



Service Heals.

Community Care

And How Yoga Serves the Chronically Ill

By Cyndi Terry Kershner

Community care is a concept that had its introduction with the book *Share the Care*, by Cappy Capossela and Sheila Warnock.¹ In it, the authors advocate an approach for caring for seriously and chronically ill individuals by setting up teams of volunteer professionals and laypeople who can provide many of the services needed to protect and maintain quality of life. This “community care” approach, as it has come to be called, also aims to take pressure off the primary caregiver and reduce isolation of both the patient and caregiver.

Community care is rich with possibilities. Community care groups, based on the Share the Care model proposed in Capossela and Warnock's book, perform a wide variety of tasks, depending on what the particular groups' talents are. In my client Fred's case, a number of professionals volunteered for the group who brought skill sets such as Yoga therapy, counseling, nursing, and massage. Fred also has volunteers who take him to and from appointments, do laundry, and assist him twice daily in transferring from bed to wheelchair. Other volunteers troubleshoot issues with his motorized chair and help him develop new adaptive approaches in his home when needed. Other community care groups will have different skill bases to draw from depending on who is able to volunteer time and expertise, and those who are able to do so are the heart of community care services for each patient.

As part of the community care group I joined, I donated Yoga therapy services to Fred, who is at the end-stage with amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease. ALS is a progressive disease of the nerve cells in the brain and spinal cord, which control voluntary muscle movements. ALS patients experience a gradual loss of muscle strength and coordination in their muscular systems, with breathing and swallowing often affected first. Because ALS typically progresses quickly, patients with ALS lose the ability to care for themselves fairly rapidly and require extensive help with the tasks of daily living. The average life expectancy after being diagnosed with ALS is 3-5 years.

Yoga Therapy Program

Fred was seeking help in maximizing his remaining functionality. He asked for assistance with the pain he experienced in his joints and muscles as a result of confinement to a wheelchair and the inability to stretch his own limbs. He was also looking for help in dealing with the generalized anxiety he

experienced as his ability to breathe comfortably decreased. I committed to working with him a minimum of once a week, and often twice a week, which I have done for one and a half years. Our sessions always take place on the bed and are generally an hour and a half long, including transfers to and from bed.

As Yoga therapists we advocate for a holistic and client-centered approach to health care that addresses a client's needs across the spectrum of all the *koshas*—five layers, or sheaths, that range from the dense physical body to the more subtle levels of emotions, mind, and spirit. According to the *kosha* system in Yogic philosophy, the nature of being human encompasses physical and psychological aspects that function as one holistic system. The *kosha* system refers to these different aspects as layers of subjective experience. As part of Fred's comprehensive health care plan, I designed his Yoga therapy program with the intention of addressing all five *koshas*—his whole being.

Annamaya kosha, the food-apparent sheath

The *kosha* system works from the level of gross to subtle, beginning with the *annamaya kosha*. I began Fred's Yoga therapy program addressing the *annamaya kosha*. To relieve pain in his hips and buttocks from sitting in a wheelchair throughout the day, I used Thai massage techniques to provide deep pressure through compression. To help release and stretch his spine, I helped him perform passive twists, both in his chair and in bed, by applying traction to his legs and neck. In working with his upper body, passive range-of-motion activities designed to stretch his shoulders, arms, and hands, along with basic massage on his shoulders to relieve the musculature pain associated with slouching forward in his chair, were employed.

Pranamaya kosha, the air-apparent sheath

Fred was not able to do any breathing practices due to the deterioration of his breathing. In sessions, he would lie in bed while using a Bi-level Positive Airway Pressure (BIPAP) machine, a breathing apparatus that helps push air into his lungs. I found other ways to assist his energy in moving such as Thai techniques, range of motion exercises, and massage. He told me that the energy in his body felt much better after we worked together with these techniques; he reported feel-



ing more clear-headed, and with the pain and tension in his body reduced, he felt more vigorous and energetic. His face color usually looked healthier as well after we finished this segment of his therapy.

Manomaya kosha, mind-stuff-apparent sheath

With serious chronic illness, and in this case terminal illness, co-morbid depression is frequent. Caregivers also typically experience burnout, and the effect of the illness on the dynamics of the family system and its functioning is profound. In considering *manomaya kosha* I noted that Fred had not experienced the onset of depression, and his primary caregiver had not experienced a significant period of burnout. I believe this is due to his caregiver designing and implementing an effective community care team very early in his illness.

Still, emotional well-being resides in the *manomaya kosha*. During each session, I offered him emotional support by creating a space where feelings about the progression of his illness could be discussed. I wanted to make it clear to him that our sessions were a time where he could express his feelings if he wanted to. We would talk for a short time at the beginning of each session about how things were going that week and if he had lost any functioning. Whatever came up, I would ask about his feelings toward it; sometimes he would want to talk about his feelings, and at other times he did not.

As a way to connect more deeply with Fred on the level of *manomaya kosha*, I used therapeutic touch, an energy medicine technique whereby the therapist uses her hands to direct the flow of chi or *prana* to induce healing in the patient. In Fred's case this simply involved the laying on of hands with very gentle pressure to his forehead while I sent healing thoughts and prayers to him. I noticed his face and body visibly relax when I did this.

Fred was expressing a lot of anxiety, however, especially over the decreased ability to breathe, and this became a therapeutic focus. With each session we worked with a meditation on the breath from Stephen Levine's book, *Healing into Life and Death*. The meditation focused on letting the breath be just as it is and accepting exactly what's there. We worked



with this meditation for about four months, and according to Fred it helped decrease his anxiety level over time.

Vijnanamaya kosha, the wisdom-apparent sheath

This same meditation on the breath also assisted Fred's ability to cultivate *vijnanamaya kosha* by helping him step outside his usual reaction pattern of anxiety and cultivate some detachment during the act of breathing. Through the course of Fred's therapy I have seen his ability to engage with this *kosha* grow exponentially; he has deepened his meditation practice through starting a meditation group, and his level of overall anxiety has decreased markedly as he is able to go deeply inside and connect with his wisdom body.

It is also important for the therapist to connect strongly with *vijnanamaya kosha* while engaged in a session. Many times throughout our sessions Fred would experience anxiety over various things: sometimes he would start coughing and not be able to stop; sometimes the wheelchair would malfunction; at other times we might have difficulty getting his BIPAP device to work properly. These occasions were stressful for both of us, and sometimes it felt like I was working in a hospital ward with all the different high-tech gadgets that he used. Whenever we ran into one of these difficulties, I remembered to engage my witness consciousness so that I would not be emotionally reactive to the situation. I could not have acted as Fred's Yoga therapist if I had not been able to do this.

Anandamaya kosha, bliss-apparent-sheath

At the time of his diagnosis, Fred already had a long-standing meditation practice, which was obvious to me in watching the way he accepted his illness and adapted his life around it. Fred is my neighbor and I have had the opportunity to see him almost daily in the two years since he has been diagnosed with ALS. During this time he has only become more loving, more compassionate, and more peaceful. It is clear that his spiritual practice helped him immensely in coming to terms with his ALS and that *anandamaya kosha* was flowering in Fred.

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Community Care continued

As the Yoga therapist on his community care team, it has been a joy to be one among a large group of folks who are each taking on different roles to help Fred while also making his primary caregiver's life much easier. A leadership group meets monthly to assess his changing needs, troubleshoot challenges, and schedule his sessions with us, though I have not been a part of that group. The larger group of the community care team does not meet because there are so many of us, but when we do run into each other there is the sense that we share a common purpose and are part of a team. This is encouraging to us in our work with Fred and his caregiver.

Over the past two years I have been touched watching Fred's community care program unfold and in seeing the effect it has had on his quality of life and that of his family. Because his wife Nancy, who is his primary care provider, invited just about everyone they knew into their journey through ALS together, Fred has had a near constant stream of regular visitors to keep him connected to the world and mentally stimulated.

The result of the constant support and involvement is that his illness has unfolded within the support of a strong community. Instead of the segregation and fearfulness that typically surround a terminally ill person, Fred's illness has been normalized and viewed as simply another stage in life that needs to be responded to with compassion, sensitivity, and care. Both his primary caregiver and immediate family have been released from the crushing burden of trying to care for him by

themselves, and his larger community has gotten the opportunity to get to know Fred in a deep and meaningful context.

As a Yoga therapist I have been impressed with the contribution that community care can make in encouraging a truly holistic and life-affirming path for the seriously or terminally ill patient and their caregivers. I encourage any Yoga therapist who works with this population to learn more about it so they can assist their clients' care providers in setting up an effective community care program.

Yoga therapists often have a unique opportunity to observe at a deeper level what is going on with our clients, their families, and caregivers. This ability to look deeper, on the levels of all the *koshas*, is a strength of Yoga as a healing art. It lends itself to facilitating the type of community care which, as in Fred's case, normalized first the experience of serious illness and now the transition from life to death. Community care created meaningful experiences for Fred, his family, and his caregivers. **YTT**

References

1. Capossela C, Warnock S. *Share the Care*. 2d edition. New York: Fireside Press; 2004.

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