

In the Mix®

LIVING WITH...

A half hour special from *IN THE MIX*, the award-winning weekly PBS series
This program was made possible by Ronald Macdonald House Charities



(check local listings)

Being a teen is tough enough as it is... but imagine if you also had to deal with a serious illness. In this program, we meet young people faced with the challenges of living with Asthma, Diabetes, Crohn's Disease, Sickle Cell Disease, Hodgkin's Disease, Leukemia, and Ewing Sarcoma. With insight, frankness, and humor, these diverse teens clear up common misconceptions about their diseases, show how they cope, and share how their experiences have impacted their lives as well as those of their family and friends, whose support is so important.

HOW TO USE THIS PROGRAM

Studies conducted by RMC Research on previous *In the Mix* specials have shown that these programs engage the interest of teenagers, deliver information, catalyze discussion on critical issues, as well as promote analytical thinking and a greater sense of self-efficacy among teens. The aim is to encourage thought and allow teens to generate their own creative solutions.

In this guide, we have outlined specific questions based on the program's content, as well as with answers. These questions can be used to open up more analytical discussion about related concepts. Also included are in-class activities and longer-term projects. We suggest showing the entire program to the group and then running individual segments followed by discussion.

DID YOU KNOW?

- Asthma is the most common chronic condition affecting children and teens in the United States, affecting nearly five million young people.
- More than one million Americans have Juvenile Diabetes (Type 1). Every year approximately 30,000 Americans are diagnosed with Type 1, over 13,000 of whom are children.
- Sickle Cell Disease is the most common inherited blood disorder in the United States, affecting 1 in 500 African-Americans, as well as Hispanics whose families originated from the Caribbean, Central America, or South America.
- 1 million Americans have Inflammatory Bowel Disease (IBD) of which 1/2 million have Crohn's Disease, a form of IBD. 50,000 Americans under age 18 have Crohn's Disease.
- Each year in the U.S., 27,000 adults and more than 2,000 children are diagnosed with Leukemia. 9,100 children each year are diagnosed with other forms of cancer.

In the Mix AWARDS

- 2002, 2000 CINE Golden Eagle Award for *Media Literacy: Get The News?; 9-11: Looking Back... Moving Forward; and Financial Literacy: On the Money*
- 2002, 2000, 1999 Young Adult Library Services Association's "Notable Videos List" for *ECSTASY; Live by the Gun, Die by the Gun; School Violence: Answers From The Inside; and 9-11: Looking Back... Moving Forward*
- 2002, 2000 Prism Award for *ECSTASY; Drug Abuse; Altered States*
- 2001, 1999 National Mental Health Association Media Awards for *Depression; In the Mix website*
- 1999 Academy of Television Arts and Sciences' Honor Roll
- Emmy for Community Service Programming

Please visit our website for descriptions, lesson plans, video clips, transcripts, guides, etc. for this and other *In the Mix* programs at: www.inthemix.org

LIVING WITH...

This guide to *Living With...* contains four major sections which include questions, discussion topics and activities, as well as a list of resources.

SECTION 1

ASTHMA AND DIABETES:

Nationally-ranked cross-country runner David, 17, talks about how asthma has affected his life and his sport. Melissa, 16, discusses the challenges of living with juvenile diabetes, while her best friend Alex reveals how Melissa's illness has impacted their relationship and her own attitude toward life.

1. What were David's first experiences with his asthma medication?

he had to use his inhaler before each race; he took it behind trees and in bathroom stalls so his competition wouldn't see him; once he forgot his medication and had to go to the hospital; afterwards he realized his medication was too important for him to care about who sees him taking it

2. What kind of problems did Melissa have socially when she was younger?

she didn't have many friends because other kids thought they could "catch" diabetes; parents of other kids wouldn't let them play with her; she was reluctant to talk to her peers about her illness because she thought they wouldn't understand or think she was a "weirdo"

Further Discussion:

If you didn't know anything about asthma and saw David using his inhaler, what would you think of him? If you weren't sure what juvenile diabetes was but you knew Melissa had it, what assumptions might you make about her? What other assumptions are sometimes made about people who have a serious illness? Why do you think people make these assumptions?

3. What does Melissa want people to know about her?
as long as she's careful she can do everything that a non-diabetic can do; that diabetes isn't contagious; she just wants people to treat her as a normal person and not as someone who has something wrong with her; she also wants people to acknowledge her illness and that she does sometimes need help
4. How does Alex, Melissa's best friend, feel she's changed as a result of their relationship?
she values being healthy because she's seen Melissa go in and out of the hospital; she realizes the importance of trust, loyalty, and not taking friendship for granted; she feels she's learned how much she really does care about people and wants to help change her friend's life

Further Discussion:

As a friend or classmate, why do you feel it's important for teens to be truthful about an illness or condition? What can you do or say to help someone with a problem? What is something that you could say without hurting the person? What kind of things might hurt or stop the friend from talking (e.g. "I know how you feel")?

SECTION 2

SICKLE CELL ANEMIA

Tiffany, Krystal, Shane-Na, and Chris share the daily ups and downs of living with the serious inherited blood disease Sickle Cell Disease.

1. According to these teens, what are some of the worst things about living with Sickle Cell Disease?
pain in their legs, back, fingers, joints, etc.; sensitivity to light and noise; they can't get cold or be in cold water; they constantly have to drink water; they have to avoid stress because it can trigger a flare up; they have to attend classes in pain and often miss school
2. The teens talk about how hard it is to take medication even though it's vital to their health. What do they say are some of the reasons for this?
they have to sometimes get excused from class to take medicine; they get bored with having to take pills every day; they're large pills and difficult to swallow; it's easy to put off taking the medication and then forget about it

Further Discussion:

Shane-Na remembers how she ended up in the hospital—and missed her graduation—as a result of not taking her medication. Why do you think it's so tempting for young people to ignore or forget to do something that will make them feel better or prevent problems?

3. You can only get Sickle Cell Disease if you're born with it. What misconceptions about their disease do these teens often encounter?
people think it's a sexually transmitted disease; they think it's contagious and they could catch it by sharing drinks, etc.

Further Discussion:

The teens mention that sometimes it's hard to tell peers about their illness because they're afraid they may not be accepted, even though it's important that people around them are informed. Do you think these teens are justified in feeling that way? Have you ever been afraid to reveal something important about yourself to a friend or classmate? Why?

4. What are some of the good things that these teens feel have come out of their experiences with Sickle Cell Disease?
they've learned not to worry too much about what other people think; they've learned to live life to its fullest; they've had the chance to meet great people who also have the disease

Further Discussion:

As we've seen with all the teens so far, regardless of their illness, a positive attitude is a great coping tool. What are some other situations in life—minor or serious—where it would be valuable to concentrate on the good instead of the bad? What are some ways to do this? (Possible situations might include: illness or death of a family member; loss of a pet; getting turned down on a job or college application; disappointing academic performance, etc.)

Further Discussion:

In addition to finding simple alternatives to things he can't eat, Zach also relies on humor to help him deal with his illness. Why do you think humor makes difficult and embarrassing subjects easier to address? When it comes to serious issues such as illness and pain, do you think humor trivializes them or helps put them into perspective?

SECTION 4

CANCER:

We meet three teens who talk about the highs and lows of their battles with cancer: Ebony, who's recovering from treatment for Hodgkin's Disease; Elliot, who fought back from Leukemia; and Mike, who was diagnosed with Ewing Sarcoma.

1. What helped Ebony, Elliot, and Mike cope during their treatment for cancer?
Ebony expressed her feelings to friends and family to make sure they understood what she was going through; Mike and Elliot joined a teen support group at the hospital that also helped them; they all stressed the importance of keeping a positive attitude
2. How did Ebony's friends help her get through the worst of her treatment?
they helped her shop for wigs when chemotherapy caused her to lose her hair; they made jokes and kept her spirits up; they made sure not to treat her any differently or be afraid to hug her
3. As Ebony prepares to go back to school, what does she want her classmates to know about her?
she's willing to talk about what happened to her and explain the details of her chemo and radiation treatment; she wants everyone to treat her the same because she hasn't changed

Further Discussion:

If you were a student at Ebony's school, what would you say to her during her first days back? What kinds of questions do you think would be appropriate to ask and how would you ask them? What wouldn't be appropriate?

4. How have their experiences with cancer changed these teens' attitudes on life?
Mike feels that he can empathize with anyone who has experienced illness; Elliot doesn't feel sorry for himself and focuses on the fact that he's still alive; Ebony feels closer to her friends and family

Further Discussion:

The teens in this program all seem to have developed a special outlook on life as a result of living with illness. How do you feel your general outlook is different from theirs? What do you feel you can learn from someone coping with a serious and/or life-threatening disease?

SECTION 3

CROHN'S DISEASE

Zach, 17, shares his experiences with the inflammatory bowel disorder Crohn's Disease. We also meet his best friend, also named Zach, who helped him through the toughest periods of his illness.

1. What are some reasons it took so long for Zach's disease to be diagnosed?
he was too embarrassed to tell anyone about his early symptoms; when his symptoms got worse he was misdiagnosed with appendicitis; symptoms of Crohn's Disease often resemble symptoms of other diseases.

Further Discussion:

Zach's best friend talks about how, when he first got sick, everyone thought he was a hypochondriac or making up his symptoms. Have you ever been in a situation where a friend was seemed ill or having some physical problems, but you weren't sure what was going on? What did you do? If not, what do you think you would do?

2. Zach talks about how he has periods where he's healthy and periods where he's sick. What are some of the things he does to deal with things when his disease flares up?
he goes on the Internet to get information and communicate with other Crohn's Disease patients; he focuses on what he has to do to get better and how long it will take; he makes sure he takes his medication, even when he starts to feel well again.
3. What are a few of Zach's dietary restrictions, and how does he deal with them?
He can't eat nuts or seeds, so when he wants to eat a burger he peels the sesame seeds off the top of the bun; he can't eat popcorn so he eats popcorn-flavored jelly beans.

Related Activities:

1. As a class, brainstorm a list of ways that young people can be supportive if a friend or relative becomes seriously ill.
2. As a class, brainstorm a list of questions that one might ask a peer who is living with disease. Discuss the appropriateness or inappropriateness of certain questions, and together “edit” questions that can be more sensitive and tactful.
3. Divide the class into groups and assign each group a “scenario” such as:
 - An ill teen is having a particularly bad day physically or emotionally.
 - A teen has to tell his/her friends that he/she has to go to the hospital for an extended stay.
 - A teen’s first day back at school after many months of treatment for an illness.Have students explore these scenarios by writing skits or improvising, then performing for the rest of the class. Follow up with discussion.
4. Invite a representative from a local medical support organization to speak to the class about young people’s experience with illness, focusing on how to help a classmate who is returning to normal activities after a long period of hospitalization or treatment. You can also refer to the organizations listed in this guide’s Resources section.
5. Get the name(s) of one or more young patients in a local hospital and develop a “pen pal” exchange between him/her and your students. As a class, you might draft letters, organize care packages, make a video, etc.
6. Divide the class into groups and assign each group a report on a specific disease or condition. Have students focus their research on Web sites of patient organizations and support groups for different diseases.
7. Assign the class group book reports on young adult fiction that addresses the subject of teens living with illness. Suggested books include:

- **Admission to the Feast** by Gunnel Beckman:
A nineteen-year-old girl, dying of leukemia, writes a long letter to a friend in an attempt to stabilize her crumbling world.
- **Between A Rock and A Hard Place** by Alden R. Carter:
Although neither fifteen-year-old Mark Severson nor his diabetic cousin Randy are looking forward to the canoe trip that is a family rite of passage, they begin to enjoy themselves as they make their way through Minnesota’s lake country, until the trip becomes a fight for survival.
- **Friends Till the End** by Todd Strasser:
The new student in the senior class develops leukemia and affects the lives of his fellow students in various ways.
- **Handful of Stars** by Todd Strasser:
Julie, a busy high school sophomore suddenly stricken with epileptic seizures, must learn to live with her condition as the doctors attempt to control it through medication.
- **Invincible Summer** by Jean Ferris:
Seventeen-year-old Robin, in treatment for leukemia, falls in love with a boy who also has the disease, and together they attempt to survive their ordeal.
- **Sugar Isn’t Everything** by Willo Davis:
Eleven-year old Amy is diagnosed with Type I diabetes. Though she feels disoriented and angry, she is immediately put into a training group with other kids around her age who have been recently diagnosed.
- **Thin Air** by David Getz:
Jacob, a sixth grader with a bad case of asthma, struggles to be a “normal kid”. He skips school because he felt discriminated because of his illness.

How To Reach *In the Mix*:

Living With... carries one-year off-air taping rights and performance rights. Check your local PBS listings for airtimes.

For information about *In the Mix*, including program descriptions and schedules, visit us at www.inthemix.org, or e-mail us at inthemix@pbs.org. You will also find discussion guides, lesson plans, transcripts, video clips, resources and more.

Other *In the Mix* programs of interest to grades 6-12 are available on topics including: *ECSTASY*; *Steroid Abuse*; *Dealing with Death*; *Sex and Abstinence*; *School Violence*; *Financial Literacy*; *Cliques*; *Drug Abuse*; *Teen Immigrants*; *Depression and Suicide*; *Gun Violence*; *Computer Literacy*; *Self-Image and the Media*; *Sports Participation*; *Media Literacy*; *Activism*; *Alcohol and DWI*; *Dating Violence*; *Getting Into College*; *School to Work Transition*; *Careers*; *Relationships*; *AIDS*; *Diversity*; and others.

For a complete catalog and ordering information, visit www.inthemix.org (Educators Section); www.castleworks.com; call (212) 684-3940 or (800) 597-9448; fax us at (212) 684-4015; or write to us at: 114 E. 32nd Street, Suite 903, New York, NY 10016.

RESOURCES

Asthma:

**Asthma & Allergy
Foundation of America
(AAFA)**
www.aafa.org
(202) 466-7443

Cancer:

American Cancer Society
www.cancer.org

**Leukemia and
Lymphoma Society**
www.leukemia-lymphoma.org
(800) 955-4572

National Cancer Institute
www.nci.nih.gov
(800) 4-CANCER

**NYU Medical Center
Hassenfeld Childrens
Center for Cancer
and Blood Disorders**
www.med.nyu.edu/Peds/
www.root/hassenfeld
(212) 263-8406

Crohn’s Disease:

**Crohn’s and Colitis
Foundation of America**
www.ccfa.org
(212) 685-3440

Diabetes:

**Juvenile Diabetes Research
Foundation International**
www.jdrf.org
(800) 533-CURE (2873)

Sickle Cell Anemia:

**Sickle Cell Information
Center**
www.SCInfo.org

**Sickle Cell Disease
Association of America**
www.sicklecelldisease.org

Sickle Cell Kids
www.sicklecelkids.org
(800) 421-8453

**St. Luke’s Roosevelt
Hospital Center**
111 Amsterdam Ave.
NY, NY 10025
(212) 523-5655