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GUEST EDITORIAL

## The courage to survive: Facing the loss of your soul-mate

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In this issue of *Palliative & Supportive Care* an essay, by Robert Mancuso, entitled “Holding On . . . and . . . Letting Go” describes the bereavement experience of a man who lost his wife to cancer. This experience led him to write a book entitled *The Courage of Hope* to help other male spouses who struggle with the terminal illness of a wife, and to make a film (described in this Editorial) entitled “The Courage to Survive, Facing the Loss of Your Soul-mate” to educate clinicians. The following Guest Editorial is by Dr. Norman Straker, who worked with Mr. Mancuso to “make something good out of something bad”. A link to the website to view the video is provided in the opening paragraph.

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Despite the improvement in the treatment of cancer, 560,000 people still die of cancer each year in the United States. The spouses and children of those who die from cancer constitute a highly vulnerable population for the development of mental illness and substance abuse. The recognition of the early signs of emotional strain, and the proper treatment intervention for anxiety disorders, depression, and complicated grief reactions of this population is the focus of a new film <http://www.journals.cambridge.org/pax2011001>

“The Courage to Survive, Facing the Loss of Your Soul Mate” tells the story of an investment banker who faced the terminal illness of his wife. It also describes the details of a dynamic psychotherapy he engaged in that allowed him to manage the crisis, parent his three children, and eventually create a new life. The film begins with Robert addressing a group of oncologists at Memorial Sloan-Kettering Cancer Center in New York City about the emotional needs and challenges facing the male spouse of a terminally ill cancer patient. He speaks poignantly about the importance of the oncologist’s need to support the spouse of a terminally ill patient and to

consider him or her for an early psychiatric referral if the spouse shows signs of mental strain.

The film then focuses on a review of Robert’s psychotherapeutic work with his former therapist Dr. Norman Straker, a consultant at Sloan-Kettering and Clinical Professor of Psychiatry at Cornell Weill School of Medicine. Physicians who see this film will have an opportunity to learn the benefits of a psychiatric treatment and that might decrease the stigma of a psychiatric referral for this population. Spouses of terminally ill patients could also view a psychotherapeutic process with an ordinary man with the hope that the film would demystify the process. The video could also be shown to mental health professionals.

Finally, the “The Courage to Survive” illustrates the fact that individuals facing tragedy often find creative solutions that permit them to transcend their loss and find a greater purpose and meaning in their life. During the final year of his psychotherapy, Robert wrote a book entitled “The Courage Of Hope,” a guide to other men who were facing the loss of their wives from cancer. He also collaborated in the development of this film so that “something good could come out of something bad.” Robert’s experiences, although unique to him, do articulate the most common problems of spouses who are the primary caretakers of their marital partners with cancer. Despite the fact that Robert is a person of financial means who could afford a private psychotherapy, similar therapy is available at an affordable cost through the departments of psychiatry at cancer centers or at private agencies such as Cancer Care or by calling American Psychosocial Oncology Society (APOS) where you can be directed to a psycho-oncologist. As mentioned earlier, the video begins with Robert’s lecture to the oncology fellows at Sloan-Kettering. He spoke of the emotional challenges that confronted him which included: (1) the loss of hope; (2) overwhelming anxiety; (3) unmanageable anger; (4) loss of faith; (5) changing roles of the spouse; (6) moving on.

## CHALLENGES

### Loss of Hope

The video illustrates the dangers of giving a very specific prognosis for life expectancy, in this case 3 months. In this case the prognosis was inaccurate and led to a *loss of hope* unnecessarily. Although it is important not to encourage false hope, stating that a patient has a definite number of months to live will be experienced as a death sentence. I suggest a more humble approach that notes that survival times reflect best guesses and are based on median survival times and are subject to individual differences, and new treatments.

### Overwhelming Anxiety

Severe anxiety brought Robert for a psychiatric consultation. He arrived at the psychiatrist's office in a state of emotional paralysis. He could no longer effectively do his job or take care of his wife and children. The rapid onset of the effects of psychiatric medication, helping the patient to function quickly, is very important in the early phases of treatment. A selective serotonin reuptake inhibitor (SSRI) and a benzodiazepine allowed for meaningful psychotherapeutic work and problem solving.

### Anger

Overwhelming anger is often the result of the injustice of the ravages of a cancer. This patient is still angry 5 years after his loss. The oncologist and the hospital are often the target of the families' anger as they have not provided the wished-for cure. Unfortunately, the oncologists often experience the anger as a personal attack or expect such an attack and withdraw when the patient can no longer be cured. This is neither good for the patient and family nor for the oncologist who can help to provide support and palliation to the patient. Communication skills need to be addressed in an oncology training program.

### Loss of Faith

Robert experienced such a loss. The movie shows how the therapist can help such patients reconnect with God and restore their faith. This can be accomplished by giving them permission and encouragement to express their anger directly at God after a perceived injustice.

### Changing Roles

A man with children, whose wife is dying, will become both mother and father as well as assuming a caregiver role. This will involve a considerable strain, especially for men. Women are more familiar with

this role and experience less role strain and usually have a much larger support system. They are also much more comfortable reaching out for help and have much less a stigma associated with contacting a mental health professional. Clearly they miss the support and the partnership of their husband. Conflict between teenage girls who are trying to separate from their controlling and conservative father are going to be problematic, as in this film.

### Moving On

The final challenge for the parent who loses their spouse to cancer is the ability to eventually move on and form a new family. The need to mourn is a necessary part of overcoming the grief. This is true for children as well as spouses. Children of all ages should not be left out of the mourning process. Religious ritual is generally helpful in initiating the mourning process, and was regrettably missing initially in this case.

Harriet, the mother of the children in the video, elected to write letters to her children, which were to be distributed after she died. This was a decision she reached as a part of her adjustment to her own death and helped her to feel that in some small way she was continuing to parent. This may appeal to some parents and might be explored. Some parents of very small children have made videos of themselves with messages for their children. This is a comfort to the parent who might want their young child to have a visual memory of them long after they died.

It is apparent in the video that grieving can return long after the loss. Robert experienced a grief response on two occasions in the video despite the passing of 5 years. He and I briefly discussed beginning to date and how children can be affected. Although Robert was consciously concerned about proper behavior and respect for his deceased wife, he was less consciously aware of his "survivor guilt," which did not allow him to consider remarriage.

Finally, it should be noted that for some spouses an important part of moving on may be to in some way memorialize one's lost spouse. Robert did it by writing a book entitled, *The Courage of Hope*.

## OTHER THEMES IN THE MOVIE

### The Role of the Oncologist

The video reminds oncologists of the very powerful position they have just by virtue of the "power of the white coat". This power can be used to do a great deal of good by:

1. Recognizing the valuable role of the spouse in the treatment of their patient.

2. Reassuring them that it is normal to be stressed and recommending that they consider counseling.
3. Supporting and encouraging them with an arm on the shoulder and other physical signs of caring
4. Exercising some caution with regard to prognostication, as a prognosis of a specific life expectancy can be experienced as a death sentence and can lead to a loss of hope.
5. Staying in touch after the chemotherapy has been discontinued.

### **The Role of the Psychiatrist or Other Mental Health Provider**

The psychiatrist or mental health professional who works with the spouse of cancer patients is in a unique position to:

1. help interpret medical information;
2. understand and support the spouse in the desire to be a good support to their ill spouse.

3. help the spouse work through the challenges as outlined by Mr. M including :
  - A. the loss of hope
  - B. the management of anxiety, anger
  - C. the loss of faith
  - D. assisting in the changing of roles
  - E. moving on, which includes accepting the death of their spouse, facilitating mourning, providing guidance to children, resolving survivor guilt, and helping the survivor to rejoin the world and seek out new companionship

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