

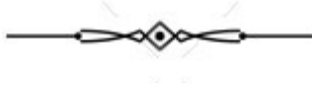
A Caregiver's Journey

By Annabel Gale

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their caregiver.*



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Cancer is everywhere. People dealing with this unforgiving disease are everywhere. And, from the day they receive their diagnosis, with the help of their medical team, they start to go to battle with it. But standing beside each of those brave cancer patients is another, equally important person: their caregiver. Some patients have several caregivers but generally one person stands faithfully by their side, taking them to every appointment, absorbing every word the doctors are saying to them and making mental notes for later, charting their meds, holding their hand in the chemo room as they sit through an injection or IV, supplying a bucket and gently rubbing their backs when they throw up and constantly reminding them at every new turn, "You WILL get through this."

My journey as a caregiver began on January 5, 2015. That is the date my husband Phil was diagnosed with Multiple Myeloma, more commonly known as bone marrow cancer. And yes, the date etched in my memory as we sat in the oncologist's office while he wrote a comparative description up on a white-board what normal readings should look like and beside it, Phil's numbers that were way out of whack, showing us how they had come to the diagnosis. It was a 2 ½ hour appointment and to be honest, the minute you hear the word "cancer" in the conversation is the minute your brain shuts down and you can get no further than the word and all its connotations. My husband had suspected he had Multiple Myeloma so had been researching on the Internet for a few days and was mentally prepared for the news. To me, it was a shock and my reaction was to burst into tears in the doctor's office. We were told that we had two options. Option 1: Do nothing. In this case, my husband would have just two years to live with decreasing quality of life. Option 2: Start chemo as soon as possible and then be assessed for a stem cell transplant. "What!" I'm thinking, "Two years! Are you kidding? We have a great marriage and a great life. How can you tell me that my husband has cancer and that, without treatment, he has only 2 unhealthy years to live. This can't be possible!"

And so the initial appointment is a shock, pure and simple. It is as much of a shock to the patient as to the caregiver. The first thing we had to do after leaving the doctor's office was to take a few days to come to terms with the news. This is life-altering. It changes everything. For Phil that meant his long-awaited retirement was going to be cut short and constantly interrupted by a whole series of unpleasant treatments and endless appointments. For me it meant that I had to get my head around the idea that my husband's lifespan would be much shorter than I had anticipated and that I had to step up in the new capacity of primary caregiver which involved challenges I could not have foreseen. A caregiver is a friend, a supporter, a cheerleader, and a nurturer; and, in some cases, you take on a motherly role. As the treatments began, I found myself becoming very angry at God for plunging me into this role that I didn't remember signing up for and angry that my marriage would be cut short and my career interrupted. I just wanted life to get back to normal because normal was really good for us. But you have to accept - and you do - that the diagnosis changes everything and this abnormal life became the new normal. For both of us it was a test of our faith.

It rapidly became increasingly difficult to handle work alongside my role as caregiver, so I opted to take a six-month leave of absence. My company was extremely compassionate and generous in allowing me to do this and I am so grateful because I soon realized that I simply couldn't have juggled it all.

In the very early days, we struggled with the question of who to tell and when was a good time to do so. First family, then friends. It wasn't easy and each telling came with a somewhat lengthy explanation of "What are the doctors planning to do for you?" We found that telling people was quite therapeutic, especially for Phil. Almost everyone has known someone close to them who has battled or is currently battling cancer. Only a small few could truly relate,

having been through a similar journey, but all were continually interested in how things were going and some wanted to fit in a visit. We followed wise advice from a friend who told us that people feel more comfortable having their role defined in your cancer journey. One kind friend supplied us with soups for our freezer, others gave me nutritious recipes, many prayed for us, some weren't interested in the nitty-gritty of the medical side of the cancer but chose to keep up a more jovial relationship with Phil. The biggest surprise for Phil was that he found himself reaching out to a large network of friends from the past and the daily emails gave him strength. For me, meeting friends for coffee and doing the odd day of work was paramount as it gave me an excuse to get out of the house and talk about something other than cancer and treatments.

There are times when your cancer patient is scared and they lash out. For you this feels like they are launching a personal attack on you but I learnt to realize that it's the frustration of the disease they are lashing out at, not you the caregiver. They need to hear you say "I love you" much more than usual, whether you are their spouse/partner, friend or family member. They need to feel secure and loved. In this new world of unknowns, you are their rock, their constant. They feel really unwell and everything else is changing around them, their body, their relationships with friends and family and even the way they view the world. They often need a calm, quiet, stress-free environment around them because they are already dealing with a high degree of stress. It is up to you to create this as much as you can. And they need as much normality around them as you can manage because this is the way they cling to what they remember is "normal".

People ask lovingly after the well-being of the patient and their well-wishes are so appreciated. But they seldom ask about the well-being of the caregiver. As tired and sick as the patient may be feeling, chances are the caregiver is feeling equally worn-out from keeping house and home together. The caregiver runs around the house sorting out the myriad needs of the patient, supplying an extra pillow or fetching meds, and ferrying all manner of things from one room to another. The caregiver cooks all the meals and snacks, does all the driving, cleans and tidies the house, washes clothing and bedsheets, tracks and administers meds, and keeps a meticulous diary of a seemingly endless round of medical appointments. Coupled with this for a lot of us is keeping a close eye on an ageing parent or two and in some cases a child as well. This adds up to one exhausted caregiver. But we love them and so we soldier on, looking for that light at the end of the tunnel and the anticipated news from their doctor that their cancer is gone or in remission. I didn't fully understand what the word "remission" meant prior to this, but translated simply it means that life can, for the time being at least, return to normal. Sweet words indeed.

One of the hardest things for a caregiver to appreciate is that it's all about the patient. In a normal marriage there is give and take, ebb and flow, between spouses, but when one of them falls seriously ill, then this balance is offset. It isn't that the patient doesn't care; it's simply that they don't have the energy to do any of the giving back. So you have to learn to put your feelings and needs to one side and that isn't easy. I remember going to see Phil's general practitioner one morning. I'd had a particularly hard week when Phil was coming down off some meds and he was withdrawn and irritable. His doctor is a really lovely guy, a gentle, Christian man and had been Phil's doc for literally years. I had a bit of a meltdown in the office because his compassion and understanding of the situation was so spot on.....and boy, did it help. Sometimes there is nothing like a good cry to relieve the stress. He explained to me that Phil was on so many meds at the time and still had the chemo drugs in his system as well. This cocktail was causing him to have a shorter fuse than normal. In addition, his brain was "pickled", as he put it, and he probably had little if any emotional energy left to interact with others. Hence he was feeling like he wanted to withdraw and was unsociable towards me and people who came over. It all made so much sense. I remember thinking, "It's his meds talking, not him. I can't wait to have my husband back when this is all over!" During this period I learned to share more of my feelings with my family and my girlfriends instead of my husband.

Yet another side-effect of the heavy narcotics is sexual dysfunction and over time this too took a toll on our marriage. His desire was there, but the drugs made achieving sex impossible. So without that physical intimacy, we had to learn

to retain our connection in non-sexual ways like holding hands wherever we went. The doctors don't warn you about that, nor are they equipped to counsel you to deal with all the side issues that come with a cancer journey.

Everyone kept saying to me, "Make time for yourself." I'd hear it over and over from well-meaning, dear friends as well as new acquaintances. But it had me baffled for a while because I didn't realize just what it meant to "take care of myself." How could I when I was so needed all the time? One morning, while we were in Vancouver for the transplant procedure, I took my husband to the hospital for his stem cell collection and they hooked him up to IVs in both arms for a period of six hours for two days straight. Prior to the appointment, I had gathered the fixings we brought into the Cancer Lodge with us for his calcium-rich breakfast, made sure we ordered pack lunches, booked the Freemasons car service to the hospital, and accompanied him to the ward. After several hours of sitting and watching the blood machine whirring round and round, I finally said, "I'm going out for a bit. I'll be back at lunchtime." Phil was a captive of the machine and under constant nursing supervision. It was then that he said, "Aren't you going to stay with me?" I finally lost it. "No!" I screamed in my head. "I have been with you day and night for the past four months, through thick and thin, attending all your appointments with you, fetching and carrying for you, getting my head around the changing meds, listening to the doctors, cooking, cleaning, driving, shopping, doing all the heavy lifting..." No. I simply had to put up my boundaries and inform him that I needed a bit of "me" time. My whole life was on hold; my every need shoved to one side. Because when you are a caregiver, it's all about the patient, all of the time. "I love you to pieces," I thought in my head, "but I just need a break." I needed to take some time to do something for myself, to recharge my batteries so that I could once again be fully there for him. This is when I discovered the meaning behind the words, "Make sure you take care of yourself".

With months and months of treatment, constantly being poked and prodded and scanned and evaluated, not to mention how ill they generally feel all the time, it's no wonder that most cancer patients finally get to the point where they say to their caregiver, "I've had enough. I can't take this anymore." I heard this just a week before the stem cell transplant. Phil was in a very fragile state of mind and the hospital psychiatry team was dispatched to assist me in convincing him that we had to go forward and through with the transplant because otherwise everything he'd been through up to that point would have been for nothing. It turned out to be one of the most valuable visits by any team of doctors that we encountered during our time in Vancouver. We were told that all cancer is emotional energy that has accumulated in the cells, usually from a build up of life's earlier traumas which haven't been sufficiently released for healing. This causes the cells to rebel, to become malignant. The deepest wounds provide the greatest opportunity for healing.

Phil was given meds to help get him through his anxiety in the short term, but we were also given some longer term emotional homework to do. I decided that I would benefit from this as well because I don't want to think that perhaps I have emotional baggage that might one day overload in my cells and cause cancer.

When I found out that free counseling was offered to the caregiver as well as the patient via the Cancer Agency, I gratefully accepted. One of the things they told me was not to be afraid to accept help when you need it. They advised me to pick the one area that stressed me the most and to call in regular help with that area. And so, even though our finances were tight, Phil was on board with allowing me to hire a cleaner to come in twice a month to clean our apartment. For some it might be a gardener, for others a Care-Aid to help bathe the patient, but for me it was a cleaner! It proved to be a godsend and just one more thing I didn't have to add to my already long "To Do" list.

For both of us, this journey tested not only our faith and our hope for the future but also the strength of our marriage. You can go either of two ways: You can elect to give up or you can choose to fight. If you choose to fight, you have to decide what you are fighting for. In Phil's case this was a few good years of retirement in order to do the things he'd been so looking forward to – writing, studying, music and travel. For me, the fight was to have my husband

around for as long as possible and have him well enough to enjoy life with. After all, this is why I wanted to be married in the first place. Companionship. As we were nearing the end of our time in Vancouver and preparing to go home, Phil told me that he was now more in love with me than he'd ever been. All those days of walking up to the hospital, fighting to make him take in even a few calories and helping him to the bathroom, all those months of accompanying him to appointment after appointment were all worth it just to hear those words.

There are times when I would have gladly thrown in the towel, but I knew I had to keep going because for me to give up would have meant him giving up also. Our roles reversed during his treatments: I became the strong one, the organizer, the one taking charge of every little detail, and he became the dependant one, the acquiescent one. Afterwards we had to re-learn how to switch back to the way we were before, except you can never fully go back to the way you were before because cancer changes you forever. It forces you to look at your priorities and to re-evaluate the quality of how you spend each day of your life going forward to make each moment count, especially as your life's time bank isn't unlimited. It gives you the opportunity to heal your past hurts and to find peace with yourself. Phil used to tell me he would switch places with me in a heartbeat just to feel well again and be pain-free even for a day. And I believed him. But neither role is easy. Patient and caregiver must both dig deeply, really deeply, into their inner resources to keep going on this unrelenting journey. Some basic advice: Go for a simple outing or take a drive with your loved one when they are feeling good; celebrate that special occasion; take a short relaxing holiday - because there will come a day when those things will all become very precious memories.

Care-giving is a relentless and often thankless job day in and day out, but it does feel good to be needed. I have been far from perfect as a caregiver. I could have done more, said more, been there more. But I remind myself that I was there at the times when it mattered most and that I did the best I could. You come out a stronger, more compassionate person and you treasure the privilege of taking this journey along with your cancer patient. In addition, you gain self-knowledge and self-evaluation also. I have learned to dig really deep into the well of my strength. I have discovered what it means to truly be of service to someone who is not capable of looking after themselves, and I know that I am certainly not the person I was six long months ago when I sat in the oncologist's office and heard the words, "Your husband has cancer".

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