As cancer caregivers, our focus is often on the biological aspects of the disease and the technology used for treatment. Amidst the sound and fury of the battle against cancer, there is a tendency to overlook the devastating psychological and spiritual consequences of the disease. This issue of Hot Spot attempts to redress this balance by focusing on spiritual care of the cancer patient. For many people, the word “spiritual” is equated with “religious”, but, as Dr. Sharon Grant shows in her lead article, spirituality is a universal phenomenon shared by all human beings, regardless of religious faith.

In other articles, Dr. Mary Vachon describes her own process of spiritual transformation through illness, and Dr. Scott Berry shares his thoughts on the ethical dilemmas surrounding care of patients with different faith backgrounds. Dr. Rebecca Wong’s research corner focuses on projects related to patients’ understanding of their illness, and the insert gives information about assessing patients’ spiritual needs and advice on how to care for yourself. As the signs of spring finally emerge, we hope you enjoy this issue of Hot Spot.

Addressing spiritual needs

By Dr. Sharon Grant

I have been working with cancer patients for almost nine years – many of them facing their deaths. I have not met one who was not spiritual. Spirituality is part of being human.

A contemporary author, Thomas Moore, speaks about spirituality for today in his book Care of the Soul. He takes a close look at our culture and notes that there are a number of emotional complaints that characterize our society. Among these are emptiness, meaninglessness, vague depression, disillusionment about marriage, family and relationships, a loss of values, yearning for personal fulfillment, and a hunger for spirituality.

Those of us who work with cancer patients have a daunting challenge. When we meet the patients who come to us, we meet people who have both the threat of an illness to their bodies, and the fear that cancer represents to the very integrity of their lives. And so, their physical complaints are but one aspect of their concerns. Other concerns, spoken or unspoken, are related to their psychological, social, and spiritual well-being.

Some may say that the “spiritual” applies to a small number of the patients they see. “Most of my patients are not religious”, they may say. It is important to note the difference between “religious” and “spiritual”.

By religious, we mean being part of a distinct faith tradition with certain rituals, practices, and values. Involved in this is participation in a community with commonly held beliefs.

By spiritual, we mean acknowledging:
• That life is more than the material needs of the body

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Dr. Sharon Grant
When the shrink gets cancer and gets spiritually transformed

By Mary L.S. Vachon, RN, PhD

In September 1996 at the terminal care meeting in Montreal I began to get ‘messages’ that my life was going to be changing. I needed to go back to church, to spend more time at Wellspring, doing meditation and yoga. I needed new topics for my research and my presentations. At the same time, I became peripherally aware of mild abdominal pain, one to two on a 10-point scale. I came back to Toronto telling people that I had a spiritual experience, and felt the afterglow for a couple of weeks.

The mild pain continued. Through my family physician, I organized an ultrasound. The results revealed six enlarged lymph nodes in my abdomen. A few more tests and biopsies, and I had a diagnosis of stage four intermediate grade lymphoma. I realized this could be serious and there was significant risk of my dying of the disease. I was scheduled to give a series of lectures in Hong Kong and Shanghai and would be traveling with my family. I decided if the trip wasn’t going to seriously jeopardize my health, we might as well have a final family trip. I had chemotherapy on Monday and headed to Hong Kong on Thursday.

I was surprised by how smoothly things went on the trip, and on my return felt a calmness that seemed quite unlike my normal personality. I carried out my normal activities. As “advised”, I returned to church and registered for meditation, yoga and qi gong at Wellspring. Gradually I became aware that I was being walked through the experience by what I came to describe as my “angels from the other side”. The next month, I had a healing touch treatment. I visualized myself at a beach in Maui. I walked away thinking that this was the second time that Hawaii had come up in the last few days and I should think about going to Hawaii next winter. Within six days I had an invitation to lecture in Hawaii. I was on that beach on the first anniversary of my remission.

Many other things that I thought about came to me. I didn’t understand what was happening, but knew that I needed to consult someone about this. I thought of a former colleague, Dr. John Thornton. A couple of weeks later, we were at a meeting together. He had developed a new form of therapy, ASIST (Self-directed Inner Seeking Therapy), involving accessing the non-conscious mind to answer questions for which one does not have a conscious answer. I found the process helpful and began to refer clients. One of them found a book on prayer and discovered that she could get the same answers praying in this way that she could through doing ASIST. This led to Dr. Thornton developing the Prayer Wheel (Rossiter-Thornton, Alternative Therapies 6:1:128: 2000), a non-denominational approach to praying in which one can receive direction for one’s life.

For me, cancer has been a spiritually transformative experience (STE). Dr. Yvonne Kason describes STEs as punctuations on life’s spiritual journey that challenge “a person’s entire world view and as a result, their ideas, values, priorities, and beliefs change. They think, feel, and see the world differently... perception of reality – and their whole personality – has been transformed and propelled in a far more spiritual direction” (Farther Shores. HarperCollins:2000). In Remarkable Recoveries, spiritual transformations have been associated with unexpected remissions.

Spirituality has now become integral to my personal and professional life. ASIST and the Prayer Wheel have allowed me and my clients to develop insights, to make changes, to heal and come to an acceptance of illness and death unlike anything I have seen before.

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Historical Vignette:
The history of hospices

By Charles Hayter, MA, MD, FRCPC, Radiation Oncologist, T-SRCC

The word “hospice” has its origin in the Latin term hospitium, a place where a guest receives hospitality. The words “hospital,” “hotel,” and “hostel” all derive from the same Latin root, and suggest places of comfort, support, and care.

In the modern world, the term “hospice” refers to an institution or organization devoted to the care of the dying. Such institutions have their historical roots in hospices attached to medieval monasteries and cathedrals, where the sick and dying were cared for by members of religious orders. Almost a thousand years ago, Augustinian monks provided care for the needy at their famous St. Bernard’s Hospice in the Swiss Alps. Later, religious orders founded two well-known London hospitals, St. Bartholomew’s and St. Thomas’.

With the rise of scientific medicine in the late nineteenth century, hospice care slid into the background as doctors focused on curing disease. In the 1950s and ’60s, the shortcomings of modern high technology medicine in caring for the dying became apparent, and there was a new emphasis on palliative care. In 1967, Cicely Saunders founded St. Christopher’s Hospice in London which became a world renowned centre in service, training, and research in palliative care. The model of care at St. Christopher’s spread around the world and influenced such initiatives as Montreal’s Palliative Care Unit, which opened in 1975. Today, the ancient notion of hospice is again a familiar part of the medical landscape.
By Dr. Scott Berry

I have often been moved by the solace my patients have found in their religious beliefs as they have battled cancer. In Toronto’s multicultural community, I have cared for people from many faiths and have learned a lot about how people from varied backgrounds gain strength from their religious traditions as they die from cancer. Unfortunately, religious beliefs are sometimes a source of conflict, not solace, when caring for dying patients. Ethical issues in end-of-life care can be thorny at the best of times. Strongly-held moral positions based on religious beliefs can add to the ethical tensions of caring for dying patients. However, much of this tension is based on misunderstanding and misinformation. Efforts to learn more about how patients from different religious backgrounds face death and dying will go a long way in easing some of the moral conflicts we face in end-of-life care.

Consider an elderly orthodox Jewish man, who is very ill with end-stage metastatic colon cancer, whom you have admitted for bowel obstruction and hepatic failure. In discussing your treatment plans, the man and his family become uneasy with the fact that you are talking about palliative care rather than more aggressive measures like surgery to deal with his bowel obstruction.

Addressing spiritual needs

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• That life is a process of the continual unfolding of the self
• That life has value and meaning
• That one has a purpose and is part of a larger community (whether that is one’s family, one’s cultural group, or one’s nation)
• That one has responsibility to others – to contribute to the good of the whole
• And that, ultimately, one aspires to transcend one’s particular individual life and somehow be part of a universal good.

So what then is spiritual care? Spiritual care attempts to address the needs of the whole person. It’s being present to another. It’s really listening to the person; letting the person tell his/her story; reverencing the narrative of the person’s life. It is in the very stuff of one’s life that meaning emerges, that values are crystallized, that the sacred is glimpsed.

These needs revolve around three locus points – self, others, higher power.

• Self. Where is one in one’s particular life journey? What are the challenges, growth points, obstacles to becoming all that one can be?
• Space. What kind of psychological and emotional space is the person in? Is it positive (life-affirming) or negative (life denying)?
• Concerns. What is concerning the person most at this time? What problems does the person express?
• Knowledge. What knowledge and understanding does the person have of his/her illness, of the prognosis? What questions does the person have? How is this knowledge integrated in one’s life meaning?
• Others. Who are the significant people in the person’s life? Who can this person count on for physical, emotional, spiritual needs?
• Reconciliation and forgiveness. Are there broken or wounded relationships in which the person seeks healing?
• Higher Power/God. What is the person’s sense of a universal connection? Does the person have a faith that is helpful at this time? In what or whom does the person put his/her faith? What gives meaning and purpose to life?

The first step in avoiding a conflict in this situation may be a willingness to consider that religious beliefs may be a potential source of conflict. Sensitive asking people about their beliefs may be the first step to a better understanding. When you probe the source of the family’s uneasiness, you find that they are concerned that without the most aggressive care, the man’s life will be ended prematurely, which is not in keeping with their religious beliefs. The man and his family tell you they want to seek the advice of their rabbi to discuss his condition and the plan for his care. The rabbi may help the family sort through the complex issues involved and advise them: “Jewish law is relatively clear that life is not to be taken before its time. It is equally clear that one is not to hinder or impede the death process once it has begun…(and the) challenge is determining when the moment for continued life is lost and the process of death has begun.” Asking the family members about their beliefs, or having some knowledge of their beliefs and asking them if they need to speak to their rabbi could help prevent conflicts from occurring.

How can a busy practitioner know about the beliefs of people from the many religions? It’s impossible to know everything, of course, but the Canadian Medical Association Journal’s “Bioethics for Clinicians” series has recently been expanded to include articles on how the beliefs of major religious traditions impact on bioethical issues. These articles include an examination of how people from different religions approach death and dying, and the implications for the ethics of end-of-life care. These articles are available in full text at the CMAJ website (www.cma.ca/cmaj/series/bioethic.htm).

As the CMAJ series points out, there are some important caveats in dealing with people from different faiths. Individuals within any religious or cultural community may have standards that differ from traditional norms, and one has to be careful not to make presumptions about someone’s wishes based solely on their background. We also must understand that knowledge and understanding of our patients’ beliefs is only part of the equation. Those of us who care for dying patients must also be aware of the impact our own religious beliefs have on the care we provide and the conflicts we face.

Self-awareness may also help prevent conflicts in end-of-life care.

Quality end-of-life care is an ethical imperative. Learning more about people’s religious beliefs will not only help us avert potential conflicts in end-of-life care, but help us improve that care by allowing us to better understand and respect people’s decisions.

• Future. What does the future look like for the person? For what does the person hope?

When we look at some aspects of what is involved in spiritual care, we can see that it does not have to be a minister or a chaplain who begins the process of addressing spiritual needs. Anyone who is spiritually sensitive and attuned to his/her own, and others’, spiritual values, can begin the process of listening to the story of another’s sacred journey.

Spirituality is all about transformation – becoming all that we are capable of being. As our lives unfold, we are privileged to share with one another in love, kindness, and compassion. Teilhard de Chardin expressed the transformation in these words: “The day will come when… we shall harness for God the energies of love. And on that day, for the second time in the history of the world, [humanity] will have discovered fire.”

Dr. Sharon Grant (Doctor of Ministry) is a chaplain in oncology and a psycho-social/spiritual consultant on the palliative care initiative.
Patients with advanced cancer encounter many psychological and physical changes during the course of their illness, and have a need to understand what is happening to them. Especially when it is a new experience, a consultation at the cancer clinic can further compound their anxiety and ability to make sense of the whole experience.

Two years ago Lou Andersson, our nurse specialist, asked the question “What are our patients’ expectations from their consultation with the RRRP?” This prompted her to take the lead and develop a patient survey. The long-term vision was to use the results of this survey to guide strategies that could allow our team to better fulfill the expectations of our patients. New patients attending our program were invited to complete a seven-item questionnaire. Sixty patients participated in the survey, which provided findings that gave us pause to think. Despite the fact that one of the criteria for referral to our program is a physician-estimated life expectancy of six months, 35% of patients believed their cancer was curable, 20% of patients expected the radiotherapy to achieve this, and close to 40% of patients expected the radiotherapy to prolong their lives!

The fact that only 30% of patients recall receiving any information about radiotherapy from their doctors may have been one of the many contributing factors. The results of this project were consistent with research done elsewhere that showed patients often do not have a clear conception of their illness.

Joan Pope, our other nurse specialist, has built on these findings and has been working hard to develop a randomized clinical trial to evaluate the impact of adding an information counselling session to our standard clinical consultation. It is hypothesized that by providing this special effort to respond to our patients’ concerns, we could improve patient satisfaction, reduce anxiety, and improve their ability to cope with their illness. The information counselling in this study will take the form of a 10- to 20-minute counselling session, typically taking place shortly after their standard clinical consultation. Counselling will be provided on a one-on-one basis by a nurse specialist. Patients will be invited to identify one to three areas of greatest concern. In addition to the personalized counselling, patients will also receive short written material, pertinent to those areas that were discussed. Specific tools will be used to measure changes between the two study groups in the areas of satisfaction, anxiety, and coping with cancer. One hundred patients will be invited to participate in this study.

Local radiotherapy can be a very effective tool to reduce symptoms from advanced cancer. Being able to deliver this in a quick, efficient way is the clinical mandate of our program. Being able to make the consultation process helpful and sensitive to our patients is the personal mandate of each member of our team. Through these projects, our research program attempts to identify and resolve areas where there are deficits in patient comprehension and understanding.
Ten steps for self-care

1. Embody healing.
“Practise what you preach” to your patients and families about caring for the self. Practise being a living example of bio-psycho-social-spiritual health and wellness.

2. Adopt principles of balance in your life.
We spend so much time thinking in health care (i.e. communicating, decision-making, planning, deciphering, solving). Integrate equal attention to your body, and to your soul, so there can be a balance. At day’s end, it will feel different, you will feel different.

3. Use time differently.
Each one of us is usually doing three things in the same moment of time. How can we be attentive and mindful of what we are doing if we layer ourselves in this way? Each of us has limits in our ability “to do”. We are not machines, yet we often push ourselves like machines, until we break down. Pacing ourselves with realistic expectations about time and productivity makes for a balanced healing practice.

Each person, each discipline and each age of our life has its own energy and spirit. The process of care and the outcomes of healing will be all the more evident if we practise honing these differences in each other and ourselves.

5. Realistically recognize environmental and vocational stressors.
Compassion fatigue is a very real occupational phenomenon within the caregiver community. Charles Figley coined this term after studying the impact of death and dying on those who are exposed to it. When we feel tired and worn, perhaps it is not solely because we need a vacation, but rather because we are involved in more complex care and are at greater risk than those who provided health care 25 years ago.

6. Implement the basic building blocks of longevity and health.
Remember the lessons of Robert Fulghum in his book All I Really Need to Know I Learned in Kindergarten. Adapting this concept: remember to eat well, take naps and sleep deeply, exercise and play nicely in the sand box with others!

7. Reflect on life, its meaning and purpose.
We can learn from research that shows that suicide is the number one cause of death in adolescents, but is infrequent in a sub-group that has strong religious and spiritual views integrated into their culture. It is difficult to imagine caring for the ill and dying without a strong belief system. Whether that belief is science, nature, god or loving kindness, research supports that belief and a personal value system can help sustain and fortify us in times of challenge and despair.

8. Tend to relationships in your professional and personal life.
Philosopher Jean Paul Sartre said, “Hell is other people”. Each of us has been to hell. It is a part of adult life. Yet each of us has found our way out of hell by resolving, avoiding, or developing relationships with others. “Heaven can be other people” as well. Many of us are good at what we do, but our care is strengthened when we do it together, practising as a community of caregivers, each with one’s own expertise. Revive the support, collegiality and strength that can come from substantial relationships in both our personal and professional life.

9. Practise being with yourself and others more authentically.
There is an African saying that claims that “God made the world round so that whatever we walk away from, we must always come back to”. You cannot walk away from yourself or your potential for being wounded by someone or something. As healers we are human, as humans we are vulnerable, yet we pretend to be invincible. We are not. We cannot walk away from our own needs for too long before we find ourselves coming face to face with what we thought we had left behind. Walk with yourself every minute of the day and feel how much better it feels than getting ahead of yourself or leaving yourself behind.

10. Embrace the lessons of failure.
When you fail at steps one through nine, forgive yourself, and try again. Poet T. S. Eliot said, “For us there is only the trying, the rest is not our business”. Don’t waste your time ruminating on failure. Focus on what you have achieved, and you will more realistically feel and acknowledge your accomplishments.

The End

...which is only the beginning...
### STEP ONE: CREATING THE ENVIRONMENT FOR SPIRITUAL ASSESSMENT

- **Be present** - make yourself available to the person
- **Acknowledge** - your human-ness in relationship to the person
- **Listen** - to the feelings behind the words

### STEP TWO: SIX KEY QUESTIONS FOR SPIRITUAL ASSESSMENT

- **Others**: Whom do you have in your life to be with you at this time?
- **Space**: What is it like for you now in your living situation?
- **Concerns**: What is concerning you most at this time?
- **Faith**: Do you have a faith that is helpful to you at this time?
- **Knowledge**: What is your present understanding of your illness?
- **Future**: What does the future look like for you?

These questions are not exhaustive or all-inclusive, but may enable you to uncover life questions with which the person is living and a need for referral to spiritual resources such as pastoral care. For information on pastoral care resources, a clergy person (minister, rabbi, etc.), hospital chaplaincy program, religious governing body or spirituality centre may be of help.

*Adapted by Charles Hayter and Sharon Grant from Sunnybrook and Women’s College Health Sciences Centre Pastoral Assessment*

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