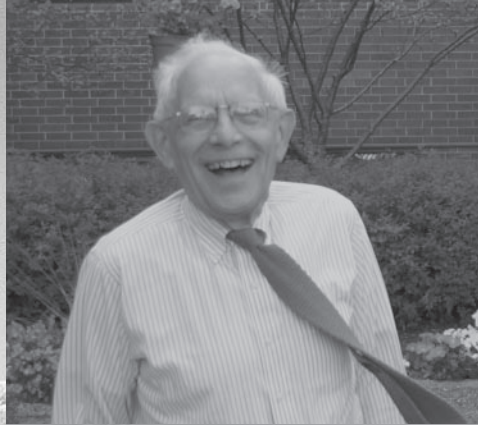


ALMOST *home* DISCUSSION GUIDE



Almost Home, a film by Brad Lichtenstein and Lisa Gildehaus, rescues the real stories of aging from an exile of denial. A stunningly intimate documentary shot on location in a nursing home, Almost Home tells the unflinchingly honest stories of couples both bonded and divided by disability and dementia, children torn between caring for their parents and caring for their children, nursing assistants doing unsavory work for poverty wages and a visionary nursing home director committed to transforming his century-old hospital-like institution into a true home.





FROM THE FILMMAKERS

I guess I shouldn't be surprised that we Americans are capable of pretending that we'll never age. After all, I do the same. I don't have plans for plastic surgery, nor do I have a medicine chest full of antiaging creams or extravagant vitamins. But I must admit that I fear being old and feeble just like the next person. Sure, if you have your health, it's fine—a time to enjoy your collected experiences and knowledge. But if you don't have your health—then what?

That's why I made this film. First, to confront the reality of aging long before I arrive at whatever age is the tipping point from middle to old. Second, to explore the "then what?" What are we, as a society, going to do with each other when age causes us to become more dependent?

After 14 months of filming and nine months of editing, I don't know for sure. What I've learned is that the most important factor that affects our experience as older adults is the kinds of relationships we experience. Medicine may keep our bodies alive, but what makes us human is our ability to love, hate, desire and engage—to not be "written off." Caring family and extraordinary friends will surround some of us when we are old. But many of us will not be so lucky. We'll need the kind of care that St. John's and others in the field strive to achieve.

But do you know what? It's hard. I learned firsthand, filming countless meetings, long days and nights on the nursing home floor, and dozens of interviews. Care giving is an industry that modeled itself on the hospital. Chucking schedules, letting people eat when and what they want, getting rid of silly regulations all sounds great—but it is *hard* to do. Economic realities and system entrenchment makes it a grail of a goal. And beyond that, the majority of direct care workers get paid next to nothing. We'll need more of them as the

boomers age, and they'll have more responsibility as we change the culture of long-term care. Is it really fair to ask someone to do our most important and intimate care for poverty wages?

Aging is hard. For ourselves. For our country. Making this film didn't alleviate all my fears. And it didn't make me magically in tune with my own aging. But it pushed me in that direction. And it made me realize that we cannot tolerate inhumane, institutional care. None of us deserves to be patronized, regimented or marginalized when we are old.

ALMOST HOME is just a movie. But a movie can be powerful. It can inspire us to change how we care for elders. It can help us trade denial for clear planning in our own lives. It can ignite our capacities for empathy by telling stories that reflect our own lives. If *ALMOST HOME* does any of this for you, then it will have been well worth the effort.

Thank you for watching.



THE FILM

The setting is St. John's on the Lake, a continuing care retirement community in Milwaukee, Wisconsin. The drama is inherent in the lives of residents and staff—the real stories of lives touched by aging: couples both bonded and divided by disability, children torn between caring for their parents and caring for their children, nursing assistants doing emotionally demanding work for poverty wages, healthy elders fearful of moving to the “dreaded” nursing home, and a visionary nursing home director committed to changes that would mold these disparate lives into a nurturing community.

ALMOST HOME captures every nuance of the complex dynamics involved in transforming St. John's from an institution based on efficient staff and compliant residents into a responsive and respectful “family” in which people invest one another's lives with meaning. Filmmaker Brad Lichtenstein doesn't oversimplify or sugar-coat. In the end, that approach gives the documentary a hopeful tone, because through the failures and frustrations, genuine caring continues to provide a guiding light.

People Who Appear in *Almost Home*

RESIDENTS

Lloyd Herrold
 Edie Herrold
 Arienne Balser
 Ralph Nelson
 Amy Polly Smith
 Dolores Haig
 Bob Haig (Dolores's husband)
 Mary Griffith

VISITORS

Edie Herrold Jr.
 Amy Blumenthal (Arienne Balser's daughter)

STAFF

John George, Administrator
 Kathie Eilers, President
 Nancy Tischer, Director of Nursing Education
 Sharon Prusow, Director of Nursing
 Renée Anderson, Director of Finance
 Anna Jonas, R.N.
 Erika Stoving, R.N.
 Enchantra Cosey, C.N.A.
 Yvonne Robinson, C.N.A.
 Tamica Burris, C.N.A.
 Jeraldine Cosey, C.N.A.
 Marilyn Farsee, C.N.A.
 Megan Hannan, Person First Consultant



BACKGROUND INFORMATION

According to projections by the U.S. Census Bureau, between now and 2030 the number of Americans aged 65 and older is expected to double, from about 36 million to 71.5 million (20 percent of the country's total population). By 2050, the 65+ population will grow to 86.7 million.

The Health Insurance Association of America estimates that by 2020, 12 million older Americans will need long-term care. Most of those people do not have insurance that would cover such care.

Links to most of these initiatives can be found at www.pioneernetwork.net/index.cfm/fuseaction/Initiatives.DocList/CategoryPK/Articles.cfm.

As baby boomers have looked to place parents in care facilities and have contemplated their own eventual need for such facilities, some have begun to rethink and reshape traditional institutional models. St. John's on the Lake, which is profiled in *ALMOST HOME*, is part of a larger movement implementing alternatives to traditional care. To find out more, you might look for information on these frequently cited projects and approaches:

- Action Pact
- Culture Change
- Eden Alternative
- Person-first care
- Person-centered care
- Pioneer Network
- Wellspring

THINKING MORE DEEPLY

Before Viewing

If you were looking for an ideal nursing home for yourself, what would you look for? Where would it be located? What kinds of services would it offer? What would your room look like? Who would be with you?

What are your concerns about aging? What do you fear the most and why?

Have you done any planning for a possible time in your life when you would not be able to care for yourself or care for a spouse? What do those plans include?

After Viewing

General

If you could have a conversation with anyone in *ALMOST HOME*, whom would you want to talk with and what would you want to talk about? Why?

Describe a moment in the film that touched your heart or that hit close to home. Did that moment change your thinking in any way or cause you to want to take action? If so, describe the change.

What did you learn from the film about aging or the experience of children who are dealing with aging parents?

Person-First Care

How is what you see in *ALMOST HOME* like or unlike nursing homes that you have been in or heard about? Would you want to live in St. John's? Why or why not? Would you want to work at St. John's? Why or why not?

What specific practices are being implemented at St. John's that you would like to see more nursing homes adopt? What do you think the impact of those practices is on the staff? What is the impact on the residents?

Administrator John George encourages his staff to approach residents as if they were family. What do you think he means by that? Is it different from approaching residents as a professional? If so, how? In your view, how does care change when caregivers know the values, accomplishments and experiences of the people in their care?

Finding Common Ground

- The administrators of the nursing home have asked the staff to create a "homelike" atmosphere. What do you think they mean by that? Does everyone share the same vision of what a home is like? How might an institution bridge the gap if they find that residents and staff members have different visions of "homelike"? What is your vision of "home"?
- Administrators acknowledge that most of the people who work at St. John's could never afford to be residents there. What kinds of difficulties do you think that situation creates? How might the socioeconomic class differences challenge attempts to create community?
- What extra challenges are added to the mix when residents (who at St. John's are all white) and CNAs (who at St. John's are predominantly black) come from different ethnic and racial backgrounds and neighborhoods? Might the community at large benefit from some of the strategies that St. John's uses to bridge the gaps between staff and residents? If so, what might people learn from the St. John's experience?
- There is no doubt that staff members care about (not just for) the residents of St. John's. So what is the source of the resistance to some of the suggestions and policy changes made by administrators? If you were running the facility, what would you do to overcome that resistance?



SUGGESTIONS FOR ACTION

Together with other audience members, brainstorm actions that you might take as an individual and that people might take as a group. If you need help getting started, you might begin your list with these suggestions:

- Investigate the approaches to care offered by the nursing homes and assisted living facilities in your community. Host a special screening of ALMOST HOME for policy makers and staff to begin a dialogue about how they might use some of the ideas in the film to improve the care they provide.
- Help staff and residents of nursing homes and assisted living facilities who are doing interesting things in your community to share their story. Invite them to speak at your school, civic group, church, club and so forth. Alert journalists to their work.
- Collect census information from your community to estimate how many nursing home beds, assisted living facilities and adult day-care spots will be needed by residents over the course of the next 20 to 30 years. Assess the number of facilities currently available. Convene a task force of stakeholders to make sure that the capacity of the facilities will meet the needs of those likely to require services.
- Many of the stresses brought on by disabilities associated with aging can be lessened by planning ahead and by making sure that everyone in your family understands your intentions. Gather family members to review plans for long-term care, medical decisions, finances and how decisions will be made should you become incapacitated. Be sure that all of your loved ones have taken care of the basics of estate planning, including having a valid will, health care proxy and durable power of attorney.

For additional outreach ideas, visit itvs.org, the website of Independent Television Service. For local information, check the website of your PBS station.

Before you leave this event, commit yourself to pursue one item from the brainstorm list.

RESOURCES FOR FURTHER STUDY AND ACTION

To Start

<http://www.almosthomedoc.org/> – The film's website includes resources on understanding aging and dealing with related challenges and links to other organizations involved in developing person-centered care.

General Information and Advocacy

www.aarp.org – American Association of Retired Persons

www.owl-national.org – Older Women's League

www.ncba-aged.org – National Caucus and Center on Black Aged

www.sagecrossroads.net – An online forum on science and policy related to aging hosted by the Alliance for Aging Research and the publishers of Science Magazine

www.empub.com/sandwichgen.shtml – Put together by a group of people who are caring for aging parents as well as for minor children; provides links to key resources for the "sandwich generation"

Nursing Homes and Person-Centered Care

www.nccnhr.org/ – National Citizens' Coalition for Nursing Home Reform

www.aahsa.org – American Association of Homes and Services for the Aging; resources section includes links to a variety of institutions and projects exploring alternative models of care. The AAHSA also runs the Institute for the Future of Aging Services, a database of research projects related to care of the aging.

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ITVS COMMUNITY is the national community engagement program of Independent Lens. ITVS Community works to leverage the unique and timely content of IL's award-winning independent films to build stronger connections among leading organizations, local communities, and public television stations around key social issues and create more opportunities for civic engagement and positive social change.

ALMOST HOME WILL AIR NATIONALLY ON THE EMMY AWARD-WINNING SERIES *INDEPENDENT LENS* ON FEBRUARY 21, 2006 AT 10:00 PM. CHECK LOCAL LISTINGS.