITY 2: FEELINGS ABOUT CHRONIC ILLNESS

1. Review the accomplishments of the previous class with students:
 - We discussed chronic illness.
 - We talked about how the person who is ill might feel and what kinds of feelings we might have if we had a chronically ill person in our family or in our class.

Explain that the class will now explore some of these feelings more thoroughly.

2. Have students take a minute to reread the charts from the previous activity. Point out that the items marked in red are those about which we can do nothing, and there's a need to accept "what is." The items marked in green are things we can do something about and are related to our feelings and behavior.
3. Tell students that they are going to start with a brief timed writing assignment. Explain that the activity will last less than three minutes. The point is to get students to put down ideas and thoughts without regard to the format, spelling, or grammar. It is intended to be a pipeline directly to the brain. Reassure the students that they aren't going to turn this in, and no one is going to see their spelling or sentence structure. Explain that you will give them the subject, they will have 30 seconds to think about the subject with no talking and no writing, and then, when you say "Go," they are to begin writing. Ask them to write as fast as they can on the subject and keep writing, even if they repeat themselves, until you tell them to stop. Give them a time limit of two and a half minutes.
4. When they understand, announce that the subject is "anger." After 30 seconds, say "Go."
5. After the timed writing is over, give students an opportunity to share their ideas with the class. Accept all the ideas but keep the discussion moving so students don't become embroiled in telling "war stories" about fights they have had. Look for illustrations of the knee-jerk response—when someone makes them angry, they lash out verbally or physically.
6. Without going into a complete anger management course, point out that we have less control over our *feelings* than we do over our *behavior*—our response to those feelings. Everyone feels angry now and then, and it may be hard not to feel that anger; but we often are able to exert control over our response to that anger.
7. Continue the discussion by asking what kinds of things might make people angry with respect to a chronically ill person—either in the family or in the school setting. Ask students to take a minute or two to jot down their ideas. (This is a touchy subject, because students already know that they should not be angry at someone who is sick. It is important to normalize the anger feelings if the student is going to get past them to accept the sick person. Anger is most likely around a parent who is ill or in a family with a chronically ill sibling. An ill parent may not be able to play a full role in the child's life and young people resent that. A family that has a chronically ill child often revolves around that child and other siblings may resent that.)
8. Once anger feelings have surfaced, work with students to build empathy with the ill person. Ask how parents probably feel when they have their first baby. Ask students to imagine what kinds of plans parents might make for their children and themselves. Lead them into a discussion of the disappointments a sick parent might feel about not being able to play a full role in the lives of their child or children.
9. When children are talking about a chronically ill sibling, help them recognize that parents may feel guilty about

having such a child. Many children who used to die because they were born very small or with serious issues are, through the marvels of modern medicine, being saved. Lead students into a discussion of this issue. Someone in the class may say that tiny, damaged babies shouldn't be saved. That will lead into an ethical discussion about love and human beings and whether you would want that baby saved if it were *your* baby.

10. In summing up the class session, talk about the fact that “politically correct speech” is no more than courteous use of terms that do not hurt feelings. Discuss pejorative terms like “retard” and how such terms make people feel. Develop a list of terms that students think of that might be hurtful to people.
11. For the next class, assign students to keep their eyes and ears open and bring to class any examples of such language that they have heard, and to think about how such terms might make someone else feel.

ACTIVITY 3: CHRONIC ILLNESS AND DEALING WITH DEPRESSION

1. Begin with a review and discussion of the words or terms that might be perceived as hurtful, which students were supposed to look out for in the previous activity.
2. Divide the class into small groups of about five students each. Appoint one student as the discussion leader. Give each group **HANDOUT 2: SCENARIOS FOR DISCUSSION** and assign each group one of the three scenarios. Allow about 10 minutes for the groups to discuss their scenario.
3. Bring the class back together to discuss these questions:
 - Do you criticize people for having a disease? How about a lifestyle disease such as alcoholism?
 - Does each of the people involved here, as a human being, deserve respect?
 - Do you think any of these people might be depressed? (The vast majority of alcoholics suffer from depression. So do many old people with health problems.)
 - What might cause depression? (Change in life situation, reduction of power to do the things a person used to do, and many other causes)
 - What seem to be the common threads in our discussions?

4. After about 10 minutes of discussion, abruptly change direction. Ask if any of the students know of Mattie Stepanek—an inspirational speaker and writer who died in his early teens of muscular dystrophy. Read aloud or give the students copies of several of Mattie J. T. Stepanek’s poems. After the poems are read, ask if they convey an impression that the poet was depressed or if there are other words that could be used to describe the poet’s voice. Provide information about his life from the website www.myhero.com or other sources.

Ask students how such a young man who knows he is going to die soon can be so positive. Many chronically ill children are brave, not at all depressed, and serve as inspiration to the rest of us. For many, strong religious convictions help them view their lives in a positive light.

5. Conclude the lesson with an upbeat discussion about children who have faced such problems in life with confidence and good spirits. Review the main ideas of the lesson:
- All of us are valuable human beings without respect to any chronic illness.
 - Each of us who is not ill can do positive things to help those who are ill to feel better.
 - Chronic illness in others is not something to be afraid of or angry about. It is one more condition in life to be met with open eyes and an open heart.

EXTENSION ACTIVITIES:

1. Read with students Nancy Mairs’s brilliant, shocking essay, “On Being a Cripple,” which can be found in her book *Plaintext*. Questions for discussion of this essay can be found at http://highered.mcgrawhill.com/sites/0072469315/student_view0/nancy_mairs-999/nbsp.html.
2. Have students research the purpose, provisions, and effects of the Americans With Disabilities Act.
3. Have students investigate community service opportunities with organizations that serve people with disabilities.
4. Direct students to the website www.myhero.com, where they will find essays written about ordinary people who have overcome difficulties. Have them write an essay about someone they know who deserves to be called a hero.

ADDITIONAL RESOURCES

Print resources:

See Appendix B for a list of recommended books from the Council for Exceptional Children.

Internet resources

For a list of terms related to disability and a discussion of their interpretations, visit

http://en.wikipedia.org/wiki/List_of_disability-related_terms_with_negative_connotations

The Justice Department's home page for the Americans with Disabilities Act

<http://www.usdoj.gov/crt/ada/adahom1.htm>

Media

[Note: Be cautious about using films that portray people with disabilities in an unrealistic fashion. *Rainman* is an excellent film, but a savant like the character portrayed by Dustin Hoffman is atypical of people with autism. Similarly, *Forrest Gump* may be heartwarming, but in reality the Army would be unlikely to accept someone functioning at his level.]

- *Freedom Machines* (DVD). A documentary film about how adaptive and assistive technology is making it possible for people with disabilities to lead fuller lives. Copies can be purchased from <http://www.freedommachines.com/>. A complete lesson plan for using the film can be found at the PBS website <http://www.pbs.org/pov/pov2004/freedommachines/for.html>.
- Students may enjoy an older film, *Wait Until Dark*, in which Audrey Hepburn portrays a recently blinded woman who uses her blindness to save herself from dangerous thieves. The film is a thriller with a famously frightening scene.
- A Heartsongs Collection: *Heartsongs* and *Journey Through Heartsongs* (Audio Cassette). An audiocassette of Mattie Stepanek reading his own poetry.
- *Music Through Heartsongs: Songs Based on the Poems of Mattie J.T. Stepanek* CD sung by Billy Gilman.



Scenarios for Discussion

SCENARIO #1

You have gone to the mall with several of your friends. It is a large area with food stands, lots of shopping, street musicians and other entertainment—an interesting place for high school kids to go and hang out. As you and your friends move along eating fries out of paper cups, you come up behind an elderly man moving slowly along the brick sidewalk pulling his personal oxygen tank along behind him. He is wearing an oxygen cannula* in his nose. It is a relatively hot and humid night in summer and obviously he is having a bit of trouble breathing.

As you come up behind him, two boys sitting on a brick wall nearby start pointing at him and laughing. “Hey, old man,” they yell. “Have you got laughing gas in that tank? You a drug addict or something? Let’s see you run. What are you doing out here? Go back to your nursing home.”

How do you feel? How do you think the elderly man feels? What do you do?

SCENARIO #2

You have made a new friend at school but you have never been to his home. He is new in the community this year and lives only a couple of blocks from your house. The two of you are both good guitarists and have played guitars together in music class. You ask him if he would like to try to form a band. He is vague about it and doesn’t give you a straight answer. He says he doesn’t know if his parents will let him and when you keep pushing, he eventually promises to ask them.

A couple of nights later on your way home from a music lesson, you stop by his house. You knock on the door and his little sister answers the door. Behind her the living room is a disaster, there is a half-empty liquor bottle sitting on the coffee table, and a man you assume to be the father is sprawled across the couch snoring with one arm resting on the floor. The little sister calls her brother before you can get away. The brother comes down, sees you, and looks horribly embarrassed. He says, “I can’t talk now. I’ll see you at school.” Then he shuts the door in your face. The next day he avoids you.

How do you feel? How do you think he feels? What do you do?

* A narrow tube that connects to an oxygen container

HANDOUT 2 ▶ P. 2

SCENARIO #3

Your four-year-old brother has been having a lot of seizures lately. Your parents have had him to doctor after doctor. You have been staying with your grandparents for a few days while they took him to a big hospital in another city. Tonight they came home, put him to bed, and sat you down to talk to you. He has a degenerative disease that will ultimately result in death. He has a life expectancy of five or six more years. Taking care of him is going to take a lot of work and most of the family money.

How do you feel? How do your parents feel? What will you do or say?