

INVITED ARTICLE

LESSONS FROM LIVING WITH CANCER

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In March 1979, I was a successful 50-year-old surgeon, hard-driving and competitive, and subject to all the stressful pressures inherent in a busy surgical practice. In addition, during the previous 18 months I had experienced a barrage of major disruptions in my life, including the breakup of my marriage, the loss of my father through death, the "loss" of one child to college and another through separation when her mother and I parted, a serious ankle injury in another child, unexpected major surgery involving two close family members, a move from my home to an apartment, and of course numerous happy, positive stressful events. I repeatedly heard warnings about the stress levels in my life and the likelihood of an associated major illness. I felt helpless to alter my life substantially or to be a different kind of person — to cope differently with life's stresses. I had also once been a long-time cigarette smoker, although I had completely stopped smoking several years before.

In April 1979, a small adenocarcinoma was discovered in the superior segment of the right lower lobe of my lung. The cancer was successfully resected along with the superior segment, beyond which there was no obvious spread. The general medical consensus was that no further treatment was necessary and that approximately 50 per cent of patients like me, with successful resection of T-1, N-0, M-0 adenocarcinoma (a tumour less than 3 cm in diameter with no discernible nodes or discernible metastases), will survive for two years, and perhaps 33 per cent will survive for five years. I was one of the fortunate few in whom lung cancer was discovered early, and there was some hope of survival. For the most part, I ignored the other side of the

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statistic, which said that I had a 50 per cent chance of not surviving. I was concerned enough about the long-term situation, however, to do extensive reading about adjunct and alternative therapies; my reading included a recently published book by O Carl and Stephanie Simonton, a husband-and-wife, radiotherapist-psychologist team. The philosophy and management programs outlined in their book, *Getting Well Again*, made a lot of sense to me. Both philosophy and programs were stimulated by their recently completed joint study of the psychological factors in cancer and its treatment. They recommend that their approach be used as an adjunct to conventional medical treatment. The Simontons state that one's wellness and illness are problems of the whole person, concerning mind as well as body. Their theory is that patients with cancer can participate actively in the enhancement of health and the strengthening of bodily defenses by altering their attitudes and expectations. In response to the treatment plan proposed in their book, I began performing daily exercises in relaxation and imagery. I practiced visualizing myself free of the tumor. I imagined a strengthening of my immune responses and my defense against malignant cells. I did more physical exercise and paid more attention to my body. I did many of the things suggested by the Simontons but hardly recognized my capacity to alter my response to stress or to make major life changes.

I recuperated quickly after surgery and enthusiastically resumed my practice. I no longer saw myself as a person with cancer who had to struggle to survive day by day. I was well. I had lived through cancer and been cured. I had beaten it, and I no longer had to deal with the problem. Although I regretted the changes in my life that were necessitated by my limited postoperative lung function, I felt very fortunate. Gradually, I became complacent and drifted away from the regular practice of relaxation and imagery.

Then, in April 1981, two years after the original diagnosis and surgery, there was new growth of the same cancer in another lobe of the lung, and even more alarming, a scan revealed the distant spread of cancer to at least three locations in my bones. I was brought up short by the recognition that I had not won the battle. The cancer was not just a thing of the past. Confrontation with the recurrence and the distant osseous spread was overwhelming to me. I had been a good patient. I had done what I was told, recovered from surgery quickly, and promptly returned to work, yet here I was with recurrent cancer and metastatic spread. I was devastated, bewildered, and very frightened. I really did not know where to turn, but I sought all the advice and conventional treatment that were available. A biopsy of a metastatic lesion in the left sixth rib and an exploratory laparotomy that ruled out visible or palpable intraabdominal metastases was followed by 1800 cGy of irradiation to a femur weakened by a metastatic lesion. The use of what would otherwise have been the first choices for chemotherapy — doxorubicin, fluorouracil, and cisplatin — was ruled out by their lack of effect against my tumor *in vitro*. Intermittent combination therapy with mitomycin (Mutamycin) and vinblastine (Velban) was initiated as a second choice, but tumor progression over the subsequent two months indicated that those agents were ineffectual also, and they were stopped. Mediastinal and right hilar irradiation (2700 cGy over nine days) was followed by the initiation of oral methotrexate at a dose level just below that which for me produced continuous ulcerative stomatitis. For the past three years I have taken a constant oral dose of methotrexate — 25 mg every five

days. The tumor progression in the hilar region seems to have been arrested.

I fully expected the conventional treatment I was undergoing to be beneficial and only minimally disabling, but the prognosis at that point was dismal. With the recurrence in a different lobe, and demonstrated distant metastases, the original survival statistics no longer applied. If the recurrent disease was thought of as a different primary tumor with distant metastases, I had become a patient with Stage III disease, with a very small chance of two-year survival (10 per cent or less) and virtually no chance of living for five years.

Simply accepting this prognosis was completely intolerable for me. I felt that I was not yet ready to be finished. I had too many things that I still had not seen and done and shared with the people I love. I began to seek new avenues of help, new approaches that might make sense to me. I found and began working with a cancer counsellor who had been trained by the Simontons. She is, without question, a major factor in my still being alive, and well, and functioning. The first session we had was an exhilarating experience. I had always been somewhat skeptical about counsellors, but in this instance I felt heard, understood, and appreciated. There was a lot to learn and to begin to accept. I think that each person who has cancer or any other life-threatening illness needs to find a sensitive, safe, and nonjudgmental listener — a counsellor of some sort who can guide the patient through the tough spots. The counsellor must be sensitive and perceptive, able to suggest available choices as well as to clarify concerns and anxieties. As a patient with cancer, I inevitably began to experience changes in my life style, appearance, sexuality, ego satisfactions, and energy levels, and the ways in which my patients related to and identified me. I needed help and was fortunate that my counsellor had the necessary knowledge and skills and was a person with whom I could relate without concern about being judged or rejected. I continue to see her at intervals of two to three weeks and find her ability to listen and interpret very supportive as changes occur in my situation. I find it strengthening to know that a listener and counsellor who knows me well is available when I feel the need to communicate with someone other than my family.

It became poignantly clear to me, as I began to receive counselling, that this was a time of real choice. I could sit back and let my disease and my treatment take their course, or I could pause and look at my life and ask, What are my priorities? How do I want to spend the time that is left? What can I do to participate more in my survival with cancer? I had to be willing to make decisions to alter my behaviour, to become a different sort of person. I had to learn to act in ways that had not seemed feasible or permissible before. There was no guarantee that attitudinal or behavioural changes on my part would alter the course of the cancer, but I became convinced that adding hope, love, and positive expectations and trying to shape a slower, more gentle life could do no harm and might be beneficial.

The first change that seemed important was to reduce the intensity of my professional life. Could I give up or at least slow down my surgical activities if it meant survival? I began taking a full day off each week. I was no longer available 24 hours a day, seven days a week. I began closing the office at four o'clock. In addition, I realized that there were certain specific surgical situations in which I tormented myself with stress and anxiety over the issue of playing God — that is, over having to make decisions that would

affect another person's life or death, or his or her way of life or livelihood. Those are decisions inherent in my profession, but there were certain operations and types of patient that I began to avoid in order to reduce the frequency of those very stressful decisions. I had to be willing to function professionally at a different level, to be satisfied with shorter days, fewer cases, and less income. Finally, more than two years after the discovery of recurrent and metastatic cancer, I was able to make the decision to stop doing major operations, and a few months later, to stop being a primary surgeon on any operation. I still greatly enjoy assisting, and I feel valued and useful helping my long-time friend and associate, who is also a highly capable vascular surgeon.

Initially, my peers were gently sympathetic and supportive. Later, as I survived, supporters expressed admiration for my struggle. Finally, now, there is a general acceptance that I will be around for awhile and that life goes on as usual. I am just completing the second half of a two-year term as elected chief of the medical staff of our 600-bed hospital. My election to the post was a gratifying measure of the confidence my colleagues had that my survival would continue — a confidence that has grown as the months have passed and the various hurdles have been overcome.

One of the really ironic things about the human experience is that many of us have to face pain or injury or even the possibility of death in order to learn the real purpose of being and how best to live a rewarding life. My priorities, pleasures, and expectations began to change. I came to realize that I could have whatever aspirations I chose to have, in spite of the diagnosis of cancer. I believe that each of us can affect our own life and health, perhaps even our death, through our attitudes toward life and toward that treatment we are undergoing.

This whole experience of disease and survival has certainly strengthened my belief in and dependence on an almighty power beyond my own. I have for years been agnostic in my approach to religion. However, the role that I believe faith, hope, and communication with some universal power have in my survival and the strength I have received from the faith and prayers of those who support me have convinced me that there is an Almighty Power, ill-defined in my mind but indubitably aiding me in my struggle.

I have faced the imminence of death and have been permitted to let death pass by. I have ceased to feel that death is a dreadful something that I need to fear. Instead, it will ultimately appear as a peaceful act of letting go when the time comes and I am ready. We are all dying; the difference between persons is only in the length and quality of the time that is left. Death ceases to be the failure; the failure is in not being willing to make the effort to grow and change.

The patients who survive with cancer or with another catastrophic illness, perhaps even in the face of almost insurmountable odds, seem to be those who have developed a very strong will to live and who value each day, one at a time. It seems helpful to me to approach each day as though it is the only day left, and to think clearly about what I want to do and say, with whom I want to be, and how I want to spend time.

I began to focus on choosing to do things every day that promote laughter, joy, and satisfaction. I decide on things like spending time alone in my garden, watching a basketball game, reading an interesting book or article, taking a slow and gentle walk at dusk with my partner, enjoying the earth and its beauty. I began to make choices to do the things that felt good to me — to allow myself the privilege of cherishing

thoughts about when to plant the peas, how much manure to use, and whether there are as many primrose blossoms as I expected. I enjoy the changes season by season in the flowers, the trees, the grass, the water, and the sky. I appreciate each of these wonders. When I take the time really to look and think about them, to let them have value for me, I am not being concerned about my impending death. I enjoy all the wonderful relationships I have. I am happier than I have ever been. These are truly among the best days of my life.

As my lightened schedule made time available, I began doing consulting work for the hospital, applying my years of surgical experience in assessing and improving the method of operation and efficiency of our surgical space. I have found great satisfaction in serving as a kind of surgical ombudsman — a valued liaison person between the medical staff, the nursing staff, and the administration. I have spoken of my experiences with cancer to many groups and have found that the insights into living with cancer that I have gained have become helpful to other people with cancer and to health-care workers responsible for such patients. I am playing a major part in the development of a new hospital and home-care service designed to provide a hospice service to a greater variety of patients with cancer and other chronic debilitating conditions. I have been able to derive great satisfaction from these alternative activities, both professional and personal, which make me feel that I am contributing and worthwhile.

I have come to realize that there is a controlling self within me that is rigid, demanding, and judgmental. Life flows far better for me and for those around me when I am able to replace that person with a more caring, gentle me. When I can forgive and forget, when I can say and feel that whatever has happened is acceptable, when I can take people in my arms and embrace them and be embraced and discover that we are each special, unique, and wondrous, then life becomes a great river that will flow no matter what I do. I can flow with it and live in peace or I can slip back into old patterns and live in despair, fighting against the current. The river does not care. It only makes a difference to me and to those around me. The choice is mine. The struggle to be a different person, to respond differently to life and to the people I know, is not a change I made once and now worry about no more. It is an ongoing struggle to be more soft and flexible, to give myself permission to enjoy who I am and what I do, to allow myself to laugh, tease, and relax in undemanding ways that really feel good. When I am successful in allowing those things to happen, my life is better for me and far better for the people around me.

Besides efforts to change who I am and how I react, another aspect of my treatment and survival program has been the regular practice of relaxation and mental imagery. My counsellor has been instrumental in teaching me to achieve deep relaxation easily, and her coaching in imagery has helped me to acquire the valuable ability to visualize progress in my battle against cancer. I try to achieve a state of deep relaxation at least once a day. During those periods of calm and detachment I construct mental pictures of what I want to happen in my battle against the cancer and in my response to treatment. I visualize an enhancement of my immune defenses against the cancer cells. I try to see momentarily a full restoration of health and the absence of tumor. The desired images do not always come readily and sometimes not at all, but those periods of withdrawal are always restorative even

when I do not achieve the desired images.

I have continued to have great confidence in my surgeon, my oncologist, and the radiotherapist who has managed my radiation therapy. All the people involved in my care have been sensitively responsive to my needs and wishes. Physicians and other health-care people often fail to recognize the importance of including the patient in decisions about the treatment plan. I was consulted about radiation scheduling so that it would fit in with my vacation plans, and I have felt fully heard and understood as I have participated in decisions about postponing chemotherapy or changing from one agent or dosage to another. I know that my position in the medical community has meant that I get special consideration, yet I also know from my own experience that it is exceedingly important to every patient to be listened to, appreciated, and understood.

In September 1983, I sensed a need and a desire to have a CT scan of my brain. The study revealed five small metastatic lesions scattered throughout my cortex. I cannot fully explain the feeling I had of needing to have the study, for I was asymptomatic except for a decrease in energy and occasional lightheadedness, but I did feel the need and responded to my inner feelings as I often do. I underwent the necessary radiotherapy (2700 cGy in nine days) without question or undue concern. I knew we would successfully eradicate the little brain lesions, just as the same time we successfully used 1800 cGy to shrink a bony lesion in one arm that had become painful. The immediate effects of radiotherapy were not pleasant. My life had to slow down for a few weeks, but then my energy returned, life resumed its pace, and soon the unpleasantness became only a vague memory.

I have received tremendous positive energy and support from a variety of people who have expressed concern and caring. I have felt warmed and strengthened as the people around me have reached out and let me know that they are grateful for my presence. Somehow, being valued by others enhances my worth. My sense of control is heightened. The people who have said that I am important to them have nourished the me that I would like to be and am intent on becoming. I have learned to love and to allow myself to be loved by many people in my life and to allow closeness, caring, and touching from many, many people. It has been said that love cures people, both those who give it and those who receive it. Certainly, both giving and receiving love are wonderfully rewarding. I have also heard it said that we need four hugs a day to survive, eight to thrive, and twelve to grow, and I make a great effort to get my full quota.

Where does all this lead me? I have said that I began to make choices that I thought were not mine to make before, to feel decisive, selective, and real about the person I began choosing to be. I am weighing priorities and making value judgments, and each day I feel more in charge. I am determining how I behave, and I am discovering that more and more I like the person I am choosing and striving to be.

Yet, inevitably, there are aspects of my life that are decreed not by choice but by the changes wrought by illness and the occasional ravages of treatment. They bring grief and loss. I do not wish to imply that all of this has been fun and games, that I just smile and go on, because I don't.

I get tired of taking pills, of bloody noses, mouth ulcers, and lack of energy. There are many days when I yearn to be out jogging, hiking the hills, or playing squash. During crisp winter hours I would love to be gliding again on cross-country skis. The restrictions

imposed by postsurgical and postirradiation bronchospasm induced by exercise and cold are hard to take for someone who has always been active and athletic. Yet the slower pace of meandering walks in the city or the countryside or of hours spent sitting by a stream looking and listening offer their own fulfillment and sense of nourishment, which I now cherish and enjoy, perhaps even more.

I get tired of being frightened by each new symptom, of feeling sorry for myself, and of fearing that my system for handling my disease is not proving effective. I sometimes feel like simply giving up and saying, "I have done enough. Why should I have to keep working so hard? Why does it have to be me? Why can't I be completely well again?" Yet, I have an amazing capacity to put aside and forget those times of distress. In reality, those negative feelings do not predominate and are not present very often or for very long. Mostly I am grateful for all the choices I have made that allow me to rejoice in being alive. Each moment is an unrepeatable miracle.

It is unrealistic for me to forget that I am surviving with a disease with which, statistically, there is no chance of survival. There is, inevitably, a conflict in my thinking between my prevailing sense that I am surviving well and a sense of disquietude when I allow myself to dwell on the fact that I have recurrent lung cancer with widespread metastases. Currently, there is no demonstrable tumor activity in either primary or metastatic sites. I have acquired a moderate anti diuretic hormone deficiency for which I take daily vasopressin (Pitressin) injections. I take methotrexate orally every five days in the belief that it helps maintain control over tumor activity. I use theophylline to alleviate bronchospasm induced by exercise and cold. With the help of these medications I am essentially asymptomatic, although my energy reserves are easily depleted and I need to rest frequently. I am up and functioning each day, and most days I work six to eight hours.

The anticipation of death has made it essential for me to give thought to emotional and practical preparations for my children, my mother, my helpmate and partner, and other important people in my life. I have a sense of great satisfaction in having arranged for such practical matters as wills, death benefits, trust funds, and a retirement plan. For the most part this activity has been associated not with a sense of impending doom or imminent death but with a sense that making these arrangements now frees me from future concern. Occasionally, however, such preparations provoke the traitorous thought that if I truly believed I could control the cancer, I would not need to be thinking about such things. But that isn't so, of course; it would be inappropriate not to be concerned about long-range expectations and not to make the necessary preparations.

I have been permitted to share wondrous moments with friends and loved ones, in and out of my family. I have been privileged, in my relationship with my partner, to know another human being who has nurtured and supported me. We have shared sadness, and we have shared great joy. We have been as gleeful and carefree as two children and as sedate and serious as a pair of monks. She has aided my survival far more than she knows, by providing love, strength and support in every way possible.

There have certainly been times when I have felt greater uncertainty about my long-term survival than I have at other times. In each of the last three autumns, I have wondered whether to plant the tulip and daffodil bulbs for the spring bloom or not to bother. Now, again

this past spring, a glory of living colour rewarded me, and once again I have planted for next spring's blooming. Sometimes plans for a vacation six months away have seemed almost ludicrous. Yet, not long ago I returned with my partner from a wonderful three weeks in another of the far-away places of which I had only dreamed before. I need to live in the present each day, yet plan for the future and try to balance the needs of today with the uncertainties of tomorrow. I choose to work, play, laugh, and cry, and I know without question that this is a good time in my life. I know inevitably that there will be milestones of change in the future,

but they need not negate the value of what each day holds.

I am very grateful just to be alive. I am very glad to have been permitted to learn to live with, rather than simply die from, my cancer. Mostly, I am glad to measure my life now not in terms of what it once was or what I might have wished it to be but in terms of how wonderful it is now. I am glad to recognize each day as a splendid, unforgettable miracle, a wonderful gift for me to savor and enjoy as fully as I can, and when my days are no longer nourishing and good, I hope that I can simply let go and allow myself to rest in peace.