DISCUSSION GUIDE

WHO CARES:
Chronic Illness in America
Dear Viewer,

America’s health care system is in crisis. Advances in medicine and healthier lifestyles enable people to live longer today with diseases that in the past might have been fatal or confined them to a hospital bed. People with serious chronic illness are America’s most costly and fastest growing group of patients, but our nation’s health care system remains focused on acute care, which constitutes a significantly smaller percentage of medical care. As a consequence, long-term chronic medical conditions like hypertension, asthma, diabetes, arthritis, Alzheimer’s, heart disease, and many others have increased, affecting virtually every family, workplace, and community in America – causing family stress, economic distress, loss of productivity, and other hardships. While the symptoms of the diseases are different, all people with chronic conditions – and their loved ones – must face many of the same agonizing choices.

How can we improve the way health care is managed and financed so that it can better address the enormous challenges of chronic illness? How can we better inform and support family caregivers? What can be done to help the uninsured? The PBS program WHO CARES: Chronic Illness in America continues the Fred Friendly Seminars tradition of asking tough questions about critical issues that affect us all.

But the television broadcast is just the start. Through the outreach efforts of a host of partner organizations and public television stations nationwide, WHO CARES: Chronic Illness in America is serving as the catalyst for a national campaign to promote dialogue and positive change. The campaign is reaching out to businesses, health care providers, community organizations, government officials, students, caregivers, and of course, people who live with chronic illness every day. This Discussion Guide and the resources located on our Web site (www.pbs.org/fredfriendly/whocares) will help you join in through your own group discussions and activities.

Chronic illness is a problem that touches us all. Dealing with the challenges it presents rests with all of us, and we look forward to your participation in the conversation.

Ruth Friendly

More information about this series, including resources and local broadcast times are available at: www.pbs.org/fredfriendly/whocares
Fred Friendly Seminars

Since they were introduced on television in 1981 by the distinguished broadcast journalist the series is named for, the Fred Friendly Seminars have probed a broad spectrum of national and international issues and have won every major broadcasting award.

Each program brings together a panel of experts and stakeholders who represent different perspectives on the complex issues at hand. They are challenged by the moderator to role play what they would do in “the hypothetical” – a situation that brings the issue down to human scale. The panelists are not told in advance what the hypothetical scenario will be, nor the roles they will be asked to play.

By introducing twists and turns in the hypothetical story line, the moderator forces the panelists to take a hard look at their own beliefs and listen to the points of view of those who disagree. As panelists wrestle with the hypothetical where there is not always a “right” answer, the drama created helps the audience consider the issues in all their complexity.

Moderator

- John Hockenberry, correspondent for Dateline NBC

Panelists

- Dr. Keith Ablow, Psychiatrist
- Richard J. Bringewatt, President of the National Chronic Care Consortium
- Terrell Cannon, Home health aide and instructor
- Arthur Caplan, Director of the Center for Bioethics at the University of Pennsylvania
- Dr. Charles M. Cutler, Chief medical officer for the American Association of Health Plans
- Andrea C. Davis, Caregiver, television writer and producer
- Susan Dentzer, Correspondent and head of the Health Policy Unit at The NewsHour with Jim Lehrer
- Rev. Will Dublin Jr., Project director of Interfaith Volunteer Caregivers
- Dr. Pedro Jose Greer Jr., Assistant dean at the University of Miami Medical School
- Suzanne Mintz, President of the National Family Caregivers Association
- Rachel Mont, High school senior; asthmatic
- Eleanor Thornton, Director of Community Outreach for Asthma Care at Howard University’s College of Medicine
Directing a Discussion

The WHO CARES: Chronic Illness in America Discussion Guide is designed to be used in conjunction with the broadcast program.

Discussions may be structured in a variety of ways, depending on the audience and the time available. Pre-screen the program to determine the best strategy and segments for your group. The segments you choose may be screened one at a time, with discussions after each segment, or the program may be viewed in its entirety with a discussion following. For a single viewing, moderators may select a sampling of questions offered throughout the guide, or use the questions in the Conclusion section (page 9).

Here are some recommendations for leading an effective discussion:

- Have participants introduce themselves.
- Ask some general introductory questions to get participants thinking about the issues.
- Share “Facts to Consider” to frame the problem of chronic illness. (Some “Facts to Consider” are located on page 9; others are available on the Web site: www.pbs.org/fredfriendly/whocares.)
- Explain what participants will be seeing, how the discussion will proceed and what is expected of them.
- Begin each segment by raising the specific pre-screening questions for that segment.
- If you plan to discuss a particular segment, play and pause the segment as instructed.
- Consider the listed discussion questions as suggestions. Feel free to alter them or create new ones, especially if you know enough about the participants' backgrounds to select issues that are meaningful to them. Listen carefully to the answers and adjust your next questions accordingly.
- Stay flexible, ask open-ended questions, and guide the discussion, don’t control it.
- Encourage debate and differences of opinion by playing devil’s advocate at times.
- Have participants explain how they reached their conclusions.
- Encourage members of the group to interact with one another, discussing the ideas expressed and keeping criticism constructive.
- Summarize key points raised at the conclusion of the discussion, and consider plans for “next steps” with participants.
WHO CARES: Chronic Illness in America

Pre-viewing questions:

- Your (son/daughter) has been taken to the emergency room. It’s the 7th or 8th time this has happened since you started your job a year ago. Your boss is sympathetic, but she needs you to be at work. What would you do?

- Have you ever had to make the choice between helping a loved one or fulfilling your professional obligations?

- Have you ever had to deal with an employee or co-worker who needed to leave work often to take care of an ill family member?

Segment 1

The Phone Call: When helping your child could endanger your job.

Segment 1 begins: With program opening graphics

Play video: For approximately 5 ½ minutes (start at 00:00)

Pause video: After John Hockenberry says: “We’ll let you go. You’re out the door.” (pause at 05:40)

DISCUSSION: What options does Eleanor have? You’re Eleanor – what would you do? Should Eleanor’s employer let her go take care of her child without any consequences? What if the employer feels that Eleanor’s absenteeism is causing the pharmacy to lose business?

Resume video: For approximately 1 minute

Pause video: After John Hockenberry says: “You’ve decided you’re going to make a call to that person who’s looking for work.” (pause at 06:45)

DISCUSSION: What would you do if you owned the store? Eleanor faces a very difficult dilemma. What are some ways to resolve it? Should business owners be required by law to give employees time off to care for family members who are ill? Should employers be compensated? If so, how?
Pre-viewing questions:
- Have you or someone you know ever been taken to the emergency room for a recurring condition?
- What was your experience?
- Did you get the kind of attention you needed?
- What questions did you have?
- Was the doctor able to answer your questions and offer suggestions?
- What problems was the emergency room facing?

Segment 2

The Emergency Room Trap: Care for acute, not chronic, illness.

Segment 2 begins with John Hockenberry saying: “Eleanor, you arrive at the emergency room; your daughter is in what condition?”

Play video: For approximately 5 minutes (start at 06:58)
Pause video: After Arthur Caplan says: “They’ve got the drugs. They’ve got the ability to manage this.” (pause at 11:46)

DISCUSSION: How does Rachel’s condition affect her parents? Are there solutions to their problems they haven’t considered?

Resume video: For approximately 1 minute.
Pause video: After Keith Ablow says: “I’m sorry I’m going to have to go.” (pause at 12:46)

DISCUSSION: Why can’t the doctor be more helpful? Doesn’t he have a responsibility to help Rachel and her parents? What is the doctor’s dilemma? If emergency rooms are overflowing with critical cases and E.R. doctors are stretched to their limits, where does that leave people like Rachel with long term chronic conditions? Can emergency rooms deal with chronic conditions? Should they? If so, how? And if not, then where should the chronically ill turn for help?

Resume video: For approximately 7 minutes
Pause video: After Richard J. Bringewatt says: “People like this are really left out in the cold.” (pause at 19:46)

DISCUSSION: If the E.R. doctors can get a chronically ill person through an acute attack, then why is there a problem? What complications might follow for the patient? When chronically ill patients show up repeatedly at emergency rooms, what effect does it have on hospitals and the health care system? What alternatives exist? What options do people without insurance have? Where should the funds come from to cover these uninsured?

Resume video: For approximately 1 minute until John Hockenberry says: “We’re going to freeze the action here and look at another family.”
Pre-viewing questions:

- At what point should an ill person be released from the hospital?
- Why do you think hospitals send patients home as soon as possible?
- Do you know someone who was released from the hospital without adequate arrangements for home care?
- What kinds of challenges face a caregiver for a family member who is chronically ill?

Segment 3

**Life Is More Than Just Vital Signs:** After the patient is released from the hospital, then what?

Segment 3 begins with montage entitled “Scenario 2”

Play video: For approximately 6 minutes. (start at 20:25)

Pause video: After Keith Ablow says: “But we clearly don’t care enough to change those dynamics.” (pause at 26:35)

**DISCUSSION:** When hospitals release a patient who is stable but still suffering from a serious chronic condition, what procedures should they follow to ensure the welfare of the patient? If the condition is medically complicated what kinds of choices are available to the family? You’re Suzanne -- what would you do? What if you and your spouse worked and couldn’t take care of an ill parent? What kinds of preparation and training would help caregivers cope?
Pre-viewing questions:

- If the family is not prepared to take on the role of caregiver, what alternatives are there?
- If one of your parents had a chronic illness, would they be comfortable with a stranger in the house taking care of them?
- Do you think insurance provides for chronically ill individuals who cannot take care of themselves?

Segment 4

**Home Care on Life Support: The crisis of home health care.**

Segment 4 begins: With John Hockenberry saying: “Suzanne, Ed’s about to come home.”

Play video: For approximately 4 ½ minutes (start at 26:40)

Pause video: After Arthur Caplan says: “If Ed can get his third stroke and be comatose, he can go in the hospital and get all the care he wants.” (pause at 31:18)

**DISCUSSION:** What should Suzanne do? Why does Terrell want to leave her? Why doesn’t Medicare help?

Resume video: For approximately 3 minutes

Pause video: After Terrell Cannon says: “Yes it is.” (pause at 34:01)

**DISCUSSION:** Why is a good home health care professional so hard to find? Why are they so poorly paid? What are the difficulties faced by a home health care worker like Terrell? How could these problems be addressed?

Resume video: For 4 minutes

Pause video: After Arthur Caplan says: “. . . we’re going to have 80% of the programs in most states covering Ed.” (pause at 38:00)

**DISCUSSION:** Is long term care insurance an answer? What is the solution for those who can’t afford it? Shouldn’t home health care be covered by Medicare? Why does Suzanne feel that a nursing home is not a solution? What about Medicaid?

Resume video: For approximately 5 minutes

Pause video: After John Hockenberry says: “We’re going to freeze the action.” (pause at 42:40)

**DISCUSSION:** What is the dilemma expressed by the daughter (Rachel) to her mother (Andrea)? What other problems do family members face when a parent is the caregiver? When a child is chronically ill, what problems do the siblings face? Why does the media focus on high-tech medicine? How could more media and public attention be focused on chronic care problems? What is needed in your community?
Pre-viewing questions:

- Where are your medical records kept?
- Do you know the medications your parents might be taking?
- If you were to arrive unconscious at an emergency room, how would the doctors find out your medical history or what medications you were taking?

Segment 5

**The Doctors’ Dilemma:** Insurance company procedures and lack of coordination among doctors interfere with safe and effective care.

**Segment 5 begins** with a montage entitled “Scenario 3”

**Play video:** For approximately 7 ½ minutes (start at 42:40)

**Pause video:** After Charles Cutler says “and there’s an incentive for some employers to choose lower cost plans.” (pause at 50:13)

**DISCUSSION:** Why can’t the doctors find out the patient’s medical history? Why don’t doctors communicate more with one another about patients? What might be done to resolve this problem? Sometimes unnecessary treatment is performed; sometimes the treatment is insufficient. Who’s in charge of making decisions regarding treatment for the patient – the doctor or the insurance company? What are the advantages and disadvantages of this arrangement? How does it affect the treatment the patient finally receives? Have any practical solutions or models been proposed to restructure the decision-making process? What role do economics and profit motives play?
Facts to Consider

- 125 million Americans have a chronic illness; about 60 million live with multiple chronic conditions.
- Three out every four dollars spent on health care in America are spent on chronic illnesses.
- Over the next 20 years, direct medical costs for chronic illnesses are expected to double to $1 trillion.
- 26% of Americans have provided care for an ill family member or friend during the past year.
- By 2020, the number of Americans with chronic illness will rise to 157 million.
- 89% of Americans say it is difficult to get adequate health insurance for chronic conditions.
- 72% of Americans say that it is difficult for people with chronic illness to get necessary care from their health care providers.

Conclusion

- **Who Cares?** “My family and I are healthy. So what does all this have to do with me?”

Conclusion begins: With John Hockenberry saying, “All right, care may come from health plans, it may come from charity-based organizations . . .” (start at 50:13)

Stop video: After John Hockenberry says: “Thank you so much for this discussion.” (stop at 55:18)

**DISCUSSION:** Why is chronic illness causing a crisis in America? Why does the health care system focus on acute care? Why does Medicare cover hospital stays and other acute care expenses, but not long-term care and home health care? What can be done about it? How can you make a difference?
WHO CARES: Chronic Illness in America

*Investigate and take further action:*

► Is it easy to research caregiver resources in your community? What could you do to improve awareness and access?

► Are there some effective programs? Could you contact your newspaper, local television or radio stations to raise awareness of these options?

► Who could help to effect change? Could you write to your state and local legislators? Organize a meeting with health care providers? Bring together faith-based groups in your community to discuss solutions? Speak to human resources professionals, business people and labor groups about the benefits their companies provide?

► Are there other ways you could share information about this campaign with others?

► Could you get the professional organizations to which you belong involved?

The dialogue continues at www.pbs.org/fredfriendly/whocares.

► **At the site you can:**

  • Learn what constitutes a chronic illness and access a directory of diseases.

  • Get to know patients and caregivers who deal with chronic illnesses every day.

  • Share your experiences caring for those who are chronically ill.

  • Learn more about the TV program and its participants.

  • Learn about the expanding group of organizations partnering with Fred Friendly Seminars to raise awareness about the issues surrounding chronic illness.

  • Email friends and colleagues about the program and outreach campaign ...and more.
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More information is available at:
www.pbs.org/fredfriendly/whocares