

ALMOST HOME

Countering America's denial and stereotyping of aging, *Almost Home* is a verité documentary about people who live, work and visit in an "old-age home."

Consider this. The last wave of baby boomers will soon reach sixty; meaning half of all Americans must contemplate eldercare for themselves or a loved one. That's 200 million of us dealing with eldercare. Now consider that those same 200 million live in a country steeped in denial of its aging, frightened by the specter of dependency and death. We combat aging with pills and surgery, dismiss it with humor, and avoid it by neglecting to plan ahead. We proffer images of "positive aging," like 90-year-old marathon runners, and shun common realities of frailty and dementia. *Almost Home*, a cinema verité documentary about a year in the life of people who live and work in an "old age home," rescues the true stories of older adults and those who care for them from an exile of denial.

Almost Home combines handheld mini-dv verité footage and "in the moment" interviews to tell the extraordinary story of Saint John's in Milwaukee, a typical continuing care community (or "old age home") transforming its 135-year-old medical model of care (think hospital) into a holistic, social one (think neighborhood) that focuses on the whole person rather than her ailments, and embraces dignity, autonomy and equality. This "culture-change" revolution tears down traditional walls between residents, staff, administration and families to replace the stigma of nursing homes as institutions of loneliness and death with a vision of "community" where people want to live, work and visit, and where healing isn't encumbered by medical trappings. To succeed, the visionaries will have to win over cynical managers skeptical of change; resistant nurses mired in regulations; overworked and underpaid nursing assistants juggling precarious lives; and complacent residents and families used to being excluded from many of the decisions that affect them.

While PBS programs have addressed issues of aging before, none have offered an intimate portrait of a diverse, multi-generational universe of people connected by aging and care giving. Utilizing our total access to Saint John's¹, we will present their stories in their own words and actions without interpretation by experts, narration or a host. Direct cinema is hardly a new approach to filmmaking, but it is a radical choice for this subject because several people in the film suffer from dementia. One of our greatest challenges (and rewards) is adapting a standard verité approach to one that captures the drama and personality of people unable to access memory or understand their own lives as a continuum. Giving such people a voice is among our major goals.

Our perspective is 360 degrees — each moment can be understood from multiple characters' points of view. Shooting for a full year, we will be able to interconnect stories through overlapping characters, and weave them together into an overarching narrative about whether Saint John's will succeed in its grand culture change experiment, and help lead America to rethink our approach to elder care. *Almost Home* is drama that elicits important issues: coping with physical and mental disability; coping with and planning for death; negotiating family care responsibilities; dealing with the challenges posed by high staff turnover and worker stress; the challenge of innovation in a field governed by intense regulation and shrinking resources. Eighteen weeks into a 52-week shoot schedule, the following stories are unfolding before our camera:

John George, the young, gay, hip manager of the nursing home, grew up in a hardscrabble, stoic family near the Wisconsin-Canadian border. During a family visit he lies to cover up a journey to his grandmother's grave, "just to talk." At the gravesite he tells us of the close relationship with his grandma that inspired his career. At a "culture change" conference the speaker asks who would put their parents up in the institution where they work. No one raises their hands, including John. "That's my goal," he tells us later, "to create a place where I would send my grandma."

But changing the culture of care is hard and the management team grows impatient with John, finally exploding with a barrage of accusations: why spend so much money on culture change in the nursing home when Saint

¹ 500+ releases from residents, staff and families

John's lake-view independent living apartments are the prime marketing tool? One manager strikes the heart of much of the resistance to change: nurses resist "managerial fads" and CNAs, who are mostly African-American, resent all-white management "coaching", which often seems patronizing. John tries to model the new mode of care, forming tight bonds with residents like **Lloyd Herrold**, whom he takes on visits to the art museum. Riding home he confesses his failure to a colleague. But John is driven. He puts full faith in his staff and gives them the power to make decisions, while issuing the edict that staff must change or move on. Those who stay transform into a team that throws out the institutional mentality, working together to create a home where residents can wake, eat and sleep on their own schedules. Staff start interviewing residents and posting their stories for all to see. Wheel-chair "slumpers" slowly become engaged, death becomes a shared experience between residents and staff, and Saint John's culture transforms.

Edie and Lloyd Herrold, once notables on Milwaukee's social circuit, are now separated by Lloyd's Parkinson's, which forces him to move from their independent living apartment to the nursing home. Publicly, Edie is comforted by friends who ask after Lloyd. Privately, she is racked with guilt for not providing his care. What nobody knows is that she also faces surgery for a nerve disease, and fears it may force a move to the nursing home. (We will film her informing Lloyd and experiencing surgery in June). Lloyd, meanwhile, is working feverishly in therapy to walk again, hoping to return to their apartment. Desperate to leave the nursing home, he is often found wandering into elevators and ripping off his WanderGuard bracelet. Embracing new culture change principles of autonomy, nurse **Erika Stoving** meets with him to discuss leaving, but the combination of his clouded brain and her determination that he remain in the nursing home makes for an awkward affair. In the wee morning hours a somewhat lucid Lloyd eloquently articulates the painful experience of Parkinson's — the words are there, but he can't mouth them — which frustrates him to the point that his entire body freezes. The words surface again at the art museum where he interprets for **John George** several paintings, touching on personal themes of loneliness, untapped strength and fantasies of escape. Perhaps the brightest light comes from a fellow resident with Alzheimers who takes to helping Lloyd walk up and down the halls, laughing all the way.

Erika Stoving is the epitome of a dedicated nurse, working hours beyond her shift to care for every detail of the residents while also caring for her 2-year-old baby girl at home. It's a delicate balance thrown off kilter by the new changes at work that make her uncertain about where she stands. She's accountable when a resident is dropped, but instead of embracing the new culture's transparency, she follows orders not to tell the resident's family all of the details in order to protect the institution. When she meets with **Lloyd Herrold** she is again caught, wanting to honor his autonomy but knowing he can't function outside of the nursing home. And when **Edie Herrold**, angry about losing her once dapper husband, insists that Erika put a bib on Lloyd, Erika is again caught between the new culture's mandate to reject bibs as degrading and a family member's request.

Nursing supervisor **Sharon Prusow** is also caught in the crossfire over the new changes. Families appreciate the time she now gives them, like when **Lloyd Herrold's** daughter inquires about missing clothes and Sharon calmly explains how her father wanders the halls and often places his clothing in other resident's drawers. But her nurses resist changes, claiming that doing away with an institutional medical cart in the hall or ceasing pulse checks in the middle of the night makes their job too difficult and risks residents' lives. And when state inspectors issue the first violations she has received in her entire career, she feels that culture change may have distracted her attention to details. **John George** places her on probation, wrestling privately with the dilemma of whether to fire one of his best friends. In response, Sharon starts cracking down on her staff.

What she might not know is the ordeal of daily life faced by many nursing assistants like **Enchantra Cosey** who, like most of her colleagues, is poor (making less than \$8/hour), African American, and working two jobs. Enchantra deals with the seamy side of care, changing diapers and bathing residents. At home she is raising two grandchildren fathered by her 15 year-old boy, while her oldest son is in prison. She, however, embraces the new culture change which encourages her bond with **Pauline Coggs**, one of the few African American residents. In death, Pauline has taught Enchantra about strength. Fearless, Pauline instructs an official gathering of staff (including Enchantra) to end her therapies and withhold lifesaving measures. Free of the burden of

keeping her body functional, she attains a kind of bliss, which Enchantra relishes whenever she has a moment, listening to Pauline's stories and jazz floating from her room. These moments offset the more difficult ones her job presents, like when **Delores Haig**, who has Alzheimer's, slaps Enchantra while she assists her to the toilet.

Delores can be belligerent with staff. Her husband, **Bob Haig**, does what he can to calm her. Bob is 90, and goes to work at his photography studio every day. Before work he walks from his independent living apartment to the nursing home to wake up, dress and make-up Delores. It is sweet and sad to see him "doll her up," as staff put it. They understand Bob pines for the wife Alzheimer's has stolen from him. In a meeting with **Erika Stoving** and **John George**, Bob spends the entire time remembering his and Delores' global adventures. In his photography studio he confesses to being utterly confused about how to deal with Delores. When he throws her an 88th birthday party she seems happy, even a little saucy, until they visit the apartment they used to share. In a rare moment of clarity she declares to her grandchildren "I miss this place, you should see the dump where I live now." Hurt, Bob finally takes **John George** up on his offer to enroll him in a support group.

Winding his way through all of these lives is the indomitable **Ralph Nelson**. He sails. He woodworks. He surfs the internet. After losing his wife 12 years ago, he is finally ready to date again. A fixture at cocktail parties and other functions, Ralph pours his heart into everything he does. Knowing how difficult it is for **Edie Herrold** and **Bob Haig** to accept their spouses' deterioration, he joins them for lunch to ease the pain. Knowing how strapped Saint John's is for cash, he leads trash pick-up brigades and refinishes the building's benches. But there is one line he will not cross — the threshold to the nursing home. He explains that his projects are a way to do for the nursing home residents in lieu of visits. The truth is he is afraid of becoming frail, which is why he stays active and volunteers in a program with 2nd graders. "Just let me fall down, dead, when my time comes," he says. "I don't want to lose my independence." He is just the person **John George** hope to comfort by achieving a culture change that makes the nursing home less frightening.

Providing an antidote to our youth-obsessed culture, *Almost Home* portrays older adults as they really are: people who cope with disability, dementia and death while also continuing to love, desire and engage in meaningful relationships. *Almost Home* will resonate with older adults who rarely see themselves depicted honestly on television. Already a significant PBS audience for cultural and arts programming, we hope to expand their viewing horizons. *Almost Home* is also a multi-generational drama that reflects the reality of the long-term care industry where upper management is often white, while frontline workers are often minority. To build relevant audiences we have forged partnerships with organizations like AARP and the National Association for the Black Aged. Because *Almost Home* features the stories of so many people from a variety of generations — second graders to middle-aged adult children to the older adults — and racial, economic and educational backgrounds, we are poised to appeal to an unusually broad and diverse audience.

To ensure that we reach the diverse populations represented in *Almost Home*, and to fulfill the core PBS mission of delivering both quality television *and* meaningful community service, we are organizing an ambitious \$250,000 national educational outreach effort. We will partner with national organizations not associated with aging (NAACP, YMCA, American Library Association) and local coalitions of aging professionals, community groups and public television stations in 20 communities across the nation to design and implement a grassroots effort to reach out to people who do not yet identify themselves as potential caregivers or care recipients and encourage their recognition, understanding and consideration of long-term care issues. We are also working with a national board of advisors to develop a curriculum that can be woven into continuing education courses for professional caregivers who must obtain such credits to keep their licenses active. A comprehensive web site will support all outreach efforts.

Wisconsin Public Television is our producing partner station, and PBS has registered support for our project at a length of 90 minutes, leaving time for a 30-minute follow-up by local stations. Editing begins in July, and delivery is planned for April. More than 77% of our budget has been raised.²

² Through savings such as Wisconsin Public Television's low post-production rates, our budget's bottom line is shrinking.