

CAREGIVER AS LEADER

Caregiver as Leader: Giving Care to the Caregiver

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Abstract

This paper is based on the Capstone project, “Care for the Caregiver” and my personal experience in caregiving as a leader, daughter, and spouse for aging loved ones. I would assume by my own life experience and my research that there are many confused and frustrated family caregivers in our country and world today. These people are not alone in their journey, but because of the often desperate and isolated nature of these caregiving situations it is hard to reach out and find one another for solace and connectedness. Caregivers need care too. This is my discovery throughout the time as a caregiver, and a transformative, yet quiet leader.

Introduction

A Society of Care Givers Would Be Nice.

In America today the percentage of elderly is rising at an alarming rate. In 2011, 80% of older adults in the U.S. had one chronic condition. Half of all older adults had at least two. The aging of the U.S. population is one of the major public health challenges we face in the 21st century. One of CDC's highest priorities as the nation's health protection agency is to increase the number of older adults who live longer, high-quality, productive, and independent lives.

(CDC, 2015)

It is my belief that if older people had a caregiver trained to offer wholesome care by their side, they would live healthier lives until the end, saving the health care system billions of dollars and providing quality of life to individuals that otherwise wouldn't have it.

Proper education in the schools from Kindergarten through college level programs could groom those who naturally "care" into professional level caregivers that could provide good care for the elderly, children, and anyone that is sick, deprived and needs help.

How do we, as a collective, inspire and elicit care? Is care innate, or can it be developed? These questions and others I intend to answer over time, but for now I am a concerned caregiver, giving care.

Introduction into Transformative Leadership

My leadership vision and experience in TLD

In August of 2013 I began an online graduate program in Transformative Leadership at California Institute of Integral Studies. My original intention within the TLD program was to learn about myself as a leader. At the time I thought that being a leader was something I was not and maybe never could be, but I assumed that I would find and develop my leadership skills throughout my studies. My previous concept of leadership consisted of "winning over a movement, and teaching those within the movement." However, what I have discovered throughout my two years of study is more about myself, the wisdom I already carried within and the fact that my life has been destined for leadership as a caregiver. I give care in many ways, as a counselor, a home health aide, a non-profit volunteer and more. And I've been doing this most of my life, naturally and instinctively.

As my parents and my life partner aged, and other family members headed for death, my life as a graduate student was also ridden by that reality. I love my family and as they become sick in their older years, I seem to be the only one that has the time, devotion, patience and instinctual knowledge of how to be a proper caregiver.

Transformative leadership is ambiguous. It requires that I be amenable to its power and flow, and thus accept the fact that life is not always what my ego desires it to be.

After caring for family elders with dementia, knee and hip replacements, three bypass surgeries, five major strokes, 10 heart stents, kidney failure and more, I still survive. During my stay at CIIS I saw 12 family members and close friends become ill, many of whom have since

passed away. I must say that this experience has been incredibly transformative and dauntingly humbling.

Does all of this loss inspire leadership? Certainly it does. Being a caregiver requires the “self” to be strong and often ‘selfless’. If one were cooking a meal, one would place the food that is already prepared on the back burner, probably on low simmer. This is what a caregiver sometimes must do with the self. For me, being the only family member giving care at times, it requires that I be present 24/7. There often isn’t a break for days or weeks at a time. And during times of acute illness, as in recovery from surgery or as in terminal illness for my loved one, a full range of emotions can come to the surface for both of us. The responsibilities and duties can be exhausting and overwhelming much of the time.

In my experience, friends I’ve had for years have become absent during these times. They are busy living their lives of course, but I feel some don’t realize that my caregiving role has been taken on both out of necessity and the fact that I sincerely care. When I say I can’t go out to dinner or to a movie, or even spend time talking by phone with my friends, I am being genuine. I truly can’t because I am the only caregiver and because my resources are limited. I don’t have another caregiver to replace me even for a short while, and secondly I give up my paying job to care for my loved ones during these times.

”Instead of subsidizing people who quit their jobs to take care of their loved ones, the government’s response to this crisis is the opposite of what’s needed. It has slashed Medicare benefits and funding for home health-care givers. This myopia is creating secondary health costs and declines in caregivers’ own health.” (Sheehy, 2010, p. 49)

In fact, I write this while my life partner is resting on the couch, only four days after extremely risky spinal surgery. We do not have resources available for him to go into

rehabilitation, so it will be my duty to help him recover properly without injuring himself. I too am now wearing a back brace so that I can help lift him from the lying position. These are the types of caregiving responsibilities older couples face. Some elders live alone and have no one to care for them.

I'm not the only person in America in this situation. I've done research and have started connecting with other caregivers. I am connecting with those caregivers in my community that wish to have support from other caregivers in similar situations. Hence, the beginning of the day outing, "Care for the Caregivers", that my coalition of three and myself are holding once a month.

I write this expose from a first-hand position. Much of what I have experienced as a caregiver, others have been doing for generations. These family caregivers can identify with my story. Who takes care of the caregiver? We take care of ourselves, and at times not very effectively. I don't have time for haircuts, makeup and often don't eat well. I have been known to spend my last dollar on medicine for my patient. After years of caregiving I am learning to navigate (what can be) the complicated world of the medical system, the recovery process and how to provide holistic care for myself and my patient.

The Quiet Leader as Caregiver

Resourcefulness has become a leadership trait that I have embellished throughout these years as a caregiver for family elders. Much of my experience in this role as caregiver was a "learn as you go" process. I took on the silent titles of a student-learner within the medical system, a home nurse/doctor, counselor, physical therapist and other roles deemed necessary at any given stage of the caregiving. I sometimes call myself a care coordinator, as well as a

caregiver. With no education in this capacity I had to be self-taught, and questioned how other individuals and families in these situations managed.

Throughout my years of taking patients to clinics, hospitals, treatment centers and the like I began to have quiet conversations with other family caregivers and professional about their experiences with aging loved ones and/or patients. My findings have provided me some comfort and affirmation that indeed, I was not the only one having these sometimes frustrating yet blessed experiences.

I also wondered what happens to an elderly person that doesn't have a family member or friend to give care. They may die alone in their old beat up recliners, in hospital beds, or a lonely nursing home situation. It is human nature to want the care of another person but family members don't always recognize the signs that a loved one is dying a slow death, alone and in pain.

Sheehy states that,

We must work out a whole new way of relating to our parents, or to a life partner who is weakened and frightened by illness. —a time for regretting or a time for rejoicing. The bottom line is that most of us believe we should take care of our parents as they get older. Fate or genetics will also command many of us to tend to a husband or a wife whose health is compromised when they're still in early adulthood or midlife. (2010, p. 13)

“The role of caregiver is often assigned, early in life, by family dynamics or cultural expectations. It usually falls to the daughter. In traditional families it's usually the eldest daughter.” (Sheehy 2010, p. 46) I was the eldest daughter. Both of my parents have since passed away. My mother took care of her mother. My grandmother took care of my great-grandmother

and so on. They were all the eldest daughters. But in their days it seemed that family lived geographically closer to one another, and were more enmeshed in the daily lives of one another. I wasn't as receptive to being the family caregiver in the beginning.

My role as the family and spousal caregiver has been expected of me in my life. As an only child until the age of six I automatically began to take on responsibilities at an early stage. Then when my parents began to get sick due to aging I helped them as much as I could. Also, during those years my life partner began to have major physical problems as well. I traveled the 1000 miles from one household to another often and for extended lengths of time to care for my aging loved ones, and to maneuver the walk through medical institutions by the dozens. I like to say I became a professional caregiver for my loved ones. Sheehy agrees that the role of family caregiver can often be as important to healing as the medical professionals if it is done correctly.

Why, I wondered, did so many caregivers I interviewed adamantly refuse to recognize the vital, professional-level job they were performing? –women have been socialized to believe this is their responsibility—and until recently medical professionals showed scant respect for the family caregiver. Fortunately, that is slowly changing. Geriatricians and many nurses now bring in the family caregiver as part of the decision-making team. More and more the family caregiver is the backbone of our broken health-care system. (Sheehy, 2010, p. 13)

I recently had an x-ray technician say to me that I was a “blessing” in my partner's life. I'd not had anyone praise me or compliment what I'd been doing before this, and it brightened my day. Often, the caregiver is dismissed in decisions and sometimes treated like they are getting in the way. Having a family or personal caregiver with the patient during crucial care times can remove some of the burden for the professionals, especially when the patient will

eventually be going home into the care of that caregiver. I feel it is imperative that the medical team bring on the family caregiver in determining the care of their patients, especially if the caregiver is the one that will be giving primary care at home.

So, how is it that a caregiver becomes the leader? In many cases she or he is the only one taking care of the indigent person needing the care. One of my elder loved ones suffered from severe dementia and could not care for self as I could. And when there was another illness or surgical procedure necessary I was the one that provided some of the proper care at home and in the hospital. There wasn't enough staff on duty to give the extreme amount of care that my loved one needed during this time. I became the leader of that and other so-called caregiving missions.

“The acute caregiver is expected, overnight to take on the roles performed in the hospital by three shifts of skilled professionals, from the IV nurse to the dietician to the visiting specialists and resident doctors.” (Sheehy 2010, p. 33) This is definitely leadership, albeit not be the boisterous kind, but rather the performer of duties within quiet leadership.

As I perform my duties of the quiet caregiver as leader I must remember to:

- 1.) Be self-aware
- 2.) Be cognizant of the other
- 3.) Continue to learn and expand my consciousness

As the quiet leader and caregiver I often take time for myself to meditate, exercise, learn all that I can to grow, and keep my awareness of the true needs of others present and realistic. The boundaries between caregiver and enabler can become confused, so it is important to remain self-aware even when self must be put on the back burner.

“That’s why I think that cultivating, ‘becoming a real human being,’ really is the primary leadership issue of our time, but on a scale never required before. It’s a very old idea that may actually hold the key to a new age of ‘global democracy.’” (Senge 2004, p. 186)

Compassion and Trust in Caregiving Leadership

Throughout my time in the Transformative Leadership program I have come to acknowledge that my leadership style must coincide with my personality and soul traits of being a highly sensitive individual, an introvert having artistic flair, and I also have a natural inclination (due to my clairvoyant and psychic gifts) to be the healer type and idealist. I believe that individuals have the power to heal themselves and others, but I do understand the physical, emotional, and mental limitations of this human existence. Therefore, I honor and respect those going through illness, as we are all conditioned to this life of pain and ill-repute. Compassion is my mainstay as a caregiver and a quiet leader.

“If you want others to be happy, practice compassion. If you want to be happy, practice compassion.” – *Dalai Lama*

When we look through the lens of the Synergistic Inquiry model of leadership, a good caregiver must have *self-knowing* in order to be present with *other-knowing*. One must take care of the other, but not without the finely-tuned awareness of self.

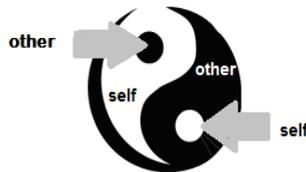
“22 Expansion of consciousness refers to those transformative changes in the structure of our consciousness that enable us to engage the world differently. An expansion of consciousness is an inward process that cannot be legislated.” (Tang 2006, p. 22)

It is important in caregiving to know self, and then get to know the other. It is difficult to retain judgment of the other’s belief system when being genuine in caring. In my circumstance I

have long followed the premise that I can heal most conditions within myself without medical intervention and medicine. But as I age I become more sympathetic to others that are growing older and their bodies are failing them in ways they don't understand. A healthy mindset is important, but it isn't always enough. Exercise, eating right and doing things in moderation is good medicine, but sometimes not enough to keep the doctor away either.

There are many factors that contribute to ill health and without knowing my patient's history, way of thinking, being and living, I cannot know how to care for that individual. Caring for parents and a partner is easier in some regard because I do know these things. I know self, know the other so I can *hold the differences* between us with compassion and together we *transcend the differences* to become one during the care giving and receiving process. Caregiving thus becomes a project.

Differences Holding



Differences Transcending

In the above representation the yin yang, the Tai-gi-tu becomes the symbol that defines the synergistic union of opposites. In this instance the symbol is used to demonstrate the Synergic Inquiry methodology of self-knowing, other-knowing, differences holding and differences transcending. (Tang 2006, p. 129-132)

First, the self must look inward to inquire and reflect. Then as the self peers into knowing the other and brings back the wisdom that was obtained by observation and inquiry, it helps the

self grow and integrate parts of that other-knowing. As the other will peer into the self, s/he too begins to know its other (me or myself). As a group consciousness it can then grow and expand building upon the Tai-gi-tu union. The only way the harmony and balance of this process can continue is for differences within self and other- knowing be held respectfully and brought to the transcendent and ultimate knowing space in consciousness. This cycle continues upward in a DNA type spiral, interwoven yet separate.

Since I've determined that long-term caregiving is a project between caregiver and patient, then holding the patient (other) in a space of non-judgment and using inquiry, discussion, and sharing personal stories, much of this conflict can be resolved for the sake of our working union. Much healing can be possible, and the project at hand—is care.

It is my opinion that many people do not assess their lives on a regular basis, but often leave it until the end days of life. I've seen many of my loved ones start talking about things they regret, how much they care for me and others, and things they'd like to relive. A major psychic cleansing process takes place when one is transcending into another state of consciousness, either as in death or during a traumatic situation that brings them near death.

The metaphor of death as a teacher and liberator, as the beginning of a new way of being, and as the stimulus to knowledge of divine reality, is found in all the great spiritual traditions of humankind. Confirmation of this view has come from three different groups of people: those that have almost died but returned; those who have experienced the death of a close relative; and those approaching death slowly in terminal illness. All three situations can be triggers for far-reaching and profound changes in consciousness and personality. (Sheehy 2010, p. 143)

The impending death, or long term illness of a loved one can bring upon spiritual transformation, or sense of transcendent emergence within the caregiver. Isolation and loneliness may occur because of the necessity of care giving responsibilities and the fact that she feels no one else cares or understands her situation and what she might be going through. A crisis of faith may ensue.

According to Grof, “Not only do those facing such an existential crisis feel isolated, but they also feel insignificant.” (Grof, et al 1990)

It can be very easy for both the caregiver and the patient to fall into a state of Geriatric Depression. Sheehy has found,

“When people are really sick, they often revert to old defenses, such as denial or blaming everybody but themselves. I later discovered from scientific literature why seriously ill people often seem ungrateful or even hostile to those helping them. The brain area that normally focuses on other people and the outer world shuts down when we become really sick, allowing another area that focuses on internal organs to become more active. When we are really sick the burdened immune system literally erases all memory of our surroundings.” (Sheehy 2010)

Depression is often the result of long-term chronic illness and aging. It is hard for the caregiver, (especially if s/he is living with the patient) not to also become depressed, despondent, anxious and exhausted. I like to refer to the old nursery rhyme when talking to caregiving spouses:

Jack and Jill went up the hill to fetch a pail of water.

Jack fell down and broke his crown,

And Jill came tumbling after. (Walter 1919)

As a caregiver for a spouse it is important to remember that if your loved one goes falling down the hill (or as I say, “falling down the rabbit hole”) due to health conditions, it is crucial not to fall down with them and end up becoming sick yourself. As the caregiver, you are also needed to give care to yourself. You are important. Caregivers can be the most important element in healing and quality of life for the patient. This is why I decided to begin my project “Care for the Caregiver” right here at home in my most immediate community.

“It is important for the caregiver to take time for self-care.” Sheehy recommends “physical exercise, meditation, taking a break away from the patient, eating well, rewarding yourself with a massage, manicure, a movie, dinner with a friend, or explore spirituality.” (Sheehy, p. 134)

Before I explain the actual *Care for the Caregiver* project, I must give some of the backstory that led me here. In addition to the fact that I’ve been the family caregiver for years, it wasn’t until recently that I began really delving into what the systemic issues are in caregiving. These issues can result as isolated family incidents or delve into the expanded picture of the family now involved within the larger cog of the medical system wheel. The two don’t necessarily jive or click together in a homeostatic flow. In fact, they often fight one another when it comes to the aging population that may be resistant and perhaps naïve or ignorant to care in this fashion.

I am often conflicted myself when medical assistance is required in quantity for an aging loved one. My partner was raised by a traditional herbalist. His great-grandmother would make concoctions from various plants and elements she pulled from her front yard and out of the air. She lived to be 100 years of age. Since being raised this way my loved one has been conflicted with the idea that the medical system is also here to help. In this day, it is hard to say that the

manufactured supplements and herbal formulas are as pure and as strong as they once were. Pesticides and environmental toxins, and the money-making corporations have made discernment regarding which products to use a bit complicated. So, I believe that a combination of anything natural that can assist in healing, and medical help when necessary is the best medicine.

In dealing with my parents however, they were convinced that doctors were the end-all, know it all solution to all physical maladies. This is the augmented purpose of the medical profession. In fact, the Hippocratic Oath will attest to this intent. "If I do not violate this oath, may I enjoy life and art, respected while I live and remembered with affection thereafter. May I always act so as to preserve the finest traditions of my calling and may I long experience the joy of healing those who seek my help." (Lasagna 1964)

As a child, our Doc O. would stop at our house on his way home from work to attend to our illnesses. It was usually a shot of penicillin and a lollipop. But in these days there are many more discovered afflictions. Medicine has become complex and many more people need treatment today. It's not as simple as it was when I was a child.

We must remember that doctors are just as human as we are. Albeit extremely educated regarding their craft, they do become overwhelmed and overworked. Nurses and physician's assistants take the brunt of much of patient ills these days because doctors don't have time to see all of their patients on a regular basis. America's aging population has increased tri-fold over the last decade and the medical institutions cannot always keep up with the fast moving changes necessary to serve all patients equally and well. This then becomes a systemic problem of epidemic proportions. How do we solve all these differences created by fast moving medical changes, an aging population that may not understand and is resisting, and by the population

increase of those that need medical care? One way to help offset these problems and begin shifting the dynamic is to foster the caregivers that are and could assist in patient care, whether it be a family member (that is compensated) or a paid professional trained for just such purpose.

Nightingale: A Great Caregiving Leader of Past

As a youngster I was very taken with the stories of Florence Nightingale, the late 19th century nurse that made astounding leaps in the area of patient care and healing. She was truly a leader as she tended to the sick, embattled and impoverished population during an early time when conditions were abhorred. She did more for nursing and patients than most have done over time.

Under Florence's leadership, the nurses brought cleanliness, sanitation, nutritious food and comfort to the patients. Nightingale was known for providing the kind of personal care, like writing letters home for soldiers that comforted them and improved their psychological health. Her group of nurses transformed the hospital into a healthy environment within six months, and as a result, the death rate of patients fell from 40 to 2 percent. (Nightingale, Special Edition 1982, p. 226)

In my caregiving experience with my aging loved ones, I have met some incredible health care professionals. Some of the work that they carry out is above and beyond their job description and is definitely noteworthy.

The chaplain at a long established Baltimore hospital told me that they had prayer meetings and hands-on healing groups that visited patients within the hospital. There was no official research on the success of these visits and the healing, but the chaplain stated that there

often was improvement with patients, or at least some peace came over them as the result of the prayer. In this manner the patient could heal and/or transition into a comfortable death.

The managing nurse at a large rehabilitation center spoke openly about his concerns regarding the larger medical industries that dictate non-personal treatment plans for patients. His concern was that each person as his patient is individual and should be treated according to their personal needs, not according to the dictates of the pharmaceutical, money-driven industry. His care for the patients was amazing and at times alternative, as he put his own job on the line to give care and attention more than was permitted by his supervising medical teams. He is dedicated and devoted to giving care.

I've learned as caregiver that I cannot assume a patient can "get over" being sick, and that the pain is real for them. In one instance, I rushed my loved one to the hospital emergency room because I was sure he was having a heart attack. Because he'd never been diagnosed with a heart problem or arterial disease, it was assumed by several doctors that my loved one was not in any danger of a heart attack. Not until they caught an attack on an electrocardiogram (EKG) did they believe what I kept insisting. Our patient then was immediately rushed into open heart surgery.

Nightingale is noted for her genuine support of patients,

I think it is a very common error among the well to think that "with a little more self-control" the sick might, if they choose, "dismiss painful thoughts" which "aggravate their disease". Believe me, almost any sick person, who behaves decently well, exercises more self-control every moment of his day than you will ever know till you are sick yourself. Almost every step that crosses his room is painful to him; almost every thought

that crosses his brain is painful to him: and if he can speak without being savage, and look without being unpleasant, he is exercising self-control. (Nightingale 1982)

Nurse Tony knew that his patients were in pain, and he knew that many were exercising exquisite self-control in the light of how much agony they were in, and yet he was very discerning about handing out narcotic types of medication to alleviate pain. He knew that patients often needed exercise and movement, and fresh air to bring the spirit back to their aching bodies. His goal was healing with dignity for all of his patients, and for the most part he was succeeding despite pressure from the system.

So if a medical institution is market driven, which inherently is the case much of the time in our commercially based economic system, then employees are driven by those higher ups that are looking at the bottom line. Sometimes then, staff are hired and fired based on their desire to work at sub-standard wages because they most likely need to provide for self and family; not always because they have empathy for patients or passion for the work that they do. But as I've seen recently, there is a large movement out that that is determined to change some of these systematic dysfunctions.

“When it comes to business, we rarely hear people praised, let alone rewarded for their empathy.” (Goleman, et al 2002, p. 49)

Shouldn't professional caregivers be given proper recognition when deserved and reprimanded with appropriate disciplinary action when the situation calls for either? In the chapter “When Leaders Don't Listen”, the authors tell us to, “Consider the estimated 100,000 deaths each year in U.S. hospitals caused by routine medical errors. Often these mistakes could have been prevented if the command and control culture in most medical organizations had been acknowledged and changed.” (Goleman 2002, p. 193)

Coordination of care can become more challenging when one's client or patient goes into the medical world. There are many things to organize, keep watch on, and coordinate. As a caregiver, coordination of care involves some manipulation when providing care for a person that is receiving medical treatment within or from a facility that experiences organizational dissonance and dysfunction. It requires intuitive understanding of the dynamics going on within the organization that trickle down to the staff that are taking over temporary care of your patient. You become a handler as such.

I always make sure that my name and phone number are left with every team of caregivers and on the white board in my family member's patient room. I make my presence known. I shake hands, learn names of the nursing care team, and I use their names when addressing them. I also am good at asking questions about the personal lives of some of my patient's care team members when they have time. The professional caregivers "take care" of patients day in and day out. I believe that they deserve to have a moment to talk about their lives too. They need care as well. We are working together as a team in regard to my sick loved one, so they too become our temporary family members.

Often I will send emails or written notes thanking the staff at the facility where my loved one has stayed in the case of rehabilitation or even Intensive Care Units. I feel it is important to acknowledge the good service that these professionals give day in and day out. The kinds of feedback and support that I give cannot fix the organizational problems per se, but I can give support in small ways to people that matter.

Perhaps the most unfortunate aspect of organizational dissonance is what it does to the individuals who work there: As their passion diminishes, they can lose touch with their own best qualities. In place of excellence and self-confidence, we've seen in such

companies displays of false bravado, thoughtless compliance, or open resentment. People show up for work, in body at least, day after day—but they leave their hearts and souls elsewhere. (Goleman 2001, p. 197)

Within functional organizations, those that have taken a look at their flaws and dissonance as a whole, and have chosen to provide a balanced workplace for employees and patients, it is much easier for an outside caregiver to release their beloved patient into the care of the facility providing treatment.

Going from the intimate and sometimes a dysfunctional family system that has perhaps functioned on its own for years, into a medical situation within a huge medical system can be frightening and confusing for both patient and caregiver. This upsets the homeostatic balance of the family, traditional roles begin changing and a new way of functioning must supervene.

Sheehy calls this the New Normal. For the caregiver, “You realize that you have a new role as family caregiver. And this isn’t a sprint. This is going to be a marathon. You are living with a new uncertainty, and you are not going back to the old normal.” (Sheehy 2010, p. 23-24)

The homeostatic balance of the family is altered for good, and a new way of functioning that includes bigger system intervention must be established. Homeostasis in any system is seen as the qualities within which variables must be regulated so that internal conditions remain stable and relatively constant. A family unit has homeostasis, and sometimes this original set of conditions are in place for many years, and often include many generations of members.

“Bert Hellinger, the founder of Family Constellation work, who studied and treated families for more than 50 years, observed that many of us unconsciously "take on" destructive familial patterns of anxiety, depression, anger, guilt, aloneness, alcoholism and even illness as a way of "belonging" in our families. Bonded by a deep love, a child will often sacrifice his own

best interests in a vain attempt to ease the suffering of a parent or other family member.”

(Hellinger website 2015)

Caregivers often face obstinacies, anger and resentment when a family member experiences health changes and challenges. This is something for which to prepare and understand, so as not taking these behaviors from our loved ones personally.

“When people are really sick, they often revert to old defenses, such as denial or blaming everybody but themselves. I later discovered from scientific literature why seriously ill people often seem ungrateful or even hostile to those helping them. The brain area that normally focuses on other people and the outer world shuts down when we become really sick, allowing another area that focuses on internal organs to become more active. When we are really sick the burdened immune system literally erases all memory of our surroundings.” (Sheehy 2101, p. 184)

If the family is open to it mental health therapy, systemic and family treatment options are available.

Systemic therapy seeks instead to identify stagnant patterns of behavior in groups of people such as a family, and address those patterns directly. The systemic therapist's role is to help systems to change themselves by introducing creative “nudges”. Systemic therapy neither attempts a 'treatment of causes' nor of symptoms, rather it gives living systems nudges that help them to develop new patterns together, taking on a new organizational structure that allows growth.” (McDaniel et al 1992, p. 26)

“Medical family therapy promotes both agency and communion. The term agency is used to describe active involvement of the patient and family in and commitment to one’s own care. Communion refers to emotional bonds that often are frayed by illness and contact

with the health care system. A good therapist, social worker or patient advocate within the system can help to promote both agency and communion for the patient and family caregiver. (Watson 2005, p. 8-9)

However, in some cases access to this type of therapeutic expertise is not available, not provided, or not wanted by the sick family member. I found it necessary to reach out to other family caregivers to hear their experiences. I found many that did not have a support system for themselves or their patient. This doubles the stress on the caregiver.

According to Rolland, “Internally the family must reorganize in response to new developmental imperatives brought on by a (new) or progressive illness. Major illnesses cause the family sufficient stress to require major adaptational shifts in family rules in order to ensure continuity of family life.” (Rolland 1994, p. 66-67)

Many of the spousal caregivers I spoke to had very little or no help from family members. As these caregiving spouses tended to be elder themselves I asked in our conversations how they were getting on with their lives. Many of them talked about the loss they were feeling as their spouses aged with illness related complications. In some cases they told me stories of days gone by when their spouse was agile, mentally alert and funny. “A myriad of feelings and transactions associated with anticipatory loss complicates all aspects of family life over time.” (Rolland 1994, p. 164)

Although I’d experienced much of these feelings myself, I wanted to give back in the small way that I could. As a primary caregiver at the time I decided to hold a function in my home for a small group of caregivers. This would be my way of giving others some relief from their daily caregiving responsibilities. I planned the day, advertised in my local community, called together a few people to help me prepare the function and shared a day of relaxation,

education and laughter with these beautiful people. Here is my Capstone project account of the *Care for the Caregiver* day outing. It was so successful that a few others are now helping me make this a monthly event.

Caregiver's Getaway

Saturday, June 13, 2015, 12 to 4 PM

A day for YOU, the Caregiver to get away, have fun and let go of your "cares".

For information on location & to register call: 1- [REDACTED]

(leave msg.) free of charge to all registered caregivers.

Hi, I'm Jules Kennedy. Some of you know me, others do not. I am offering a day for caregivers of elders, children, those with illness and/or recovering and anyone that gives care, personal or professional.

The plan for the day is:

12:00 - 1:00 PM, Social time—get to know one another & a de-stress meditation.

1:00 - 2:00 PM, Let's Eat Lunch--with guest Speaker Kathy (Cardiac Rehab)-she will talk about heart health and staying well as a caregiver. A Heart Healthy Lunch prepared by John, Shelly and Jules.

2:00 - 3:30 PM, Fun and Games, Laughter Therapy, more social time, a walk through Pinon Hills (gorgeous views of the Peaks) or whatever you wish to do.

Finishing up with a mediation for strength in caregiving.



The day began roughly before noon Mountain time. Two women arrived together about 11:50. They had been laughing and having a nice journey to my home. The rest of our guests began trailing in right after 12 PM.

Group demographic: Originally we had 10 registrations, but only seven showed up. One woman brought her husband for whom she gives care. He spent the time with my husband for the duration, but the couple only stayed for lunch and then went home. They both are in their 70's and needed their afternoon nap.

All seven registrants were women. Four of them care full-time for their ailing spouses. Another woman is a social worker, serving families in the county and also cares for her ailing husband when at home. One woman cares for her grown son that has mental health issues. Another woman has full custody of her three step-grandsons, all under six years old. She is in her late 50's. I now care for my husband that has been sick these last few years, and is undergoing his second major surgery within the last four months.

All women in this group are caregivers. Most care for elderly spouses, but just the same caregiving has some very similar elements no matter the age group of the persons receiving the care.

Social hour went well. Guests chatted among themselves sharing caregiving stories and giving support to one another. At 1 PM we shared a lunch made by my husband, a young female friend of mine and me. We had heart healthy salads, New Mexico style burritos and tacos, and a selection of deserts.

Before lunch began, everyone took a turn introducing themselves, and then I shared a brief meditation to set the energy of the room as a good place to release stress and just spend the day relaxing.

During lunch the cardiac rehabilitation therapist of a local hospital talked to the group informally about taking care of self while being in demand as a caregiver. All the women could relate to her message. She showed us some relaxation techniques and shared a community resource list for all those interested. Some of the ladies shared their stories as a caregiver. But mostly we enjoyed lunch, had a few laughs and talked about things of interest for each individual.

One of the women is 83 years young and retired from the military. She said that she spent most of her years surrounded by military men in positions of power. She shared how difficult that life was as one of the few women in the types of positions she carried. She also shared that the challenges she faced in her career were not nearly as difficult as being the primary caretaker for her husband that suffers from multiple disorders including onset Alzheimer's. He is also retired military and is still very strong. Sometimes she cannot handle him, so they were planning a move to a larger metropolitan area to an assisted living facility where she can get some help.

“By 2030, the number of Americans with a confirmed diagnosis of dementia is expected to more than double to 5.2 million.” (D.J. Thurman, MD, CDC, unpublished data, 2006)

I shared with the group my identity as a psychic/physical and emotional empath and received some grand advice from Kathy. She has worked with patients and caregivers for many years as a cardiac rehabilitation specialist. She suggested that I take time for myself in quiet to identify which energy was my own and that which belongs to others. When constantly caring for a sick person, especially a loved one, lines can become crossed. As an empath I automatically

pick up on the ills and emotions of other people I am around. I've had empathic heart attacks, labor pains, fainted when coming in contact with a burn patient (due to the intensity of the pain he was feeling underneath the mask of the pain-killing drugs), kidney issues and much more. Although this is sympathetic or rather phantom pain, I feel it as though it is my own. This can be hard on my body and emotional strength. So I must be careful to remain clear as to which pain I am taking on and the reasons why. I would imagine then that other caregivers do much the same, but perhaps unknowingly. The group thanked me for my contribution. One guest acknowledged that the same sort of things happen to her when she is caring for her husband.

Even though I found some of the stories sad, it was my intention to allow the guests to speak candidly about their experiences, and then have a little fun. We cleared the tables of dishes and I set out the games, and offered up what I call Laughter Therapy. We began with a chuckle and ended up laughing hysterically, looking at one another all the while. This inspired more laughter and even tears. What a positive relief for all.

It was then that several women began a game of cards, while the rest of us set out for a walk down our ¼ mile drive onto the road. After two dips and hills on the road there is the most magnificent view of the Rocky Mountains on all three sides. Of course most of us are used to this view, as many of us live in some beautiful places, but we still marvel at the beauty. This is why many people stay here. The consensus is that the medical services locally are a bit challenging for anyone with major complications, but the beauty of the land is almost worth staying until it just is not possible to care for our loved ones any more.

It felt good for me to relate to these women. Most of them were older than I am and are retired with income. I am still working as much as I can to help support all the medical costs. So I may seem worn for being younger. In any case, being a caregiver can be very draining and will

encroach on the health of the caregiver. A day outing once a month will be a great experience for all attending.

We ended the day in circle. We stood holding hands and praised the land for its suppleness. This year we have had much rain, so the Earth is very green and fertile for being high desert. We also thanked our abilities as caregivers and gave ourselves a pat on the back, a reward for being so dutiful to our loved ones. We envisioned peace, good health and harmony for the group, the people we care for and the community at large. We hugged as a group and individually. It was agreed that we will do a second caregiver's getaway, and continue each month on the second Saturday. I can no longer hold it in my home as the house is now up for sale and I have moved but others volunteered to bring food and find other locations

This communion of souls was very stimulating for me, and it helped me to feel a sense of belonging. Caregiving can be very isolating and I must admit I feel lonely at times. In this group the loneliness went away. It's true that most of us cannot get away much, but we all agreed that once a month we could do so. The local social worker from the group helped a couple of the women get respite care providers for the day, and also helped one of them set up home care once a week.

I felt that the event went well. Everyone said they had a good time, and felt better about their caregiving experiences. This wasn't intended to be a support group but rather a "getaway". There is a local support group that meets regularly to help with the emotional part of being a caregiver. I wanted to provide something more fun and connected, and that is what was delivered.

I have been building a coalition of healers and helpers all over the world for many years. I've been fortunate that, because of my gifts and the work that I have been doing as a psychic

consultant for 35 years, I have met clients and healers from many countries. A Mongolian Lama is saying prayers on my behalf for my husband and me because a client from Switzerland knows our situation. These connections do help.

The power of prayer is very strong in my heart. I have healed myself from cancer with my own prayer, the help of prayers from others, and medical treatment from some very wonderful medical professionals that believed in prayer power.

Spirituality: The essence of our being. It permeates our living in relationships and infuses our unfolding awareness of who we are, our purpose in being and our inner resources.

Spirituality informs the ways we live and experience life, the ways we encounter mystery, and the ways we relate to all aspects of life. It is the way we experience living through our connectedness with the Sacred Source, the self, others and nature.

Spirituality often eludes the cognitive mind because it is intangible in many ways and defies quantification. Spiritual caregiving requires an understanding that spirituality is broader than religion and a recognition that, although some people may not be religious, everyone is spiritual by virtue of being human. (Watson 2005, p. 617-618)

Beyond the logistical, practical, physical piece of care coordination, it seems imperative that we bring compassion and love, connection and collectiveness, surrender and trust into our work as the caregiver. This becomes the spiritual and transpersonal aspect of care that is often forgotten or overlooked. But when people are sick, what they often need most besides medical treatment and physical care is understanding and compassion.

Compassion doesn't always come easy. Yes, love may be there---that sense of connection that just won't ever let up because it's there...all the time. But compassion takes effort.

“Ecologist John Thompson notes that “just as the richness of social behaviors may increase mutualism with other species, so may some mutualisms allow for the evolution of new social behaviors. In true co-evolutionary fashion, coevolution breeds coevolution.” (Kelly 1995, p. 74)

Stewart Brand wrote, “Evolution is adapting to meet ones needs, Coevolution, the larger view, is adapting to meet each other’s needs.” (Kelly 1995, p. 75)

In this regard, we could easily become a society of care givers—alternating care responsibilities with independence and interdependence, which then in turn would give each one of us a caregiver when needed and also provide the tools necessary to be a caregiver. We cannot live as isolated beings. We must not allow others to isolate for long periods of time when they are young or aging and ill.

“Nothing changes without also moving closer to its changing neighbors.” (Kelly 1995, p. 74)

If we each begin to practice, feeling within and deliver compassion to ourselves and others, a collective begins. We can connect to our loved ones for whom we give care, and we take on the essence of true caring within our being. That is expressed to others in automatic ways. We begin to cloak and eventually become that compassion.

“A truly compassionate attitude toward others does not change even if they behave negatively or hurt you.” –Dalai Lama

Trust between the family member that is ill and the family caregiver is also important. ““Where trust is strong, each person knows that both will go the extra mile for the other, or for the cause.” (Aucoin 2007, p. 234)

I began to operate my collection of duties as a project. “Complex projects sorely need trust.” Then as a project I had to manage it with love, compassion, non-judgment all while

building the trust level between myself and my loved one needing care. Since my project team member is always a loved one in these caregiving situations, trust had to be rebuilt and reformed within the new normal or new homeostasis within the family system.

What was once a solid, non-penetrable homeostatic boundary of our family system, now had to allow for medical interruptions (often crisis level interventions) and the invading entities of medical and human service organizations. In the situations with my aging parents there was plenty of resistance to these so-called invasions and change. So as the primary caregiver slash eldest daughter, I had to manage the project gently with a lot of graciousness on my part. This required a great deal of trust between my parents and myself.

The goal of my aging parents and many elders is often to re-establish the same old patterns of living within their homes and family systems, even after major medical changes have taken place. It brings them comfort and familiarity as they deal with a new set of physical conditions mandated by their bodies and medical professionals.

My role was then to instill a new sense of balance within the home, while coordinating care between medical appointments, medicine distribution, physical rehabilitation routines, all while making sure that the home was safe and still reliable for the patients.

“A high level of trust has a significant bottom-line payoff.” Using principles from the Right Brain Toolkit such as “respect, communicating promptly and openly, solving problems quickly” helped all of us “reach our goals” of trust and developing the new normal homeostasis that had to be flexible throughout time. (Aucoin 2007, p. 237, 251)

Watson explains, “One interpretation of burnout among healthcare professionals is that it represents the inability to find ways to tend the spirit as one suffers the suffering of another.”

(Watson 2005, p. 6230)

Jean Watson is known for her Caring Science programs and use of the Caritas (meaning charity) processes in her work with hospitals nationwide. The Caritas are a set of rules or principles originally used by Catholic nuns when caring for patients. The Caritas include the use of practicing loving kindness with self and others, developing trusting, caring relationships, and “creating a healing environment for the physical and spiritual self which respects human dignity.” (Watson 2007)

Most importantly within Watson’s work in the compassion field she is, “Open to mystery that allow miracles to enter. As there is an increase in Love/Caring in the world, there is a higher evolution of human consciousness affecting the whole.” (p.141)

“ In these emerging frameworks, we are called to attend to our own evolving consciousness and self-care practices for our own healing and re-patterning toward Caring/Loving intentionality and Consciousness for healing, and if we are to co-participate in moving humanity closer to honoring and connecting with the Infinity field of universal love, from which deep caring and healing comes.” (10 Caritas Processes, p.141)

The Integrative Medicine Department at Abbott Northwestern Hospital in Minneapolis, Minnesota has focused on its threefold mission of service to patients in the areas of clinical services, education and research. . The department provides programs and services that enhance the innate healing of patients and staff. The educational program for clinician staff “includes education to transform nursing practice by incorporating the principles of healing and holistic nursing. It also presents a primer on mind-body therapies, traditional Chinese medicine, massage, and stress management techniques. (Dossey 2005, p. 527-528)

Patients, practitioners and hospital leadership are recognizing the need to engage in an integrative approach to health and healing. By making patient care the most important focus, the

changes that organizations make will be profound. I recently was visiting a loved one in a hospital that has been recognized often for “Excellence in Care.” One of the nurses told me that they are evaluated on their level of and ability to give care. Each staff member seemed to be tremendously compassionate and caring. I’ve had the exact opposite experience in other medical facilities where I have been shunned, told that my loved ones’ problems were not important enough to be seen by a doctor, and have been hung up on many times while trying to make doctor appointments by phone. It is very refreshing to see how many of the larger medical facilities are working to make it right for the patients and family caregivers. One facility even had a guest room waiting for me as a caregiver so that I could spend the nights close to my loved one. I felt respected and “seen”.

Although studying leadership has not been my forte, it is a great segway into my doctoral studies and work in transpersonal psychology, consciousness and creative studies. As a polished quiet leader I can assist others in understanding how creativity can open up consciousness and rise to a spiritual place where all things are possible. As a spiritually based quiet leader within the role as family or professional caregiver I bring my best to the healing team for my patients. I can be a guide through the physical, emotional, mental and spiritual healing and transition for those whom I give care.

Evaluation (Caregiver as Leader, by Jules Kennedy)

Evaluator: 1

Please evaluate: 5 being the best, 1 being the worst

Quality of paper?

1 ___ 2 ___ 3 ___ 4 ___ 5 X ___

Thoroughness of paper?

1 ___ 2 ___ 3 ___ 4 ___ 5 X ___

Topic quality?

1 ___ 2 ___ 3 ___ 4 ___ 5 X ___

Does the paper make sense to you? If so, please comment. If not, could you make a few suggestions of what didn't work for you?

The paper not only makes sense, I think it should be published. In my work as a hospice chaplain, I know that this paper would really help caregivers as well as medical professionals.

Additional Comments (optional):

I may borrow the idea of a caregiver's getaway day for my employer – a home health and hospice organization.

Evaluation (Caregiver as Leader, by Jules Kennedy)

Evaluator: 2

Please evaluate: 5 being the best, 1 being the worst

Quality of paper?

1 ___ 2 ___ 3 ___ 4 x 5 ___

Thoroughness of paper?

1 ___ 2 ___ 3 ___ 4 x 5 ___

Topic quality?

1 ___ 2 ___ 3 x 4 ___ 5 ___

Does the paper make sense to you? If so, please comment. If not, could you make a few suggestions of what didn't work for you?

It does make sense, however, I felt very triggered reading this paper and witnessed so many of my own judgements surface. I found myself feeling discompassionate and wanting the author to give more self-care to herself than I heard being advocated or disclaimed within the paper.

I did value the topic generally, as it made me ponder why our society disregards compassionate caregiving. I found myself exploring the realms of fear and lack of internal resources as potential reasons.

“When it comes to business, we rarely hear people praised, let alone rewarded for their empathy.” (Goleman, et al 2002, p. 49) This statement is key to my discombobulation in reading the paper and my passion to proffer internal resources in the workplace. This paper forced me to locate the intersections between elderly care-giving and hostility in the workplace.

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