



Share the Care for the LGBT Community

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Share the Care for the LGBT Community

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Tompkins County, where I have lived for more than forty years, is located 250 miles upstate from New York City. Ithaca, the small city at the heart of the county, is a culturally rich, scenically beautiful, “enlightened” college town, home to Cornell University and Ithaca College. Although we have both city (no struggle) and county (big struggle) anti-discrimination ordinances dating back almost twenty years, and a very large lesbian, gay, bisexual, and transgender (LGBT) population of both permanent residents and students, the kind of “all-purpose” LGBT service organization found in many metropolitan areas does not exist here.

LGBT students have extensive college-supported services and groups. Planned Parenthood offers LGBT health and sexuality counseling. But those of us who are “aging” are dependent on the same public and private institutions and services as the substantially larger heterosexual population: institutions that are often neither culturally competent nor interested in actively engaging in any but the most rudimentary ways with the “isms.” This is, after all, a rural, predominantly White, conservative county once you exit Ithaca’s “borders.” As the popular local bumper sticker proclaims: “Ithaca: ten square miles surrounded by reality.”

My close friend Candace was diagnosed with a slow-growing soft tissue cancer in 1998, a cancer that she was told, from the very beginning, would eventually kill her. In keeping with how she had lived her lesbian life before cancer, she sought to be fully alive as long as it was possible for her to do so. And she was, until her death seven years later at the age of sixty-two. Co-founding (with me) the Tompkins County Working Group on LGBT Aging, camping with her oxygen equipment in tow, cheering on her partner of twenty-plus years as she swam in the annual hospice fundraising event—all of this and more made possible, in part, during the last eighteen months of her life by the group of thirty people who formed her “share the care” team.

Share the Care: How to Organize a Group to Care for Someone Who Is Seriously Ill by Cappy Capossela and Sheila Warnock is a book originally published the year before Candace died.¹ In her continuing desire to be

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present for her own living/dying, Candace read widely on the subject, came across *Share the Care*, and set the wheels in motion for the formation of a group that would become part of her process. I was one of the women in this group.

If the goal was to be able to stay in one's home as long as possible, and nonmedical care—everything from watering the plants and walking the dog, rides to and from medical appointments, shopping for groceries and cooking some meals, companionship provided by a network of those who check in and hang out—is what “share the care” can provide, this is what we gave Candace. One major benefit was that our involvement allowed the people closest in, including her partner and grown children, to have more quality time with her.

Rather than the depressing but necessary undertaking I had anticipated, I found my “share the care” experience incredibly moving, instructive, and energizing. Being one of Candace's caretakers taught me how caring for someone who is seriously ill, in this case someone who was dying, could be an integral part of living—a bittersweet part, but one with deep and life-altering rewards. I also came to understand that if you are not solely responsible for someone's care (assuming that one person could actually do it solo), you have the psychic room to become that much more emotionally involved. Being a deeply involved caretaker was a shared responsibility.

Following Candace's death, the Working Group that Candace helped start undertook the development of a Share the Care for the LGBT Community project. Would it be possible, we asked, to put together a group of thirty people, like Candace's group, if the person needing help was seventy-one or eighty-one, rather than sixty-one years old, especially if the person didn't have as wide a circle of friends/family as Candace had? Probably not, we realized, given the physical limitations of age and the decreasing number of those of us who would still be around as our part of the community aged.

What would be required to make it happen? In addition to the core group of one's own family of birth or choice/friends/co-workers/religious or spiritual group members, could we turn to the larger LGBT community, call on people who are not actively in one's life but are a “member of the tribe”? If you're going to have strangers in your home, wouldn't it be better to have those strangers be comfortable with your LGBTness? This is the caregiving support structure we are working to develop.

As women, our lives and our socialization have taught us to care for and emotionally support others. As lesbians, we have cultivated our own strengths and learned to both develop self-sufficiency and build community. It is no big surprise, therefore, that thus far all of those who have expressed active interest in Share the Care for the LGBT Community, despite personal contacts, focus groups, and outreach efforts, have been lesbians.

The Share the Care for the LGBT Community model is potentially adaptable in as many different settings as one has the imagination and organizational skills to implement. It is obviously easier to utilize with people who are “out” rather than those whose lives have been extremely private and closeted. Basic computer knowledge helps with setting up a group and communicating, although our thirty-member Candace group coordinated everything by phone and loose leaf notebook. Now there are easy-to-use websites (e.g., www.caringbridge.org) that facilitate the sharing of health and other vital information with as large an audience as the person being helped wants to reach. The idea is to build upon the individual’s needs and resources to make the experience the most meaningful for all.

Even a cursory examination of the services and benefits that exist for the general public when dealing with serious illness and/or pre-hospice medical conditions (without taking into account the exclusions and invisibility imposed by homophobia) will show the inadequacy of what is actually available. Particularly for those wanting to remain in their own homes. Share the Care for the LGBT Community is one possible model for addressing some very real needs. Not as social as the traditional potluck, but drawing on behaviors that have long been part of lesbian life.

NOTE

1. Cappy Capossela and Sheila Warnock, *Share the Care: How to Organize a Group to Care for Someone Who Is Seriously Ill* (New York: Simon and Schuster, 2004, rev. ed.).

CONTRIBUTOR

Nancy K. Bereano is the former Editor and Publisher of the award-winning lesbian and feminist publishing company, Firebrand Books. She is the co-founder of the Tompkins County Working Group on LGBT Aging, has served on LAIN (LGBT Aging Issues Network Council) of the American Society on Aging, and is a trained facilitator for the Tompkins County Multicultural Resource Center’s Talking Circles on Race and Racism.