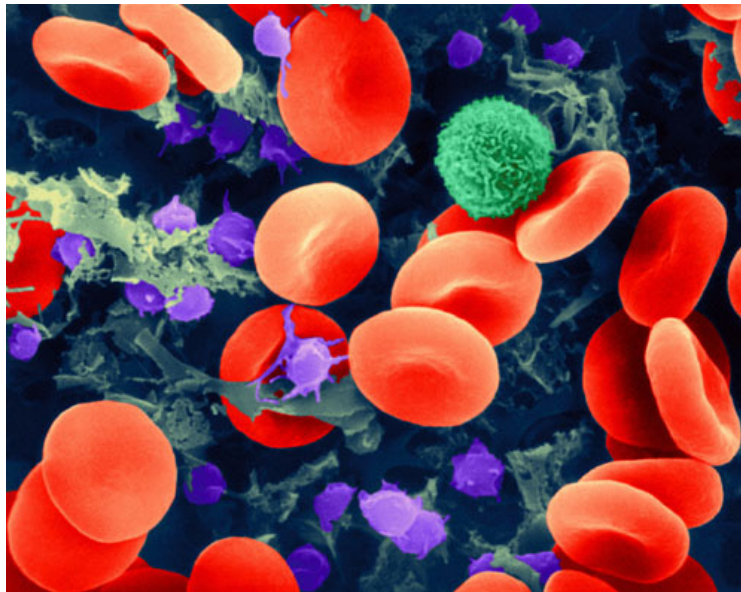


Unit 4: Stigma and Infectious Diseases

Instructional Activities for Ages 9-12



PKIDs' Infectious Disease Workshop

Made possible by grants from the Northwest Health Foundation,
the Children's Vaccine Program at PATH and PKIDs.

PKIDs' Infectious Disease Workshop

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There are people who've helped us whose names are not on this printed list. That omission is not deliberate, but rather from our own clumsiness in losing important pieces of paper, and we apologize.

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The authors specifically disclaim any responsibility for any liability, loss, or risk, personal or otherwise, which is incurred as a consequence, directly or indirectly, of the use and application of any of the contents of this workshop.

Introduction

PKIDs (Parents of Kids with Infectious Diseases) is a national nonprofit agency whose mission is to educate the public about infectious diseases, the methods of prevention and transmission, and the latest advances in medicine; to eliminate the social stigma borne by the infected; and to assist the families of the children living with hepatitis, HIV/AIDS, or other chronic, viral infectious diseases with emotional, financial and informational support.

Remaining true to our mission, we have designed the *Infectious Disease Workshop (IDW)*, an educational tool for people of all ages and with all levels of understanding about infectious diseases. In this workshop, you will learn about bacteria and viruses, how to prevent infections, and how to eliminate the social stigma that too often accompanies diseases such as HIV or hepatitis C.

We hope that both instructors and participants come away from this workshop feeling comfortable with their new level of education on infectious diseases.

The IDW is designed to “train-the-trainer,” providing instructors not only with background materials but also with age-appropriate activities for the participants. Instructors do not need to be professional educators to use these materials. They were designed with both educators and laypersons in mind.

The IDW is comprised of a master Instructor’s Background Text, which is divided into six units: Introduction to Infectious Diseases, Disease Prevention, Sports and Infectious Disease, Stigma and Infectious Disease, Civil Rights and Infectious Disease, and Bioterrorism and Infectious Disease.

For each unit, instructors will find fun and helpful activities for participants in five age groups: 2 to 6 years of age, 6 to 9 years of age, 9 to 12 years of age, 13 to 18 years of age and adults.

We welcome any questions, comments, or feedback you may have about the IDW or any other issue relating to infectious diseases in children.

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Dear Parents,

Our class will soon be studying infectious diseases. We will learn about what germs are and ways we can keep from spreading germs. We will also learn that people who have infectious diseases don't have to be treated differently or singled out just because they have a disease.

The workshop we will use has been created by PKIDs (Parents of Kids with Infectious Diseases), a national nonprofit organization dedicated to supporting families touched by infectious diseases.

Your child may have questions about germs or may come home with new ideas about preventing the spread of germs. Here are a few ways you can stay informed:

View PKIDs' website. PKIDs' website can be found at www.pkids.org. You may also request information by calling PKIDs at 1-877-55-PKIDS.

View the instructor's background text for the Infectious Disease Workshop (IDW). The primary purpose of this text is to provide teachers with background information on infectious diseases. It is a good text for anyone seeking general information on infectious diseases. The text provides information about specific diseases, methods of disease prevention, and civil rights for those affected by infectious disease. Visit www.pkids.org for a link to the IDW background texts in PDF format.

View descriptions of the activities we will be doing in class. Visit www.pkids.org for a link to the activities and handouts in PDF format.

The world becomes smaller every day and germs from near and far continue to threaten our health. It is extremely important to educate our young people, equipping them with prevention methods to protect their health and stop the spread of disease.

As always, please feel free to contact me with any questions!

Sincerely,

“CHOOSE YOUR OWN ADVENTURE” What Is Life Like for Kids with Infectious Diseases?

LEVEL

Ages 9-12

OBJECTIVE

- Students will take the perspective of a child with an infectious disease.
- Students will evaluate and choose which actions they, as an infected child, would or would not take.

MATERIALS

1 copy of the “Choose Your Own Adventure” style story (included with lesson) for the whole class, or 1 copy for each child.

PREP

Determine whether the story will be read:

- By the teacher to the class, with the class making decisions.
- By individual students at different times.
- By individual students at the same time.

INSTRUCTIONAL COMPONENTS

1. Introduce the story as a way for students to try to understand what life is like for kids who have infectious diseases.
 - Explain that when we treat people differently or exclude them from our lives because they have an infectious disease, we are stigmatizing them. We sometimes think that by excluding a person with an infectious disease, we are keeping ourselves safe from the disease, but stigmatizing people is not an effective way to stay safe from diseases. Only by practicing standard precautions with everyone are we as safe as we can be. Attaching a stigma to someone in this way only hurts that person.
 - Explain that they will need to listen to the Adventure story and make decisions throughout the story.
2. If reading the story to the whole class, have the students vote on which decision should be made. (This might keep individual students from feeling embarrassed, for whatever reason, about which answer they would choose.)
3. After the story concludes, read other choices that weren't chosen. Ask students follow-up assessment questions.

ASSESSMENT

Questions:

1. Was it hard to make these decisions? Why or why not?
2. If someone told you they had a disease like hepatitis B, what would you do?
3. How did you feel when you thought about being this person and being treated differently by

people?

4. Is it possible for a person to have a disease and not know it?
5. If we all practice *standard precautions* (e.g., washing our hands, keeping barriers between ourselves and blood), then do we really need to worry about whether or not a person has an infectious disease?
6. If we are afraid of something we don't know much about, what should we do?

“Choose Your Own Adventure”

Thinking About Stigma

It is a rainy Wednesday. Your teacher is reviewing the answers for the math test the class took yesterday, which you missed because you were at a doctor’s appointment. You sit at your desk, hearing the doctor’s voice over and over again, saying, “...you have hepatitis B.” You feel fine but can’t escape thinking about this disease. You don’t know that much about it, but you do know that it could make you very sick in the years to come. You also know that it is infectious—that is, someone else could get it from you, just like you got it from someone, somewhere, at some unknown point in your past. The doctor said people get hepatitis B from contact with blood that has this virus in it. You strain your brain, trying to think of some past event when this could have happened...

Your thoughts wander to your parents. You heard them talking last night...about how they were going to get vaccinated against hepatitis B, so they wouldn’t ever have to feel afraid—*afraid* of their own child—and so they would always be able to help you if you got hurt and bled. You also heard how sad they were—sad that they didn’t know the hepatitis B vaccine could be so important. After all, that vaccine wasn’t required when you were younger like the other vaccines were...

RINNNNNNG!!! The recess bell. You are shaken from your thoughts, and slowly get up from your desk, not feeling at all like playing ball, or doing the things you were so happy doing just yesterday. Suddenly, your best friend shakes your arm. “Hey, are you O.K.?” You don’t know what to say. Should you tell your friend you have hepatitis B?

If you decide to tell your friend, turn to page 2.

If you decide not to tell your friend, turn to page 3.



You decide to tell your friend.

“I went to the doctor yesterday—she said I have hepatitis B.”

Your friend looks confused. “What’s that?”

“I don’t really know,” you say. “It’s something we get somehow from other people’s blood, if they have it, too.” Part of you wishes you hadn’t said that, but you feel like you want to be honest with your friend—after all, you don’t want your friend to get hepatitis B, either.

“Oh...” says your friend.

“So, do you want to play some tetherball or something?” you ask in an attempt to take your mind off things and lift your spirits.

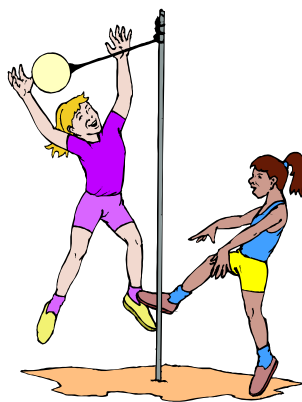
“Um, yeah...maybe some other time. I was gonna play kickball today, actually.”

You hate kickball, and can’t believe your friend has forgotten that. Or maybe your friend is afraid of getting hepatitis B?

You are angry and sad that your friend has treated you this way. You wonder if confiding in your teacher would help you feel better about it.

If you decide to tell your teacher, turn to page 8.

If you decide not to tell your teacher, turn to page 9.



Page 3

You decide not to tell your friend.

“Nothing’s wrong. I’m fine. Let’s just play tetherball or something.” Fortunately, the tetherball is not being used, and, in all the fun, you forget you have this strange, new disease. Then suddenly—BAM!—the tetherball whacks you in the face. You stop and discover that your nose is bleeding. Then it hits you like a ton of bricks—you remember that hepatitis B is in blood.

“Are you OK?” your friend asks, trying to help you. You feel panicky—what should you do?

If you decide to go to the school nurse and take your friend with you, turn to page 4.

If you decide to go to the bathroom and just keep it to yourself, turn to page 5.



You go to the nurse.

You and your friend quickly make your way into the school and down the hall to the nurse's office. "Oh dear! That's a doozy," she says as she puts on rubber gloves. She hands you a tissue to hold against your nose. Then you notice that some of your blood is on your friend's shirt. You don't know what to do! *Is it dangerous?* you think to yourself. *Nah...what are the chances that my friend could get this disease that way?* Then you realize you don't know. Just then the nurse also sees the blood on your friend's shirt. She brings two shirts out of the closet and has you remove your stained shirts and put them in plastic bags. She seals the bags with twist ties while you and your friend wash your hands vigorously with soap and water.

"Why do we have to do all this?" your friend asks, somewhat irritated.

"Because sometimes blood can carry diseases," the nurse says. *Oh no, does she know?* you think, not wanting her to tell your friend. "A disease can be in my blood, or your blood, or anybody's blood. If we get somebody's infected blood on us and we rub our eye, get their blood in a cut we have, or something like that, it's possible to get that disease. Most of the time, you can't tell who has a disease by looking at someone, and many people with bloodborne diseases don't even know they have a disease. So, we treat all blood like it might have a disease, and that way we can keep ourselves from getting diseases or giving them to others, and we don't have to single people out just because they might have one of these diseases."

Later that night, as you are thinking about what happened, you find that the nurse's words helped you feel better. But you worry—what if your friend touched your blood and then rubbed his eye before he was able to wash his hands? Could he get hepatitis that way? You tell your parents about what happened. They are worried too. They wonder if they should tell your friend's parents.

*If your parents decide to tell your friend's parents, turn to page 7.
If they don't tell, turn to page 6.*



You decide to keep the bloody nose incident to yourself.

You go to the bathroom and grab some paper towels. Fortunately, the bleeding has pretty much stopped. You notice you've left some blood here and there on the countertop and paper towel dispenser, so you wipe it off and don't think that much about it and return to class.

Later that night, you ask your parents how hepatitis B is transmitted. "Well, we don't know that much about it yet. One way people get it is by sharing things that might have blood on them, like fingernail clippers. If you cut your fingernails with someone else's dirty clippers, and you cut yourself, you can get their hepatitis B in your blood. That's why things that have or may have blood on them need to be cleaned in a certain way before anyone else can use them."

You think about your blood having been on the countertop in the bathroom. It looked like you wiped it up, but what if there were tiny bits left here and there? You realize now that the chances of someone getting hepatitis this way are very low and that probably nothing will happen. But it makes you wish you had gone to the nurse, or to someone who would have known the right thing to do.

You hate feeling like you are living with a dark secret, but you are afraid of what people will think if you tell them. Still, even if you don't tell everyone you have hepatitis B, you think you should tell your teacher so that if it happens again, she will be able to help you.

If you decide to tell your teacher, turn to page 8.

If you keep it to yourself, turn to page 9.



Page 6

You don't tell your friend's parents.

“Before we do anything, we should find out more about hepatitis B,” your parents say.

“Besides, it probably isn't the first time your friend has been exposed to an infectious disease, and it probably won't be the last.”

Turn to page 12.



You and your parents decide to tell your friend’s parents about the bloody nose incident.

You listen to your dad’s side of the conversation over the phone. Something doesn’t sound right. He hangs up the phone and stares at his shoes. “I don’t know how to tell you this, but—they don’t want you two to play together any more.”

You don’t know what to think. You have been best friends since kindergarten! Your dad goes on: “What’s even worse is that they want to make sure everyone in your class and their parents all know you have hepatitis. We thought telling them would be the right thing to do, but it was not!”

Over the next few days, you notice that other kids are treating you differently. They don’t want to sit where you’ve sat, and they don’t want you to be on their kickball team at recess. You also weren’t invited to the birthday party this weekend, even though the rest of the class was. While you are at school, you choke back the tears until you can get home to your room and cry where nobody is watching.

Turn to page 12.



You tell your teacher you have hepatitis B.

“Oh, I’m so sorry,” she says. She reaches out to pat you on the shoulder. You notice she hesitates before doing so. You don’t think much of it, but after a couple of weeks have gone by, you notice that other kids are acting weird around you. They don’t want to sit where you’ve sat, and they don’t want you to be on their kickball team at recess. You also weren’t invited to the last birthday party, even though the rest of the class was. You realize that, somehow, they must know you have hepatitis B. *Why are they so afraid of me? Don’t they know they can’t get it just by being around me, or being on my team, or having fun with me?* You choke back the tears until you get home to your room and cry where nobody is watching.

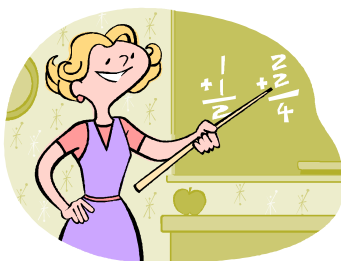
Your mom comes into your room and puts her arm around you. “Did you tell anyone about having hepatitis B?” she asks.

You nod. “Just my teacher.” Your mom says nothing and rubs her face with her hands, staring at the ceiling. “Why? What happened?” you ask.

“Well, your teacher is a good and caring person, but apparently she felt like she needed to tell the parents of your classmates that you have hepatitis B. She must have thought that, somehow, telling them about you would keep them from getting it too, even though there are probably other kids in your class or your school who have it too, but just don’t know it.”

“I just thought that I was doing the right thing...” you say.

Turn to page 12.



Page 9

You don't tell your teacher.

You like your teacher a lot, but you aren't sure if she would tell other people or not. You continue to go to school, just as you did before you found out you had hepatitis B, except that in the back of your mind, you always wonder what people would do or say if they found out. *Would they make fun of me? Would my friends stop inviting me over? Would they not want to come to my house, either? What if something happens to me and no one wants to help me because they're afraid of getting hepatitis B?*

All these questions swirl in your mind, but fortunately, your doctor and your parents are able to help you with some of them. You are glad basketball season is almost here so you can be on the team again, and maybe think about something other than hepatitis for a change! Your parents seem uneasy when you talk about it, though. They decide that you can try out but that they want to tell the coach you have hepatitis B. They think it would be best for him to know about it in case you are injured during practices or games.

If you decide to tell the coach, turn to page 11.

If you decide not to tell the coach, turn to page 10.



You decide you don't want your parents to tell the coach.

You don't want the coach to treat you differently. Fortunately, you and your parents now know that you don't have to tell anyone that you have an infectious disease. Telling somebody like a coach or a teacher that you have an infectious disease doesn't mean everyone will be safer. This is because there are so many people out there who don't know they even have an infectious disease. Or maybe they do know, but they don't want to tell anyone—just like you didn't want to tell your coach you have hepatitis B.

Maybe instead, your parents could ask the coach if he and his staff could make sure everyone follows *standard precautions*. Standard precautions are basic things that we can do every day (like washing our hands and using rubber gloves) to keep us and other people healthier. Knowing and following standard precautions is the only way we can stay safe from infectious diseases.

Turn to page 12.



Page 11

You decide to tell the coach.

Before the first practice, your parents tell the coach you have hepatitis B. Unfortunately, he does not know much about hepatitis B, and simply says that you can't be on the team. Your parents know that this is against the law, though, and they tell him so. He eventually lets you on the team, but only after your parents fight to enforce the law that says people with infectious diseases can't be kept from doing things simply because they have an infectious disease. You are glad you get to play, but somehow it isn't as fun as it used to be.

Turn to page 12.



Page 12

In an ideal world, you wouldn't have to worry about whether or not other people know you have an infectious disease. The problem is that other people don't know much about hepatitis B and other infectious diseases. They don't know that you can be vaccinated for some diseases. They don't know that doing simple things like washing hands after using the restroom and using non-permeable gloves when cleaning up blood can prevent diseases from spreading.

Instead of learning about how to prevent the spread of disease, they'd rather avoid people with infectious diseases. This is not a very practical thing to do, since we can't tell by looking at someone whether or not they have an infectious disease. While we are avoiding one person that we know has a disease, we are probably friends with someone else who has a disease but has chosen not to tell us. Or perhaps our friend simply doesn't know he has an infectious disease.

Not everyone you would want to tell would treat you badly, but you find that you just aren't sure who would and who wouldn't, so you try never to let anyone know your secret. It's not a great way to live, but until everyone understands about how diseases can and can't be transmitted, it's the safest way.

The End



A TALE OF TWO CITIES

Ryan White's Struggle with Stigma

LEVEL

Ages 9-12

OBJECTIVE

- Students will analyze differing reactions to people with AIDS.
- Students will apply concepts learned from Ryan White's struggle with stigma to their own, present-day lives.

MATERIALS

Included text and handouts.

PREP

- Predetermine groups, if desired.
- Write questions on board or overhead.

INSTRUCTIONAL COMPONENTS

1. Read the text to the students.
2. Have students answer discussion questions, individually or in groups. Students should discuss their answers.

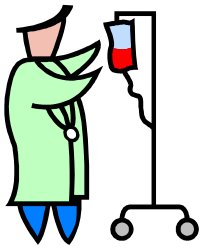
ASSESSMENT

See handout for questions.

A TALE OF TWO CITIES

Ryan White's Struggle with Stigma

In 1984, a boy named Ryan White was diagnosed with AIDS. Ryan was 13 years old at the time. He was a middle school student who lived in Kokomo, Indiana, with his mother, Jeanne, and younger sister, Andrea. Ryan was born with hemophilia, a disease that kept his blood from clotting. Sometimes when we get hurt, we bleed, but our blood starts clotting right away, and our bleeding soon stops. When a person has hemophilia, their blood doesn't clot; it just keeps bleeding. Even a little injury can be a big deal! People who have hemophilia are sometimes afraid to do things that might cause them to get hurt, like running or playing baseball—things the rest of us can do every day. As a hemophiliac, Ryan had already learned that in order to have any fun in life, he had to stay tough and optimistic, despite the fact that he could get hurt and bleed.



So how did Ryan get infected with HIV, the virus that causes AIDS? He got HIV through injections of *Factor VIII*. Factor VIII is a blood product given to hemophiliacs that causes their blood to clot. That way, if they get hurt, they won't lose so much blood. Factor VIII is made from the blood of many people who donate blood. The doctors concluded that somebody with HIV must have donated blood. Ryan White and many other hemophiliacs received Factor VIII made from that contaminated blood. HIV lives in blood, and you can get it if someone's infected blood gets into yours. Today, doctors know how to look for HIV in blood that is donated. But in the early 1980s, HIV/AIDS was a very new disease. No one was sure what to do about it, but they did know that everyone who developed AIDS died from it. Doctors did not think Ryan would live very long, but he lived to be 18—almost 6 more years.

Anyone can get an infectious disease. Ryan was just an ordinary boy who liked collecting comic books, skateboarding, and watching TV. But some people in Ryan's hometown, Kokomo, didn't treat him like he was an ordinary boy. They were afraid of AIDS, and they were afraid that, somehow, Ryan might give them AIDS. Because of this, they *stigmatized* Ryan and his family.

Some people simply refused to shake Ryan's hand, or to use the restroom after him. Some parents of kids at Ryan's middle school were afraid their kids might get AIDS from Ryan, so they petitioned the school to keep Ryan out. For a while, they won, and Ryan had to stay home and listen to his teachers over the phone. Some kids avoided him and didn't want to sit by him. Other kids vandalized his locker and wrote hurtful things on it. Sometimes people would drive by his house and throw garbage into the yard or yell terrible things at Ryan, his mom, or his sister. Ryan was banned from swimming pools. People accused Ryan of things he never did, like spitting on vegetables at the store or biting people.



After a couple of years, Ryan and his family moved to another town—Cicero.

They hoped they would find new friends there who would not treat them badly. The people in Cicero were mostly very friendly, just as the Whites had hoped. The town and school knew the Whites were moving there, so the teachers and students learned all about HIV and AIDS. Some parents were still afraid to let their kids go to school with Ryan, but because the kids had learned all about AIDS, they were able to tell their parents why they didn't need to be afraid. The school also sent people to churches and community meetings to teach other people in the town about HIV and AIDS.



Ryan's fight for equal treatment was widely publicized. A movie was made about his family's struggle with stigma, and he met many celebrities. While he always said that he would trade fame for health any day, Ryan did try to make the most of the times he agreed to speak publicly.

He hoped that because of him, other people with AIDS would not be treated so cruelly. Ryan pointed out how stupid some people were at times—they would not sit next to him, but they would sit next to people who did sit beside him. Ryan's goal was to "make AIDS a disease—not a dirty word."

QUESTIONS

1. Why did some people in Kokomo stigmatize Ryan and his family? Have you seen examples of this happening in your school? Explain.
2. Why did many people in Cicero react positively to Ryan?
3. Have you seen examples of this happening in your school? Explain.
4. What can we learn from Ryan's story to help us avoid stigmatizing people with infectious diseases?
5. If you were to meet somebody with an infectious disease that you don't know much about, what would you do?

STIGMA STORIES

LEVEL

Ages 9-12

OBJECTIVE

Students will compose short stories/skits/puppet shows for younger students to help teach them why we should avoid stigmatizing people.

MATERIALS

- Materials for writing stories/scripts (paper or computer).
- Materials for making necessary costumes, props, or puppets.
- Materials for illustrating stories.



PREP

1. This activity should probably be done after the other stigma activities have been completed.
2. Find preschool, kindergarten, and early primary classes who would be willing to have a group of students from your class read a story or perform a skit or puppet show for that class about stigma. It would be helpful if the teachers of these classes are also willing to videotape the performance for you to view later.
3. Assign students to groups, if desired.

INSTRUCTIONAL COMPONENTS

1. Talk with students about what they have learned about stigma so far — what it is, what it does, and why we should avoid stigmatizing people.
2. Introduce the project. Now that they have learned about stigma, they will teach younger students about stigma.
 - It might be wise to post a list of the classes in which the students will be performing.
 - Suggestions for performance format include an illustrated story, skit, or puppet show.
3. Suggestions to help students develop a successful performance:
 - Talk with the teacher of the class to which your group is assigned. Find out what they are studying. If they are studying butterflies, for example, the story could be about a stigmatized butterfly.
 - Make your performance age-appropriate. Young kids may not understand the word “stigma,” but they will understand “being mean to somebody because they seem different.”
 - Be professional! As performing guests in another classroom, be mindful of the rules observed by that class as well as your own.
4. Set dates for the performances. It may be best for only one group at a time to be absent from the room.

ASSESSMENT

Students will present their performance to another class. A videotape of the performance may be useful so that students understand their performances are to be taken seriously.

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www.ed.gov

U.S. Department of Justice: The Americans with Disabilities Act
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Additional Activities and Resources for Teachers, Students and Parents

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