

Esperar – Care for the Caregiver

By Michael Parra

Paul sat upright. The hair on the back of his head looked blond, and then I realized I was seeing his scalp through his thinning hair. His nurses said that it was unusual for a patient to hold onto his hair two months into chemotherapy, but was that a good sign or a bad one? A lot of small things had me worried lately.

Paul was staring into the depths of his coffee cup and I leaned back into the pillow to watch the dawn discover his skin. His back was still a broad, muscular V despite his weight loss.

“Michael,” he said, lifting his head to the window. “There’s something I didn’t mention about yesterday’s conversation with my oncologist...”

A solitary desk candle sputtered but otherwise the room was silent.

Paul half turned in my direction, “I asked the doctor about the success rate for people with Hodgkin’s Lymphoma,” he said. “I asked for a progress report. I wanted to know if –.” He looked back out the window. “I asked him if I could make travel plans for next summer or....”

I closed my eyes.

“...or not,” Paul finished, his voice hushed. “He told me the eighty-five percentile survival rate we read about on the internet pertained to people with early diagnosis and treatment. For a Stage IV patient like me it’s closer to fifty percent.”

Fifty percent, I thought. Half a chance...like flipping a coin.

Will it fall heads or tails?

“Michael, I waited so long to find someone like you. My life only recently became happy. I’m not ready to go.”

I wrapped my arms around him and we wept.

The Quest for a Happy Ending

For the caregiver, cancer is the ultimate waiting game. The patient waits for doctor appointments, lab results, treatments, drug studies to bring new protocols and more waiting. The caregiver also waits, but without the satisfaction of any subsequent action. Together they wait for the patient’s side effects to subside or worsen, an insurance company to process claims, friends and family to provide assurance and perhaps logistical assistance, and above all, they wait for a return to normalcy, to the life they used to know. “I just want my life back!” is the anthem of cancer patients.

That request does not seem too much to ask, but it is beyond the power of their caregiver to grant. Nevertheless, the very center, the core and heart of the caregiver’s job is the task of replenishing hope. The patient’s job is to get well or at the very least, endure. The caregiver is responsible for affirming life in the face of death. Theirs is the relentless search for a happy ending.

Talk about a waiting game.

In the Spanish language, the verb “to wait” and the verb “to hope” are the same word – Esperar. I think it asserts a profound philosophical position.

Hope is waiting. It casts one's focus out of present time and into the future. That perspective stands in direct opposition to the primary life lesson inherent in the circumstance of the mortally ill – Live In Present Time. A cancer patient is like a walking billboard, flashing the rest of us an urgent message, "Live for now!" Meanwhile their caregiver is wrestling with the future and wondering if tomorrow will come.

The emotional challenges overlying the logistical ones imposed upon the caregiver are daunting. There are questions arising from fear, guilt, fatigue and despair that reveal increasing doubt in the basic goodness of the world in which we live. These doubts are like cracks in the ground beneath our feet, deepening and widening until they become dark, interior chasms.

The answer an individual caregiver gives to a difficult question such as: "How will I manage my own survival needs while juggling those of my sick loved one?" will be colored by one of three shades of difficulty depending on the patient's prognosis or expectations of health. We can think of the caregiver's choice of approach as a spectrum of shadow, moving from a light, melancholic blue to the deepest, darkest indigo of despair. There are those people like myself who care for someone with a temporary if intensely difficult disease where the expected outcome is a return to health. There's the darker hue of caregivers attending someone who is terminal and expected to die soon; and then there are people who anticipate many years of care giving through their loved one's gradual decline.

Caregivers in all three scenarios face similar issues as they tend for someone very ill. For example, Paul and I maintain separate households and for the most part he sees to his own physical needs. We sustain this autonomous model because we anticipate only a six-month chemotherapy treatment schedule resulting in remission or cure of his lymphoma. Our choices would be very different if his prognosis changed. I participate in an online caregiver support group in which other caregivers paint darker pictures, caring for loved ones with aggressive, terminal lung cancer, or managing partners or parents with Alzheimer's dementia. The expectation of short term management leading to grief or long term care without respite, changes the caregiver's answers to the questions. Bearing this significant variance of response in mind, the hardships all caregivers face are unhappily similar.

Surprise!

Panic, the initial reaction to a loved one's diagnosis of cancer, is only the first of many surprises for the caregiver. Bewilderment mounts as the days and then months go by. New emotional challenges are joined by old demons that the caregiver may have considered long buried or resolved; and he may find himself wondering, "Why am I so bothered (angry, impatient, confused, anxious) by little things that I use to ignore or take in my stride?" The world has been turned upside-down for the caregiver. The normal flow of life, all the systems he put in place for comfort, is disrupted; and with it his sense of security and sanctuary are lost. The new situation invalidates prior assumptions about life. Plans and moral values are shuffled. He doesn't talk

about it because the person with whom he would have processed all these changes is very ill and has enough upset with which to contend. Thus the caregiver finds himself with a very short fuse and no where to blow off steam.

I've experienced and identified the main emotional troubles for caregivers, and because they often manifest as dilemmas that cause us to second guess our choices, I've posed them below as questions. I've grouped the worries into four categories of fear, guilt, fatigue and despair; though any single doubt may include all four emotions.

Fear Based Challenges

1. What about me? How do I live with the awareness that I will die?

Denise, one of Paul's favorite oncology nurses, was exercising on my Pilates table, her cheerful voice in peculiar contrast to the burdensome topic I had just posed: "What do you find most difficult about caring for your patients?"

"The main difficulty is that the work brings one's own mortality, which is one's own vulnerability, to the fore. A sense of humor is essential, that and getting along with fellow staff members."

Existential angst is not limited to cancer patients and caregivers. Everyone ponders their mortality from time to time, but most people can set that knowledge aside. Caregivers however, don't get to forget. Relentless reminders of death hang overhead like a dark cloud. No diversion, distraction or denial blankets their reality for long. Religion may provide solace. Nature and the great outdoors may bring peace and a sense of balance, but a degree of resignation is unavoidable.

So, in addition to happy endings, caregivers also hunt for silver linings. The best place for them to look is right in front of them. Their patients hold the answers on how to cope. The struggles of life-imperiled people teach the healthy about what's really important. A cancer patient thus bestows lessons, like blessings, on the rest of us. At the darkest of times, these truths can act as beacons, shedding light on mysterious and otherwise overwhelming misfortune.

Gifts from the life-imperiled – Simple Truths that Help Us Cope with Adversity

Whether the mortally ill patient conducts himself with courage and grace or makes life hell for everyone around him, that person serves as a reminder to stay focused on the present moment, and that how we interpret and respond to our lot in life is our choice. A caregiver occupies a unique place to receive this education, at arm's distance from death. If the truths listed below sound cliché it is because they are universal and obvious, part of the often taken-for-granted background of daily life.

- **Live for now** – All the other lessons that follow derive from the fact that tomorrow may never come. Last summer, before Paul even suspected that he was seriously ill, he turned to me and pulled down the collar of his t-shirt, "Michael, what do you think about this?" A lump the size of a golf ball protruded from the left side of his neck. With my instant panic came

with the realization that today may be our last. Responsibility does not diminish. A caregiver must still plan; but however mundane, plans should not detract from the moment at hand. Hope, expectation and worry cast focus into the future. Regret and disappointment emphasize the past.

- **Be Grateful for the Life you Have** – However demanding a caregiver’s circumstances may be, they are nothing compared with those of the patient. “There but for the grace of God go I.” One’s own life looks pretty good when contrasted with someone in a hospitable bed, tethered with an intravenous drip line. The lesson here is not only to be grateful for what you have, but also gratitude for what you DON’T have.
- **“Ain’t Nothin’ So Bad it Cain’t Get Worse”** – This is an admonition not to complain, not to allow hope to cloud observation and to keep going through the toughest times. When I sit with Paul in his oncologist’s waiting room, the hardships of the other patients are tear jerkers. An old Chinese man teeters on his grand daughter’s arm while she translates the nurse’s instructions. The girl tenderly delivers a dizzying array of medical procedures and appointment schedules. Other patients talk about how they’ll manage their illness while continuing to work and parent their children. There are worse things than lymphoma.
- **Don’t Sweat the Small Stuff** – In the face of cancer, long held priorities shuffle. You recognize that you’ve been playing a game of trivial pursuit most of your life. Sometimes fear takes over and even the simplest tasks appear overwhelmingly difficult; but at other times a strange inner calm grants you detachment from the anxiety of life’s struggles. Before Paul’s health crisis, a career transition such as I recently experienced would have had me in tears with a knot in my stomach. This time I smiled with ease and quit. It’s all small stuff. The lump on Paul’s neck, that’s big.
- **Allow the Circumstances of Each Moment to Set the Pace** – Paul and I were eating at our favorite cafe, a place where the counter staff comes to visit our table, stare with concern at his shrunken features and sincerely ask, “How are you doing today?” Usually I wolf down my food while Paul stares at his plate and digs around inside for some semblance of an appetite. This time however, I was practicing my diet program. I’ve got a blog going where people get directions for dieting (www.fitnesssundays.blogspot.com), and this week’s assignment is to put down the fork after every bite; so Paul and I had a leisurely, civilized brunch that we finished together. It’s not so different from when we’re strolling through the neighborhood so slow we’re almost standing still; but on the worst days even that speed is too much and he has to sit. The lesson: to be deliberate with one’s pace. It’s an education in how to take nothing for granted. It feels like the piano compositions of Chopin.

"Rubato" - music with some notes arbitrarily lengthened or shortened, intentionally and temporarily deviating from a strict tempo.

- **It's Later than You Think** – The main room of my Volition Fitness gym (www.volitionfitness.com) is a bit small for a dance studio, but it could hold a beautiful, intimate yoga class. Just prior to Paul's diagnosis, I enrolled in a yoga teacher training program. The practical response to his terrible news would be to withdraw from the school. Why spend over three thousand dollars and every weekend for five months on an endeavor that strains resources needed to take care of Paul? Because, as his plight clearly demonstrated, there might not be a second chance, a better time. For all any of us knows, it's now or never. Make a daring attempt to manifest your dreams today.
- **See Challenges as Signs Pointing to Purpose** – For the past eight years I've watched two of my colleagues, Regan Fedric and Jane Clark, create exercise programs for cancer patients. I admired their spunk and dedication as they formed their own non-profit corporation called Sunflower Wellness (www.sunflowerwellness.org) to provide services to life-threatened populations. I attended a couple of educational workshops, but I told myself that I was too busy developing my own business to participate in theirs. Paul and I are both Certified Fitness Trainers, and Paul is an experienced support group leader. He and I have frequently talked about joining forces and working together. Even though I know that it is hubris to think of Paul's illness as a heaven sent message, I'll take meaning where I can find it. To the caregiver's hunt for a happy ending and a silver lining add a third, the search for a noble purpose.

2. Do I stay or leave? How much giving is enough?

One morning early on in his illness, Paul and I took a break from the hospital. We sat at the window of a local restaurant. I looked into his eyes as he talked about his upcoming medical procedures. By the time our breakfast arrived the whites of his eyes resembled the color of my eggs. I could hardly swallow. An upwelling of concern and affection was counterbalanced by a self-protective urge to withdraw, a desire to flee before grief hits. I called four doctors within the hour. The jaundice and the immediate threat to his liver passed. However, the profound experience of danger endures, "If not now then later, if not this illness then perhaps the next, if not you then me." The underlying problem here is confronting inevitable loss. There is no right answer and the only solution is acceptance.

Guilt Based Challenges

3. **When demands conflict, how do I choose between my needs and those of my ill loved one?**

There are minor requests like accompanying him to the pharmacy to select the best gauze and bandage combination for the skin eruptions that result from chemotherapy. There are small comforts that become increasingly difficult to grant as time goes by, such as spending a beautiful day off indoors beside him because he hasn't the strength to leave the bed, and he shouldn't get sun exposure while on his current medications anyway. There are demands he makes that frustrate me because I can't do much to make a difference, like attending a debriefing with his oncologist.

I find that it helps for me to be flexible but to have hard and fast rules. For instance, as a fitness trainer I can cancel and reschedule private clients, but these people are my bread and butter. It's tempting to rearrange my business in order to give Paul the dinner hour. He worries that he won't eat. This is the time of day when he needs me most; however it's also my most lucrative work shift. If I play footloose with my clientele schedule then I won't eat. I'll cook for Paul on the weekend and join him for supper during the week when my last session of the day cancels.

4. How and when do I say “No”, or “Stop”?

A civil tongue and mutual show of respect is another hard boundary. Rude or offensive behavior is possible from us both, mine engendered by frustration and fatigue and Paul's propelled by many variables: pain, the mind clouding medication he takes to alleviate that pain, fear and a sense of losing control; so I cut him some slack. My response to his occasionally sharp words is non-combative, gentle but consistent. I leave. When he snarls I let my feet do the talking.

Real boundary declaration discussions are necessary within any relationship, be it a romantic couple, a pair of siblings, or a parent and child. However, the heat of an argument is not the optimum time for a serious discussion of personal boundaries. The caregiver/patient relationship imposes new roles on both parties and through the application of constant stress, aggravates any interpersonal problems that may have gone unaddressed for years. Taking calm time to talk about old offences and to identify new ones that have arisen since the onset of illness is a valuable conversation. Better to take a break and reconvene when a sense of safety surrounds us.

5. How much voice should I have in my patient's treatment and care choices?

When considering medical treatment options and selecting among various care provisions, the caregiver asks, “How much do I want to take on? How much responsibility do I want to accept for the consequences of the decision?” Problems arise when the caregiver disagrees with the patient's choices, especially as those decisions impact the life of the caregiver. When a therapy is better at a distant location than someplace nearby, who's doing the driving?

As side effects of his chemotherapy escalated, Paul felt as imperiled by the treatment as he did by the disease. A lean man to begin with, he lost ten percent of his body weight. When his physician mentioned possible extension of

the chemotherapy schedule, Paul told me he might decline it. If I supported a decision to cease treatment and his lymphoma reoccurred as a result, would I be obligated to partner him through the ordeal again? The life of a patient is sustained by collaboration.

6. How can I allow myself to enjoy life when my loved one is so miserable?

Three distinct avenues for guilt arise as I contemplate putting on my cowboy boots to go country-western dancing without Paul.

The first culpability comes from excluding the patient from a group of friends or potential friends at a time when he needs all the people he can muster to see him through his current ordeal.

The second censure comes from feeling physically vigorous and attractive. I look pretty sexy in my boots. Until his diagnosis, Paul and I were both fitness trainers, with closets full of tight t-shirts.

“Don’t look at me,” Paul commands as he steps out of the shower and quickly drapes himself in a bathrobe.

The third and saddest part is withholding joy, not talking about good times because they exclude the patient. This is a mistake. It separates the patient further from the life he misses, the life that could motivate a return to health.

7. How do I voice and process my own troubles when they seem so petty compared to my patient’s?

If the caregiver withholds good news because it excludes the ill loved one, and also mutes bad reports because they sound trivial compared to the patient’s troubles, then there isn’t much to talk about. Conversation centers on the patient who is living a reduced existence with limited subject matter. The caregiver must take joy in small, mundane aspects of shared moments and find ways and times to disclose their own separate joys and sorrows. This is bridge building, and it takes patience and practice.

Fatigue Based Challenges:

8. Can we please talk about something other than the illness?

Once the urgency of a new diagnosis subsides, cancer is boring. Almost every week a new side effect from chemotherapy get added to the list of existing ones. If any end is in sight, it may be far away. Sustaining interest can easily turn into feigning interest.

“Michael, what can I do to be a better patient, to make your experience easier?” Paul asked.

I told him that it would help if he could find a creative project, an interest other than managing his health. It needn’t be anything grand or work related, just something that grabs his imagination.

“How about planning our next trip to Los Angeles?”

The problem for the caregiver is not that ministering to symptoms becomes tedious, but the lack of anything else. As the patient’s life becomes

more and more limited, the caregiver sees the scope of his own life narrow. Then, as the days acquire a dreary sameness, a new challenge arises. The caregiver begins to suspect that the quality of the care he provides is slipping. He fears he may drop the ball, imperiling his loved one's health or at the very least, their friendship.

9. Will I ever know fun again?

One bright morning, Paul and I braved the winter chill to walk to our favorite café. As we glumly wrapped our coats tighter about us, we noticed a young couple across the street from us, laughing merrily as they strolled beneath barren tree branches.

"Will we ever regain that care free feeling?" Paul asked.

If replenishment of hope is the caregiver's chief duty, then creating good times is the main task. For both patient and caregiver, innocence and trust are replaced by worry and emotional armoring. We're always on the lookout for the next threat. The smallest symptoms, if left unchecked, may result in disastrous consequences. That means that even the most buoyant of times carry the heavy ballast of mortality, the unwelcome weight of awareness.

Cancer makes smiling hard work, but it's worth the effort. Laughter really is the best medicine.

10. What happens if I get sick too?

The full moon illuminated the vineyards of Sonoma Valley as I drove south. A red hot line of emergency flares and highway patrol cars blocked my path home and sent me the long way around around San Francisco Bay. It would have been a beautiful, autumn expedition were I not coughing uncontrollably with a flu that was about to force me to bed for most of November. The one person who might take care of me was in no shape to do so. Not only that, but since a person undergoing chemotherapy is immune suppressed, Paul couldn't risk contact with me while I showed signs of infection. Misery may love company, but in this situation we couldn't be together.

We got through the month by becoming self-reliant and by keeping our visits short and at arm's distance from one another. It was hell. A better choice would have been to enlist the support of our other friends and relatives.

Despair Based Challenges:

11. Can I think of my loved one the way that I used to see him, with an emotion other than pity?

As I write this, Paul is nauseous while making our lunch. The man with cancer is treating the healthy caregiver.

"No, let me do it," Paul insists as he clears the plates from the table.

It is not easy for the caregiver to balance sympathy with respect. One minute assistance is needed and the next his offers of help can be intrusive. The patient needs to occasionally reclaim his power and prove his capability; and the caregiver has to listen for those moments and say "Thank you" rather than insist

on taking charge. It's okay for the patient to fumble without blaming it on illness. Love may motivate the caregiver, but pity can become a permanent perspective.

12. How do I satisfy my desire for physical affection?

"I have no libido," Paul tells his doctor, who doesn't even look up from the chart as he waves away the patient's concern.

"No one does in your circumstances. Don't even bother with it."

When the caregiver and patient are romantic partners, they must bother with it. Sexual relations are better discussed than ignored or dismissed. Love must be reassured in some way, and that need increases for both parties when physical affection is restricted.

This is true even within platonic caregiver-patient relationships. There are times when the caregiver wants to demonstrate affection with a hug, or receive one himself, but the patient may be surrounded with medical monitors and plastic tubes, or he may be nauseous, or wants to protect skin abrasions, or feels self-conscious. The caregiver must wait and seize every opportunity for affection.

I'm a big believer in small caresses, a hand squeeze, a back of the head brush. Frequent touch is important.

13. Am I alone?

The most pervasive fear a caregiver (or any human for that matter) experiences is the sense of impending loneliness and abandonment. Every problem is magnified when it is met with a sense of isolation. That's true for both patient and caregiver.

The best strategy is to spread the challenge and the responsibility of care among several people, but that is easier said than done, and too often recognized only as an afterthought.

Many friends contacted Paul with offers of assistance. Many of my friends sent me a note telling me to use them for practical or emotional support; but for the most part Paul and I erected a kind of two-man shield, leaning on one another and shutting most of the rest of world out. This was mistake. Friends only make their offer once because they do not want to intrude on a sensitive situation. Support groups are few and far between and in hindsight I should have created my own and gathered a network for myself, independent from Paul's friends and supporters.

It is easy to misinterpret the silence of old friends as indifference, the old, "You find out who your real friends are." This too is a mistake. Many people simply don't know how to respond or are silenced by their fears of death; and most of them would be relieved to be given a concrete task that allows them to demonstrate their loyalty. The caregiver must resist disenchantment with old friends and remember that for both himself and for the patient: Hope requires constant replenishment but disappointment is cumulative.

Esperar

Paul's eyes darted between the metal blinds and me sitting at his desk. He checked his phone messages for the fifth time then threw up his arms and paced

the room again. I had witnessed this anxious, energetic behavior before on similar mid-cycle Mondays.

I kept my eyes on the computer screen as he wandered back towards the kitchen where he called to me rhetorically.

“When is that damn doctor going to call?”

Paul had driven himself to radiology that morning. It wasn't his first P.E.T. and C.T. scan; and he assured me that my presence wasn't needed for the procedure. This waiting for the results though...argh!

The phone rang. I stopped typing.

“Yes? That's great. Then this means I'm done for now, right? The chemo stops? Thank you, thank you, thank you!”

Paul grinned at me. He was skinny, bald and bandaged and ecstatic. He lifted my hands from the keyboard and we did a happy dance around the room. His scans showed that he was now cancer free. This time we wept tears of joy.