

A Lion in the House

a film by Steven Bognar and Julia Reichert

DISCUSSION GUIDE



A LION IN THE HOUSE offers an unprecedented look at the cancer journeys of five young people and their families, whose stories unfold over a six-year period. Through this groundbreaking PBS mini-series we come face to face with the uncertainty of the entire cancer journey and its rippling effects on family, community and professional caregivers. At the core of A LION IN THE HOUSE, we discover five extraordinary young people who inspire us with their resilience, courage and wisdom.



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INTRODUCTION



THE FILM

A LION IN THE HOUSE is a story of five American families facing the challenge of childhood cancer. Told over six years, the documentary follows each family's experience as they make their way from first hearing, "Your child has cancer," through treatment, relapse, loss, and recovery. This intimate series brings viewers face-to-face with the uncertainty of the entire cancer journey and its effects on family, community, and professional caregivers. It provides a complex portrait of human resilience, family bonds, the relationships between families and the medical teams who care for their children, and, ultimately, how we—as a nation—take care of one another.

The Modules

To facilitate using the series for discussion purposes, excerpts from the four-hour miniseries have been divided into three modules, plus the film's trailer and an introduction to the featured children. The modules, based on the themes of the Community Engagement Campaign for *A LION IN THE HOUSE* include the following:

FOR CANCER HEALTH DISPARITIES:

Stories of Resilience (37 min.) focuses on how a cancer diagnosis and the extensive treatment that follows heighten preexisting family issues. It reveals how family structures and access (or lack of access) to economic resources affect family members as well as the treatment and recovery process. Finally, the module reveals the amazing resiliency and wisdom of children and the evolving strategies that families adopt to make it through the crisis. This module will be especially useful for starting discussions on how health professionals, social service providers, educators, volunteers, and community and faith-based organizations can provide culturally sensitive support for families.

FOR SURVIVORSHIP:

Stories of Survivorship (50 min.) focuses on the challenges and opportunities of cancer's aftermath—how the struggles toward recovery of young people and their families extend beyond the fight against this disease, and how lives must be restarted, redefined, and reclaimed. This module can support discussions about the kinds of support that children and families need, including ongoing involvement from health professionals, educators, youth development specialists, and other community and faith-based organizations.

FOR PEDIATRIC END-OF-LIFE AND BEREAVEMENT CARE:

Facing the End of Life (35 min.) focuses on the often muddled choices faced by families and health professionals when a cure for cancer is beyond reach. The clip will be especially useful for fostering discussions among health professionals, social service providers, families, civic groups, and faith-based organizations about how to improve communication, transition from active intervention to palliative care, provide emotional and spiritual support, and help families work through confusion and disagreement.

Trailer (2 min.) An introduction to the film, the families, and the challenges of childhood cancer.

Meet the Kids (5 min.) An introduction to the five kids and their families.

OUTREACH

Each year in the United States, approximately 12,500 children and adolescents are diagnosed with cancer. A surprising number of factors, often far removed from the field of medicine, influence the outcome for a given child. Parental work life, immigration status, access to transportation, and household nutrition—all of these and more impact the journeys of children with cancer. In cooperation with a committed group of national partners, the broadcast of *A LION IN THE HOUSE* seeks to focus public attention on these issues.

The outreach campaign extends the effectiveness of the broadcast, enabling you to

- Encourage and strengthen local collaborations among caregivers, educators, medical professionals, and others, including families and young people living with cancer.
- Support patients and their families, professionals, and the general public with educational resources and opportunities for community engagement.
- Heighten awareness of childhood cancer warning signs and the importance of survivor follow-up care.
- Empower young adult cancer survivors to take proactive steps to ensure their long-term health and help them and their families become skilled advocates for change.
- Educate communities about the need for palliative, hospice, and bereavement care for children and families, and stimulate efforts to improve these services.
- Increase public awareness of disparities in diagnosis, treatment, and survivorship among underserved and other populations, and help create momentum for changes in care.
- Promote efforts by health-care and social service professionals to provide culturally sensitive and appropriate support.
- Increase the volunteer base and support for organizations serving families coping with childhood cancer.

A LION IN THE HOUSE outreach modules can be screened in workshops, seminars, classrooms, conference sessions, and other public settings to help audiences look at the experiences of the featured families with an eye toward broader issues, including but not limited to the following:

- concepts of childhood
- education (and how to integrate children facing health challenges)
- end-of-life decisions and care/ hospice
- health-care equity
- health insurance
- medical ethics
- medical practice (especially in oncology)
- nursing
- palliative care
- pediatrics
- poverty
- public policy related to health care and children
- race and racism
- religion and the role of chaplains and clergy in health care
- social work and social services
- support services for children and families



Target Audiences

Because health-care policy and practice ultimately affect everyone, *A LION IN THE HOUSE* will be of interest to a wide spectrum of people in your community. Some examples:

- Civic groups, especially those involved with economic equity and social justice issues, health care and health insurance, and/or children
- Clergy and faith-based organizations
- Educators
- Friends, co-workers, neighbors, and colleagues of families with children facing cancer
- Immediate and extended families of children facing cancer
- Medical professionals
- Policy makers
- Social service professionals
- Volunteer organizations

A NOTE ON INVOLVING CHILDREN:

A LION IN THE HOUSE is not designed for children and would not be appropriate for very young viewers. It does, however, provide an opportunity to engage older children (grades 5-12) and might be used to help classmates or friends of children facing cancer better understand the experience of their peer(s).

The film might also be used to help children fighting cancer or children who have survived cancer to share their own experiences, but caution is recommended. Before involving children living with cancer, be sure to consult with parents and primary caregivers, and consider whether specific children are more likely to find it comforting to see others like themselves or to find public discussions of their situation as a burden or an intrusion.

Similarly, when considering how to involve families of children with cancer, take care to respect the emotional journeys of family members and consider whether participation in a public event is something that would benefit them at their particular stage in their journey.

USING THIS GUIDE

The discussion questions in this guide are divided into four sections. The first section includes a set of general questions that could be used for any module or for follow-up to a broadcast or full screening of *A LION IN THE HOUSE*.

The other sections apply to one of the three main outreach modules.

Note that the discussion prompts are designed for a wide range of audiences. No one should be expected to cover them all. Skip those that don't seem to apply to your situation and choose a few that seem to best meet your group's needs and interests. Also, feel free to adapt the wording to your audience. For example, where there are general phrases such as "What might you do?" you might say instead, "What can this church do?" or "What might primary care nurses do?"

In addition to discussion questions, there are suggestions for follow-up activities. While simply participating in a public discussion will be a major step for some people, for others, talking will seem like a repeat of conversations that they have had many times before. For this latter group, it is especially important to spend some time developing an action plan. Leaving an event with an action plan can turn frustration, anger, or depression into hope.

FACILITATING A DISCUSSION

AS YOU PLAN YOUR EVENT

A screening of A LION IN THE HOUSE can spark interest in any of the topics listed on p. ___ as well as inspire individual and community action. The checklist below will help ensure a high-quality and high-impact event.

Define your audience.

Is this event primarily professional development training? An opportunity to reach families who have experienced or are experiencing the challenges of childhood cancer? An effort to elicit support for families from the broader community? A chance for service providers and service recipients to engage in a dialogue? Part of a general visibility campaign? These prospective audiences have different needs, and those needs will determine who should be involved in planning and how an event should be structured.

Set realistic goals.

Will you host a single screening or use the film to spur ongoing efforts? Will you steer a panel or discussion toward a specific topic or let the audience pursue whatever issues they choose? Be sure to include your event partners in the decision-making process. Being clear about your goals will make it much easier to structure the event, target publicity, and evaluate results.

Structure your event to match your goals.

Do you need an outside facilitator, translator, or sign language interpreter? If your goal is to share information beyond what is included in the film, are there local experts on the topic who should be present? How large an audience do you want? (Large groups are appropriate for information exchanges. Small groups allow for more intensive dialogue.)

Arrange to involve all stakeholders.

It is especially important that people be allowed to speak for themselves. If you expect audience members to plan action that affects people other than those present, decide how you will give voice to those not in the room. When it would be a hardship or imposition to involve family members currently confronting cancer, you might instead involve families who have dealt with childhood cancer in the past. Events will be stronger if a cross-section of your community is represented. Include people from a range of racial, ethnic, religious, geographic, and socioeconomic backgrounds. It is also important to include a wide range of medical and social service professionals. Check the resource list on pp. ___ for ideas on the types of professionals involved in issues relating to childhood cancer.

Choose an accessible venue.

Is it wheelchair-accessible? Is it in a part of town that's easy to reach by various kinds of transportation? Can you provide clear signage? If you are bringing together different constituencies, is it neutral territory? Does the physical configuration of the room allow for the kind of discussion you hope to have? Can everyone easily see the screen and hear the film? Is the room comfortable?

Leave time to plan for action.

If you hope that your screening will have lasting impact, it is important to leave time to plan action. Planning next steps can help people leave the room feeling energized and optimistic, even when the discussion has been difficult. It is also important to facilitate networking. Consider having a sign-in sheet at the door so people can share contact information such as e-mail addresses. Let participants know exactly how that information will (and won't) be shared.

FACILITATING DIALOGUE

People who feel safe, encouraged, respected, and challenged are likely to share openly and thoughtfully. As a facilitator, you can encourage that kind of participation. Here's how:

Preparing Yourself

Identify your own hot-button issues. View the module(s) before your event and give yourself time to reflect so you aren't dealing with raw emotions at the same time as you are trying to facilitate a discussion.

Be knowledgeable. You don't need to be an expert on childhood cancer to lead an event, but knowing the basics can help you keep a discussion on track and gently correct mis-statements of fact. Prior to your event, take time to check the Background and Resources sections of this guide as well as the background information available on the ITVS Web site, www.itvs.org/outreach/lioninthehouse/resources. Know what kinds of resources are available in your community and be prepared to refer those in need of services to local providers.

Be clear about your role. Being a facilitator is not the same as being a teacher. A teacher's job is to convey specific information. In contrast, a facilitator remains neutral, helping move the discussion along without imposing personal views. For *A LION IN THE HOUSE*, you might be called upon to serve in either role, but it does not work well to try to serve in both roles simultaneously.

Know who might be present. It isn't always possible to know exactly who will attend a screening, but if you know what kinds of groups are present in your community, you may be able to predict who might be represented. Also keep in mind that issues can play out very differently for different groups of people. Factors such as geography, age, race, religion, and socioeconomic class can all have an impact on comfort levels, speaking styles, and prior knowledge. Take care not to assume that all members of a particular group share the same point of view.

Preparing the Group

Agree on ground rules about language. Before starting a discussion or Q&A session with a panel, remind the audience of basic ground rules to ensure respect and aid clarity. Typically, such rules include forbidding yelling or using slurs, and asking people to speak in the first person ("I think . . .") rather than generalizing for others ("Everyone knows that . . ."). If a speaker breaks a ground rule, gently interrupt, remind the speaker of the rule, and ask him or her to rephrase. You might also remind participants that they may be sitting next to someone who has a personal relationship with cancer and recommend that they be mindful of others' experiences when they choose their language.

Ensure that everyone has an opportunity to be heard. Clearly describe procedures for how people will take turns speaking or indicate that they want to speak. Plan a strategy to prevent one or two people from dominating the discussion.

Talk about the difference between dialogue and debate.

In a debate, participants try to convince others that they are right. In a dialogue, participants try to understand each other and expand their thinking by sharing viewpoints and listening to each other actively. Remind people that they are engaged in a dialogue. This can be especially important if the conversation drifts into areas of deep contention, such as religious convictions about medical treatment and end-of-life issues, opinions about proper parenting, or beliefs about socioeconomic class and individual responsibility.

Encourage active listening. Ask the group to think of the event as being about listening as well as discussing. Participants can be encouraged to listen for things that challenge as well as reinforce their own ideas. You may also consider asking people to practice "active listening," in which participants listen without interrupting the speaker, then rephrase what the speaker has said to see if they have heard correctly. This can be especially important for a film such as *A LION IN THE HOUSE*, which is likely to evoke deep emotional responses in a wide range of people.

Remind participants that we all see through the lens of our own experience. Who we are influences how we interpret what we see. So, everyone in the audience may have a different view about the content and meaning of the film they have just seen, and all these views may be accurate. Inviting speakers to identify the evidence on which they base their opinion can help people to understand one another's perspectives.

Take care of yourself and group members. If the intensity level rises, pause to let everyone take a deep breath. Also, think carefully about what you ask people to share publicly. Be sure that you are not asking people to reveal things that could make them vulnerable in legal, physical, or emotional ways. Let the audience and invited speakers know whether or not the press will be present.

BACKGROUND

THE KIDS

Tim is a fifteen-year-old diagnosed with Hodgkin's Disease, a type of lymphoma. His mother, Marietha, is a working-class single parent who also supports her daughter, Talietha, and serves as guardian for members of her extended family, including her young nephew, Tyrik. Uninsured and unable to meet the financial demands that Tim's illness places upon them, Marietha and her family end up on public assistance.

We also meet Tim's primary nurse, Connie Koons, and his oncologist, Dr. Vinod Balasa.

Justin has been living with leukemia for a decade. His mother, Debbie, and his father, Dale, are divorced but come together to support their son. We also meet Justin's brother, Adam, his sister, Jennifer, and his stepmother, Susan, as well as members of his medical team: senior oncologist Dr. Ted Zwerdling, oncologist Dr. Claire Mazewski, and primary nurse Linda Pohlman.

Al, whose non-Hodgkin's lymphoma was initially misdiagnosed as asthma, is the eleven-year-old son of Regina, a single mother who manages to keep her full-time job in a nursing home while still caring for her son. She has minimal health insurance but must navigate a bureaucratic maze to use it.

We also meet Al's oncologist, Dr. Fred Huang.

Jen is the eight-year-old daughter of professional parents, Beth and Frank. After the diagnosis of leukemia, Frank continues to work, but Beth quits her job as an investigator in the U.S. Attorney General's office to be Jen's primary caregiver. She is aided by a gift of eight months of paid sick leave donated by her colleagues. Jen has an older sister named Natalie.

We also meet Jen's oncologist, Dr. Cindi Delaat.

THE NATIONAL PICTURE

- Every year, 12,500 children are diagnosed with cancer.
- The cure rate for children with cancer, as measured by five-year survival, is 78 percent. Experts increasingly understand cancer as a chronic disease with life-long implications for care.
- As many as two-thirds of childhood cancer survivors encounter a medical problem or "late effect" related to their original cancer or its treatment. Late effects can occur months or even years after treatment has been completed and can be psychological, cognitive, or physical.

- Currently, there are approximately 300,000 people living in the United States who have a history of childhood cancer.
- Approximately 41 million Americans have no health insurance.
- One quarter of low-income children are uninsured. Uninsured children in the United States are less likely to get appropriate or preventive care.
- Twenty-one percent of African American, 22 percent of Caucasian, 25 percent of Hispanic, 27 percent of American Indian and Alaska Native, 31 percent of Asian and Pacific Islander youth report that they receive no routine health care.
- According to the organization SuperSibs!, over 10,000 children each year have a brother or sister diagnosed with cancer.
- According to a 2003 report by the Institute of Medicine, "Too often children with fatal or potentially fatal conditions and their families fail to receive competent, compassionate, and consistent care that meets their physical, emotional, and spiritual needs."

Additional information is available at www.itvs.org/outreach/lioninthehouse, including fact sheets that you may wish to copy and distribute.



DISCUSSION PROMPT

GENERAL

Prompts in this section can be applied to any of the modules and may be especially useful as a means of getting a discussion started.

- If you could ask anyone in the film a question, whom would you ask, what would you ask, and why is that question important to you?
- The filmmakers cite the following sentence by author Isak Dinesen in her book *Out of Africa*: "You know you are truly alive when you are living among lions." Given the quotation, why do you think the filmmakers chose "A Lion in the House" as the title of this film? What do you think the title means?
- Describe a moment in the film that was very difficult or frustrating for you to watch. Explain why you found it hard. If you had been present at that moment, what do you think you would have done?
- Describe a moment in the film that felt uplifting or hopeful to you. What evoked that feeling?
- Where do the experiences of the kids in the film fit into your concepts of what childhood is supposed to be like?
- What do you notice about how the following communicate with one another:

Parents with medical staff

Medical staff with parents

Medical staff with child

Medical staff with medical staff

Parents with their children

Is the communication effective? If so, what factors make it effective? If not, what might be changed to make it more effective?

- Describe one thing you learned from *A LION IN THE HOUSE*.

STORIES OF RESILIENCE (37 min.)

In this module we meet

- Eleven-year-old Al and his mother, Regina, who works at a full-time job while getting Al through his cancer treatment. A single mom, Regina uses humor and tough love to motivate her son.
- Eight-year-old Jen and her parents, Beth and Frank. As small as she is, Jen possesses a steel will. Her mom, Beth, a take-charge career woman, has now quit her job to be Jen's full time caretaker, cutting their family's income in half.
- Fifteen-year-old Tim and his mother, Marietha, who is raising Tim and two other kids (including her brother's child) alone. She struggles with these burdens. Tim is mischievous, and his medical team worries that he is not taking his cancer treatment seriously.

Equity

- How do monetary issues play out differently for each family? List all the specific disparities you see. How do economic means influence diagnosis, the ability to provide ongoing care, and prospects for recovery and reintegration?
- In terms of the capacity to care for their children by spending time with them, being there during medical procedures, and meeting with health-care providers, what differences do you notice between the single-parent and the dual-parent families in the film? What unique challenges do the single parents face? What unique challenges do their children face? How might communities provide support to single parents trying to care for children with major illnesses?
- From what you see in the film, how important is the relationship between family members and health-care professionals to the well-being of a child with cancer? How does economic circumstance influence the ability of a family to develop and sustain strong working relationships? What kinds of people in your community are likely to have preexisting, long-term relationships with pediatricians? What kinds of people do not have family doctors, or see the emergency room as their only care option when a child gets sick? What might your community do to make sure that children in all families develop the kinds of relationships with health-care providers that are needed to receive quality health care?

- The parents in this module represent three different approaches to work following their child's diagnosis. Jen's father continues working while her mother, Beth, stops working but is given eight months of paid leave by co-workers. Marietha quits her job, going on public assistance, in order to have time to care for her sick son and other children. Regina struggles to balance the demands of her full-time job with the demands of Al's care. Which parents had the most control over their choices? How were the children affected by their parents' employment situation? What might community members do to help each family meet its need for income so that care for all children is equitable?
- At one point, Tim's doctors are concerned about his lack of weight gain. They suspect that he is not getting adequate nutrition at home. How might communities ensure that children from families like Tim's have access to the nutritional information and food they need in order to heal?
- As the film ends, in what ways does Regina think the experience made her stronger, and what factors make her conclusion so different from that of Marietha, who "feels more tired than I have ever felt in my life"? At what stage in the process does each of these comments occur, and what difference might that make?
- Beyond healing from cancer, what other kinds of healing do people in the film seem to need? Who gets that healing, and who doesn't? What might communities do to make sure that all the people involved in treating and caring for children with cancer get the support they need?

Parenting

- What does each mother do that helps her child stick it out? How does each mother act as her child's advocate? How is the mothers' advocacy received by the medical, social service, or educational professionals around them? In your view, what factors influence how the efforts of these women are received?
- What do you see that helps keep each of the parents going? What are their sources of energy? What obstacles do they face in remaining strong and positive, and how do they overcome those obstacles?
- In terms of attitude, how do Regina, Beth, and Marietha approach their situations? In your view, what impact do their attitudes have on their children, on the medical staff, and on their families?
- In order to serve as a child's advocate, what kinds of medical information do parents need? Where do you think they might get that information? Where could someone go for information in your community? How might economic means, educational level, or ability to speak English affect access to information?

Treatment/Medical Practice

- How did it feel to watch Jen get her spinal tap? How do you, or would you, help your child or the children in your care and their loved ones deal with painful but necessary procedures?
- Tim admits that he likes the attention he gets in the hospital, contrasting it to the lack of attention he feels at home. If you were in Marietha's shoes, how would you give Tim attention without inadvertently providing him with a motive to stay sick?
- Outside the hospital, Tim spends time with his primary nurse. In your view, what gaps in Tim's life is she trying to fill, and why do those gaps exist? Does the interaction between Connie and Tim fit with your beliefs about appropriate relationships between patients and staff? In your view, is it important for medical professionals to try to keep a distance between themselves and their patients? Why or why not? Where would you draw the line between positive expressions of caring that allow a medical professional to do the job well and expressions of caring that get in the way of doing a good job? Besides having a nurse provide Tim with social support, what could be done to ensure that Tim's family could offer him experiences like going to the amusement park? How can professionals within an institution support specific kids without being unfair or inequitable to other kids and families?
- As Tim's condition worsens, the staff is concerned that his mother isn't at the hospital. Dr. Bob Noll thinks that the staff should be direct with her, saying that "if she understood that he wasn't going to be around next month, I believe she would be here." Do you think he is correct? Is she absent because she doesn't understand Tim's condition, or are there other factors that account for her irregular visits to the hospital? If you were Tim's doctor, what would you say to Marietha?
- What should members of the medical team do in such instances as the following:

- They are concerned about a family member's behavior.
- They disagree with a family member about treatment.
- They disagree with one another about treatment.

What kinds of procedures should be in place to resolve such conflicts?

- Regina says that she doesn't like people telling her that something's going to be all right, when she knows it isn't. Beth recounts a conversation with a doctor who tried to assure her that things were fine. How would you balance the need to provide parents with accurate information and the need to give them comfort or hope? What role might gender play in what doctors, male or female, tell mothers?

- How much medical information should be shared with young patients? Should the decision about what to share be made by parents or by medical professionals? Who should provide the information? How much influence should a child's age have upon the decision about what kinds of information to share? How would you balance the need to be honest with the need to provide hope?

Childhood

- As children grow and develop, they want and need to take more and more control over their own bodies and lives. How do you see the children in the film attempting to gain some control over their lives (for example, Jen counting during the spinal tap, Tim refusing to cooperate and take his medications)? How do the ways that children try to control their lives differ from the ways that adults assert control? What kinds of things might health-care professionals, educators, family, and friends do to help give kids with cancer a sense of control?
- Legally, children don't have the right to make medical decisions for themselves, yet most people feel that children who are ill need to be actively involved in the healing process. How would you balance the need to listen to children and respect their wishes with the need to make decisions that adults think are in the child's best interest? How does a desire to please parents sometimes influence what a child claims are his or her own wishes? Are there any circumstances in which children should be permitted to make medical decisions for themselves?
- Al worries about how others see him and being teased for looking different. How important is body image to the kids you know? If you were Al's teacher, how might you address his concerns?

STORIES OF SURVIVORSHIP (51 min.)

In this module we meet

- Eleven-year-old Al, who is making it through cancer with his mom, Regina, at his side as buddy and drill sergeant. But Al misses almost a full year of school, and it is unclear whether or not he will ever be able to catch up, a "side effect" that may continue to negatively influence his life long after his body is free of cancer.
- Eight-year-old Jen, who is pronounced "cured." Her parents, Beth and Frank, find themselves far less relieved than they thought they would be.
- Twenty-year-old Justin, who loses his decade-long battle against cancer. His parents, Debbie and Dale, and his siblings, Adam and Jennifer, so accustomed to centering their lives on Justin's condition, continue to be affected by his cancer experience years later.

Reintegration

- Dr. Huang talked about the important role the oncology team plays in helping survivors reintegrate into society. How would you describe successful reintegration? What services are necessary to support a survivor's reintegration? What can health-care providers, siblings, parents, teachers, and the community do to support survivors' successful reintegration?
- Compare and contrast the school experiences of Al and Jen. What impact does access to educational services have on them? What should schools be responsible for providing to childhood cancer patients and survivors? How should those services be funded? What does your school district offer? How might you ensure that children in your community receive the educational services they need?
- What do you notice about the role of humor in helping these children get through treatment? Listen carefully to the type of humor that Al uses. His sarcastic joking with adults seems to work well in the hospital; it is a sign that he is feeling OK. How do you think those same types of comments would be received in Al's school? What would you do to help Al adapt the coping skills he uses during treatment to life outside the hospital?
- Dr. Huang mentions that Al must either "redefine or rediscover himself" in order to reintegrate into society. What are the obstacles that Al might face in accomplishing this? How are his concerns as a preteen different from and similar to the concerns of a younger child, like Jen, or a young adult, like Justin? What might be the repercussions of Al's desire not to tell his teacher, and possibly others, about his leukemia experience? What obstacles might Al's mother, Regina, and the other children and family members encounter as they try to redefine or rediscover themselves? How should Al or Jen balance the desire to get back to a normal life with the fact that they need to be especially attentive to their long-term health?

Survival Skills

- What specific coping strategies do you see these children and parents using to deal with depression? What might prevent depression from being recognized and treated in the child cancer patient, siblings, or family members?
- What specific strategies do you see that help children and parents deal with fear?
- How do the members of the medical staff attempt to support the families of the kids in their care? In your community, where could people who are dealing with childhood cancer find support? What kind of support do they need, and how could they find it?
- What was it like to watch Jen have a spinal tap, especially knowing that this was the ninth time she had gone through the procedure? What was it like to watch Al have to drink

dye, knowing that it might make him vomit? What enables each of these children to get through painful or uncomfortable procedures? What enables the mothers to stand by their children at these times? Do you think the strategies these mothers and children use are effective for both the short and the long term? Why or why not?

- One way that children develop autonomy is to assert control over as many things in their lives as they can (for example, what to wear, what to eat, what toy to play with). Treatments for cancer are not often open to choice, and the disease itself takes control away from the child. Given that situation, how might you help children with cancer develop a sense of control and autonomy?
- If it had been left to Al to decide, he would have probably gone to camp, even if doing so jeopardized his treatment or health. Would you have let Al go to camp? Why or why not? How important is it to listen to the desires of young patients and involve them in decision making about their care? How would you balance the need to respect young patients with the need to sometimes make decisions that they don't like?
- Each of the people in the film faced the physical, emotional, and practical concerns of survivorship. Which specific issues did you see reflected in this module? As you think through the long-term implications of cancer and its effect on the lives of the children, their parents, and their siblings, what additional issues would you expect these survivors and their families to face as they grow and mature?

Long-Term Impact

- During her treatment for cancer, Jennifer receives methotrexate, a chemotherapy agent known to potentially cause cognitive delays in children months or even years after treatment has been completed. How might this affect Jennifer's education? What types of resources might Jennifer need to be successful in school? What kinds of educational support systems could be in place for Jen that might make the decision to use methotrexate easier?
- How did the cancer diagnosis influence the kind of relationships that family members have with one another? How did each child's disease change his or her relationship to the family culture and heritage? How might families dealing with childhood cancer instill a sense of culture in their children, despite the time consumed by hospitals and medical personnel?
- One of the "side effects" of being treated for cancer can be that a child's friends disappear. What happens when children have little or no opportunity to socialize with peers? How might a community help children with cancer develop a stable social network outside of the hospital and their immediate families?

- Why do Jen's parents feel "guarded" rather than "relieved" when she is pronounced cured? How does Jen's recovery change the family's lifestyle? What things stay the same, even after Jen finishes treatment?
- Al's oncologist says, "I just don't think it's a 100 percent success if you can cure a kid and leave him with residual behavioral and social issues that just aren't addressed." How can a community make sure that a kid like Al doesn't just survive, but succeed? Is it reasonable to expect medical personnel to take responsibility for issues beyond the treatment of disease? Why or why not? Do the oncology team and health-care system have an ongoing responsibility to stay involved with patients' lives? If so, what should that involvement look like and how would it be funded?
- Al's mother, Regina, says that her experience with childhood cancer made her stronger. What parts of her do you think it strengthened?
- Justin's sister, Jennifer, recalls that it was "hard for a twelve-year-old to understand why you can't do anything because your brother is sick." What challenges did Justin's siblings face as a result of his cancer? How might families help siblings through feelings of jealousy, anger, or fear? What resources and services exist in your community for the siblings of cancer survivors?

Lessons Learned

- Al believes that his experience made him wiser. What kinds of lessons do you think children and their families take away from their fight against cancer? What lessons did you take away from watching their journeys?
- Al reflects on what he has learned saying, "You ain't going to always be here tomorrow, so live life like you can today." In what ways does this attitude help him? In what ways might it lead a young person to make questionable choices?
- Consider the following situations and discuss how each person's experience with childhood cancer is reflected in his or her actions and choices:
 - Beth trains for and runs a marathon to raise money for leukemia research.
 - Adam reconnects with his parents as he approaches fatherhood.
 - Adam enters therapy.
- What sustains these families? What kinds of things do you see or hear that help them keep up their energy and willingness to fight? What is the role of their faith in this fight? What are you and/or local institutions doing to support similar families in your community?

- After Justin's death, his mother, Debbie, begins to turn her focus back toward herself, saying, "I hope that I do make a difference in this world because of Justin." How are others in the film inspired by their children? What, if anything, do you find inspiring in the experiences of these families? What might you be inspired to do?

FACING THE END OF LIFE (35 min.)

This module features

Twenty-year-old Justin, who, after battling cancer for more than ten years, takes a turn for the worse. As Justin's condition deteriorates, his parents, Debbie and Dale, must decide when to make the difficult choice to shift from fighting for Justin's life to making him comfortable as he dies. Also coping with Justin's impending death are siblings Adam and Jennifer and stepmother Susan.

DECISION MAKING

- When his oncologist asks Justin to think about things like creating a living will, he refuses, seeming to equate planning for the end of life with giving up on his fight to live. How might plans for death and struggles for life be reconciled so that they don't seem to be mutually exclusive? How might one address these issues with a teenager? What would you have advised Justin to do and why?
- At age twenty, Justin could have legally made his own end-of-life decisions. What ethical principles underlie this right? Should younger children also have that right? Why or why not? Should younger children be involved in end-of-life planning and decision making? If yes, how and at what age?
- As his parents and doctors consider whether to issue a do not resuscitate (DNR) order for Justin, they use different criteria as the basis for their decisions. The senior oncologist emphasizes prognosis for recovery and comfort level: "If he's not going to get better, we'd like it to be quick so that people don't suffer." His mother asks, "Will he have a chance to go home?" What would your question(s) or criteria be and why? How would you frame the decision about resuscitation in light of Justin's condition and prognosis?
- For ten years, Debbie's identity has centered on being Justin's caregiver. In your view, how does that affect her ideas about end-of-life decisions for Justin? What weight, if any, should health-care decision makers give to the needs of a parent in this situation? What if the needs of a parent are different from what the health-care professionals perceive to be in the best interest of their patient?
- There are several places where Justin could spend his final days, for example, in the Intensive Care Unit, at home, in hospice. What do you see as the advantages and disadvantages

of each? From Justin's perspective, what might be the advantages and disadvantages of each choice?

- Hospice Nurse Lynne Palazzolo acknowledges that it is harder to stop intervening when the patient is a young person. How does age factor in to your own beliefs about medical intervention?
- What are your own most important goals for end-of-life care? How have you communicated those goals to family and caregivers?
- For people of faith, what does your religion teach about the end of life? What role, if any, should faith-based institutions play in end-of-life decisions? What should happen when the religious beliefs of families differ from those of the people providing medical care or other services? What might the community do to help people resolve potential conflicts stemming from religious beliefs?

Medical Practice

- Why was Justin's primary medical team unhappy when consulting specialists shared their opinions with the family before talking with the medical team? As a family member, how would you respond if specialists told you that they needed to speak with your doctor before sharing their opinion with you?
- Justin is on an experimental treatment. What are the ethical issues that should be considered before offering experimental treatments to people with life-threatening illnesses?
- How do existing medical technologies complicate decisions about when medical interventions are creating a burden rather than helping? Identify ways that you could support someone like Justin or his family when medical interventions are no longer helpful.

Staff-Family Relationships

- If you were part of an oncology medical team, how would you help family members move past "hearing what they want to hear"? How would you help them balance the hope needed to get through treatment phases with the need to be realistic? How would you balance emotion and intellect, when both are important parts of the decision-making process?
- Historically, doctors made many decisions about treatment. Today, physicians commonly leave it up to families to make choices. What are the pros and cons of shifting the responsibility for decisions? Should medical professionals be bound by directives from family members, even when those directives go against the ethics or best judgment of the doctor(s)? Why or why not? What support systems or resources could you use to resolve the differences in opinion and values?
- Justin's father says that the family spent ten years taking things one day at a time and that they are "not next-step people." But

at this point in Justin's crisis, the medical staff needs for anticipatory decisions to be made so they know what to do if Justin "crashes." How might the doctors or nurses help the family transition from their decade-long experience with Justin's disease (when he kept rebounding) to what they believe is Justin's impending death? How might you reframe or reinterpret his current condition in contrast to his previous declines? At what point do familiar behavior patterns provide comfort (and therefore serve as important coping strategies), and at what point do they become obstacles? What is the difference between "letting go" and "giving up"? What do you think Justin's father is worrying about or is afraid of? How could you support him in his process of accepting Justin's impending death?

Coming to Terms with Death

- At Justin's birthday party, his brother, Adam, says he can't help thinking at every birthday that this will be Justin's last. In your view, how would it affect family members to see every occasion as potentially the last for their loved one?
- Adam doesn't know how Justin feels about dying: "I don't think anyone has ever talked to him about dying, about how he feels about death." Why might it be important for families to talk openly about death? When, in the course of treatment, would be an appropriate time to have that conversation so that it wouldn't take away hope? How might others facilitate conversations about dying for family members?
- Given that Justin and his family lived with his cancer for eleven years, what kinds of adjustments do they have to make in terms of their identities, the way they spend their time, and their family interactions? In your view, what might help them make those adjustments?
- What are some ways that you might help a family like Justin's create their child's legacy and begin to prepare for the end of his life?
- Hospice nurse Lynne Palazzolo observes that many people believe that parents are supposed to be able to protect their children and that, therefore, "In our world, it seems that to allow your child to die is the ultimate failure." Is this belief part of your parenting ideology? Why or why not? What are the implications of this idea for parents like Debbie and Dale?
- Think about what you have done or would do to help someone cope with a death in the family. Then look at the kinds of things you see Justin's family members doing to cope. What might you learn from their experience about how to help others through diagnosis, treatment, relapse, recovery, and grief?
- The filmmaker asks Dale and Debbie, "Are you going to be OK?" Do you think they are going to be OK? Why or why not? What are the sources of their strength and comfort?
- After Justin dies, Debbie asks how she will make meaning of her life, when her life was so filled with caring for Justin. What does she do? What do others around Justin do? How do people make meaning of their lives?

BEYOND DISCUSSION

Brainstorm actions that you might take as an individual or in a group. If you need help getting started, you might begin your list with these suggestions:

1. Convene regular meetings of stakeholders to help them understand and learn from one another how to improve care and follow-up services for kids with cancer. Invite those who have direct experience (medical staff, parents, siblings, teachers, social workers, and former patients) but are not necessarily dealing with the same child at the moment, so that the discussion can focus on policy and procedure rather than on a specific individual.
2. Develop a speaker's bureau of kids and families who are comfortable speaking to children about their experiences and the needs of kids fighting or recovering from cancer. Facilitate classroom visits so that kids who are in recovery don't have to shoulder the responsibility of answering questions by themselves.
3. Work with local groups to help with or create opportunities for the dissemination of information about childhood cancers, including what they are, how treatments for kids differ from treatments for adults, and what kinds of special needs family members have. Consider such options as booths at community events, displays in public buildings, sermons, and press releases.
4. Contact at least one of the organizations listed in the Resources section to find out how you can get involved.
5. If you haven't already done so, make a project of creating living wills for every adult in your family. Make sure that everyone knows the wishes of the other family members, discuss the reasoning behind those wishes, and make clear your intentions regarding medical interventions for minor children.
6. Make a list of any issues related to supporting families dealing with childhood cancer that were not raised in the film or in your discussion. Commit to researching those issues and reporting back to the group.
7. Consider policies and practices in any or all of the areas listed below. If you could make improvements, what changes would you want to see and what might you do to help those changes happen?
 - Hospital procedures
 - Health insurance coverage
 - Education for children with cancer
 - Contact policy makers to share your suggestions.
8. Using the charts below, assess the services available in your community. Pay attention to gaps and strengths. Brainstorm ways to fill the gaps and build on the strengths. Commit to taking at least one action.

SERVICES FOR CHILD CANCER PATIENTS AND THEIR FAMILIES				
TYPES OF ORGANIZATIONS	SERVICES NEEDED	SERVICES PROVIDED	QUALITY OF SERVICES 1=poor 5=excellent	HOW CAN YOU GET INVOLVED?
COMMUNITY SERVICES (FAITH-BASED, CIVIC, ETC.) HOSPITALS AND HOSPICES				
SCHOOLS				
BUSINESSES				
GOVERNMENT SERVICES				

SERVICES FOR CHILDHOOD CANCER SURVIVORS AND THEIR FAMILIES					
TYPES OF ORGANIZATIONS	SERVICES NEEDED	SERVICES PROVIDED	QUALITY OF SERVICES 1=poor 5=excellent	HOW CAN YOU GET INVOLVED?	
COMMUNITY SERVICES (FAITH-BASED, CIVIC, ETC.) HOSPITALS AND HOSPICES					
SCHOOLS					
BUSINESSES					
GOVERNMENT SERVICES					

SERVICES FOR MEDICAL, EDUCATIONAL, AND SOCIAL SERVICE PROFESSIONALS WHO WORK WITH CHILDHOOD CANCER PATIENTS				
TYPES OF ORGANIZATIONS	SERVICES NEEDED	SERVICES PROVIDED	QUALITY OF SERVICES 1=poor 5=excellent	HOW CAN YOU GET INVOLVED?
COMMUNITY SERVICES (FAITH-BASED, CIVIC, ETC.) HOSPITALS AND HOSPICES				
SCHOOLS				
BUSINESSES				
GOVERNMENT SERVICES				

RESOURCES

AMERICAN ACADEMY OF PEDIATRICS

The AAP is a professional association for pediatricians. The organization's Web site includes recommendations on how best to address a multitude of children's health issues, including defining best practice for children with cancer.

<http://www.aap.org/>

AAP's National Center of Medical Home Initiatives for Children with Special Needs promotes the "medical home" model of care for special-needs children, in which a pediatric clinician works in partnership with the family and patient to ensure that the medical and nonmedical needs of the patient are met. The Web site includes links to resources organized by state.

<http://www.medicalhomeinfo.org/states/index.html>

AMERICAN CANCER SOCIETY

The ACS is the nationwide community-based voluntary health organization dedicated to eliminating cancer as a major health problem through prevention and treatment, as well as diminishing suffering from cancer through research, education, advocacy, and service. The Web site includes a special section devoted to childhood cancer, including basic information, coping strategies, links to treatment centers, and more.

http://www.cancer.org/docroot/CRI/CRI_2_6x_Children_and_Cancer.asp

ASSOCIATION OF ONCOLOGY SOCIAL WORK

AOSW represents social workers providing counseling, education, resources, and referral services directly to people with cancer and their families. The social workers practice in a wide variety of settings, including hospitals, outpatient clinics, home-care and hospice agencies, community wellness programs, and patient advocacy organizations. The Web site includes standards for practice as well as information on events by region.

<http://www.aosw.org/>

CENTERS FOR DISEASE CONTROL AND PREVENTION

The CDC is a leader in nationwide cancer prevention and control, working with national organizations; state, territorial, and tribal health agencies; and other key groups to develop, implement, and promote effective cancer prevention. The Web site features the collaboratively created National Action Plan for Cancer Survivorship, a map for how the public health community can more effectively and comprehensively address cancer survivorship and improve the quality of life for survivors.

<http://www.cdc.gov/cancer/survivorship/overview.htm>

CHILDREN'S CAUSE FOR CANCER ADVOCACY

The CCCA serves as a national catalyst to stimulate the discovery and development of cancer treatment drugs and works with policy makers to advocate for research, services,

and high-quality care for childhood cancer patients and survivors, and their families. The Web site is a good source for those seeking information on the most recent developments in treatment options.

<http://www.childrenscause.org/index.shtml>

CURESEARCH

As its name implies, CureSearch unites the efforts of the National Childhood Cancer Foundation and the Children's Oncology Group in the search for a cure. The Web site is an excellent starting point for families or medical professionals seeking information, including resources searchable by type of cancer, age of the child, and stage in the process (diagnosis, treatment, end of treatment, after treatment).

<http://www.curesearch.org/>

GILDA'S CLUB WORLDWIDE

Gilda's Club is a free cancer support community for men, women, and children with any type of cancer, and their family and friends. Through participation in groups, lectures, workshops, and social events, members build social and emotional support and learn to live with cancer. Through the Web site you can locate the twenty Gilda's Clubs throughout the United States and Canada, and check out their resource links, organized by type of cancer.

<http://www.gildasclub.org/>

HEALTH MINISTRIES ASSOCIATION

HMA is an interfaith membership organization providing networking and resources for those involved in ministries integrating faith and health. The Web site provides helpful links to local and state chapters as well as national faith groups.

<http://www.hmassoc.org/>

HOPE STREET KIDS

Hope Street Kids, an initiative of the Cancer Research and Prevention Foundation, was founded by Randy Walker and Congresswoman Deborah Pryce in memory of their nine-year-old daughter, Caroline, to eliminate childhood cancer through cutting-edge research, advocacy, and education. The Web site has good general information, including a special guide for parents.

http://www.hopestreetkids.org/parent_guide/diagnosis.php

THE INTERCULTURAL CANCER COUNCIL

Baylor College of Medicine's Intercultural Cancer Council (ICC) promotes policies, programs, partnerships, and research to eliminate the unequal burden of cancer among racial and ethnic minorities and medically underserved populations in the United States and its associated territories. The Website's Cancer Fact Sheets provide valuable information on how cancer affects various ethnic and racial groups, placing statistics about insurance, disease, and care in the context of general census data.

<http://www.iccnetwork.org/cancerfacts>

THE LANCE ARMSTRONG FOUNDATION

With an emphasis on positive attitude, the LAF provides the practical information and tools that people with cancer need in order to live strong. LAF's "Livestrong" Web site includes survivorship stories and articles on the physical, emotional, and practical issues of dealing with cancer. Among its resources is a service that matches individuals with clinical trials for which they may be eligible.
http://www.livestrong.org/site/c.jvKZLbMRIsG/b.1076023/k.1BE/Clinical_Trial_Matching_Service_powered_by_Emergingmed/apps/s/link.asp

THE LEUKEMIA & LYMPHOMA SOCIETY

The LLS is the world's largest voluntary health organization dedicated to funding blood cancer research and providing related education and patient services. The society's Web site provides a broad array of resources specifically geared for people dealing with leukemia, lymphoma, Hodgkin's disease, and myeloma. Resources include a live forum and a free electronic newsletter.
http://www.leukemia-lymphoma.org/all_page?item_id=4227

NATIONAL ASSOCIATION OF SOCIAL WORKERS

The National Association of Social Workers is the largest membership organization of professional social workers in the world. Of special interest on their Web site is "Childhood Cancer Survivorship: An Overview for Social Workers" (www.socialworkers.org/practice/health/cancerFlyer0206.pdf).
<http://www.socialworkers.org/>

NATIONAL BLACK NURSES ASSOCIATION, INC.

The NBNA provides a focus for collective action by African American nurses to investigate, define, and determine the health-care needs of African Americans and to implement change to make available to African Americans and other minorities a quality of health care equal to that available to the larger society. The Web site can help you find the chapter nearest to you.
<http://www.nbna.org/index1.htm>

THE NATIONAL CANCER INSTITUTE

The National Institutes of Health's NCI coordinates the National Cancer Program, which conducts and supports research, training, health information dissemination, and other programs related to the cause, diagnosis, prevention, and treatment of cancer; rehabilitation from cancer; and the continuing care of cancer patients and the families of cancer patients. Among its many resources, the Web site has a comprehensive handbook for parents, which includes a helpful section on how parents can talk with children about their diagnosis and care.
<http://www.cancer.gov/cancertopics/youngpeople>

THE NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION

The NHPCO is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. Their Web site includes a broad range of information on end-of-life issues and care.
<http://www.nho.org/i4a/pages/Index.cfm?pageID=3254>

**THE ONCOLOGY NURSING SOCIETY/ASSOCIATION OF PEDI-
ATRIC ONCOLOGY NURSES**

The ONS and its sister organization, the APON, are professional organizations for oncology nurses. They run www.cancersource.com, which, though commercially sponsored, is one of the few cancer Web sites designed with special areas for kids. APON's own Web site provides a variety of information and continuing education resources to members.
<http://www.apon.org/>

PADRES CONTRA EL CÁNCER (PARENTS AGAINST CANCER)

Padres is a nonprofit organization committed to improving the quality of life for Latino children with cancer and their families. Padres programs, mostly based at their onsite clinic at Childrens Hospital Los Angeles, are designed to be culturally relevant, family-centered, and community-based.
<http://iamhope.org/>

SUPERSIBS!

SuperSibs! helps children redefine the "cancer sibling" experience by providing needed support services and by helping to draw out the greater and important lessons that may benefit these children later in their own lives. Visit the Web site to find their support services and resources.
<http://www.SuperSibs.org>