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Interview with Frances Shani Parker Author of *Becoming Dead Right: A Hospice Volunteer in Urban Nursing Homes*

Today, Tyler R. Tichelaar of Reader Views is privileged to speak with Frances Shani Parker, author of "Becoming Dead Right: A Hospice Volunteer in Urban Nursing Homes."

Frances Shani Parker is a writer, consultant, hospice volunteer, and former school principal who has won numerous awards, and been published in everything from poetry anthologies to educational publications.

Tyler: Welcome, Frances. I'm glad to have you here today. Obviously, you have a strong writing and educational background, but your new book differs from your previous writings. To begin, what first made you decide to be a hospice volunteer?

Frances: Over a three-year period, I helped two male acquaintances who were living with AIDS. A year after the first man died, I learned the second man had AIDS. These men, who were not close to each other or me, were people in need of caregiving support. Because I had never been attracted to caring for sick people, I wondered why these situations had come into my life. After talking with a friend who enjoyed being a hospice volunteer, I realized that I had been doing hospice work with the two men. I decided to take classes to become a certified hospice volunteer, and I've been one for nine years.

Tyler: And what experience as a hospice volunteer led you to write "Becoming Dead Right"?

Frances: As I became more involved with hospice volunteering in Detroit nursing homes, I found myself writing poetry and prose about my experiences. I shared these writings at poetry readings and noticed how eager many people were to discuss

terminally ill loved ones who impacted their lives. Their need for more caregiver and bereavement assistance became evident.

While researching death-related topics, I discovered that most books on the market did not include perspectives of people of color or those dying in urban nursing homes. I believe that one person can make a difference.

Knowing that millions of diverse baby boomers are becoming senior citizens in need of end-of-life information for their elders and themselves, I decided to write a book that would serve as an inclusive guide for literally becoming dead right.

Tyler: That's interesting that you started out with writing poetry. Are any of your creative pieces included in "Becoming Dead Right" or do you have plans to publish those pieces separately?

Frances: I'm glad you asked that. The book has sixteen chapters, a bibliography, resources, and an index. Each chapter concludes with an original poem. I've been told that the poems add another dimension that enhances the storytelling and general information. Each poem rose from a passion inspired by particular people and situations.

Tyler: Could you define for us what exactly a "hospice" worker or volunteer is? Is it solely volunteer work in a nursing home, or does it include home health care? How does it differ from being a nursing home aide?

Frances: The hospice philosophy supports quality end-of-life care physically, emotionally, socially, and spiritually. A hospice volunteer is part of a team of people who provide hospice care to dying patients wherever they live. Families of patients are also supported. After I completed my training, I had the option of volunteering with patients in private homes or nursing homes. I chose the latter.

A nursing home aide, also referred to as a CNA (Certified Nursing Assistant), is a paid healthcare employee who receives more extensive training in working with patients. In nursing homes, they provide direct, hands-on care for patients.

Tyler: Your book's subtitle is "A Hospice Volunteer in Urban Nursing Homes." Do you think there is a significant difference between urban and more rural or small-

town nursing homes? Would your book appeal to readers more acquainted with smaller-town nursing homes?

Frances: Healthcare and death are universally embraced topics, regardless of the settings in which they take place. Nursing homes reflect the uniqueness of their surroundings, but they all have basic healthcare goals for serving patients. Inclusive sharing of best practices is especially beneficial. The beauty of geographical diversity, including internationally, is that the different characteristics can serve as useful learning resources for everyone. Along those same lines, I share several scenarios about my death-related experiences growing up in New Orleans, Louisiana.

Tyler: I have heard lots of people say they hate going to nursing homes, and there are even people who refuse to visit their family members there because it is too depressing. What would you say to such people?

Frances: Nursing homes are products of a society that allows them to exist in their positive or negative conditions. There are good nursing homes, but ignoring those that aren't good only contributes to making them worse. There is a growing "culture change" movement to create person-centered nursing homes that truly focus on meeting needs of residents and staff members. This approach brings pleasure and productivity to the nursing home setting. In the last chapter of "Becoming Dead Right," a model nursing home based on current best practices is described.

To those who avoid depressing nursing homes, I would say that the best way to help patients in these environments is to commit to being advocates for them personally or on a broader scale. To abandon patients at such a critical time in their lives is to further mistreat them and contribute to the negative conditions.

Tyler: Frances, what do you think are the biggest challenges facing nursing homes and hospice workers, financially or otherwise?

Frances: Funding is fundamental to the existence of nursing homes and hospice programs. Medicare, Medicaid, and insurance companies must financially reimburse nursing homes and hospice programs more realistically in meeting patients' needs.

Disparities (racial, ethnic, gender, etc.) in the healthcare system must be eliminated. Overwhelming evidence indicates that these disparities negatively affect groups. Healthcare workers in all areas, including nursing homes and hospice programs, must take responsibility for changing unjust practices. This is not only a healthcare issue, but also a moral one.

Ongoing, expanded education about the benefits of hospice care is needed on a nationwide level in all communities. An underlying objective should be the achievement of diversity at all levels of staffing and patient care.

The many nursing homes that still reflect the traditional stereotypes of what institutional settings should not be must implement culture change that will promote harmony and efficiency for patients, caregivers, and staff workers.

Tyler: Of course, hospice workers must become attached to their patients, yet it must be a bittersweet attachment, knowing ultimately that your patients will die. What about the experience makes it rewarding?

Frances: Volunteers, especially those in nursing homes, encounter a range of experiences while serving hospice patients and their families. Some volunteers say these interactions help them become better people. Patients are also rewarded with volunteer caregivers who are solely there to assist them in having a dignified death journey.

Tyler: Earlier, you mentioned that you started out in hospice as the result of caring for two men suffering from AIDS. Have you found certain cases, such as people dying of old age, or AIDS, or cancer, more difficult, interesting, or rewarding than others?

Frances: Although their diseases vary, patients, not their diseases, are what make each case interesting and rewarding. The time I spend with a patient is also a factor in how well I get to know and interact with them at a deeper level. I have had patients who died before I met them or before my second visit. On the other hand, I have had patients who lived as long as three years.

Tyler: One of the difficult things, I know, from my own experiences is an inability to know what to say when you go to visit someone in a nursing home, and at the same time, a feeling that the time is precious because a loved one may not live long. What advice would you give for having conversations with nursing home patients?

Frances: Taking cues from patients, visitors should use good common sense. Whether patients can speak or not, they are usually glad to have company. An

analysis of physical appearance, body language, words, and room conditions can reveal a lot about what patients might need to improve their comfort levels.

Visitors should talk to patients as they would talk to anyone else, even if patients can't respond. Include patients in conversations when others are present. Encourage patients to speak for themselves when they can. Visitors should be conscious of what they say when they think patients are asleep or in a coma. Patients might still be able to hear them.

Tyler: With people living longer and the baby boomer generation now becoming senior citizens, what do you think will be the future of hospice?

Frances: Baby boomers, those born from 1946-1964, can play an important role as advocates for improving elder healthcare and nursing home reform. The future of hospice should include expanded medical treatment with a natural evolution of health services for all patients who are terminally ill. Patients would not have to wait until a doctor officially determines in writing that they have six months to live before they can receive hospice care.

Palliative care, an approach for treating incurable illnesses, can be given no matter how long a patient is expected to live and while doctors are still seeking a cure. Relieving pain and other symptoms, palliative care extends the hospice philosophy to a larger population that can benefit earlier in the illness process. Ideally, it should precede all hospice care.

Tyler: What would you recommend people do to get started if they are interested in the hospice worker profession?

Frances: If people already know that they have an attraction to hospice service with patients, I would suggest that they take this interest to the next level and speak to someone knowledgeable or take hospice volunteer training classes. This will give them a better understanding of what their companionship and service commitment would entail. Some volunteers focus on bringing therapy pets to visit patients. Others do office work, fundraising, and various jobs that support hospice operations.

Tyler: Frances, before we close, do you have any last comments you would like to make about the importance of hospice care?

Frances: Having a dignified death journey is an entitlement we all deserve. The odds of that happening are increased significantly when end-of life experiences are cloaked in a philosophy that supports the dying and their families with high-quality care.

Tyler: : Thank you so much, Frances, for joining me today. Before we go, would you please let our readers know where they can get copies of "Becoming Dead Right: A Hospice Volunteer in Urban Nursing Homes"?

Frances: Thank you for having me, Tyler. The book can be ordered online at Amazon.com, ordered from other booksellers, and found at local independent mind/body/spirit bookstores. Reviews, excerpts, and other book information can be found at my website at www.francesshaniparker.com.