



# CAP Lung Cancer Medical Writers' Circle

## *Twice Betrayed: Living with Lung Cancer and Dealing with Stigma*

Susan Hedlund, MSW, LCSW

For many people dealing with a diagnosis of cancer, a myriad of complex emotions may occur. Initially, shock, fear, and disbelief may be the overwhelming emotional responses to a new diagnosis. These are often replaced by feelings of grief and sadness, as one attempts to deal with the challenges of treatment and the impact on one's life style. Fortunately, many people are, in time, able to navigate the challenges of cancer and treatment, and find a new balance in their lives.

Some cancer diagnoses, however, are more difficult to deal with than others. Depending on the type of cancer and the stage of disease, there may be fewer treatment options available, and for some, the likelihood of long-term survival may be more remote.

For people diagnosed with lung cancer, numerous challenges exist. Depending on the stage of the cancer at diagnosis, treatment options may offer the hope for long-term recovery. However, the overall survival rate for all lung cancers remains at 15% for 5 year survival. This is significantly lower than other cancers. For example, there is close to a 100% - 5 year survival rate for men diagnosed with prostate cancer; an 89%- 5 year survival rate for women diagnosed with breast cancer; and a 65% - 5 year survival rate for people diagnosed with colon cancer. Three times as many men will die of lung cancer than of prostate cancer, and twice as many women will die of lung cancer than of other cancers. Lung cancer is the leading cause of death of all cancers in all ethnic groups. Lung cancer accounts for 1 in 3 cancer related deaths, and approximately 152,000 people are expected to die of lung cancer in the U.S. in 2009.

As if this news is not difficult enough, many people diagnosed with lung cancer face an additional burden of feeling "blamed" for their disease. Whether one has a history of having smoked or not, most studies report that people with lung cancer feel stigmatized for having the disease. While 87% of lung cancers may be related to a smoking history, other lung cancers are caused by environmental causes, genetics, or age. Also, reviewing the cultural aspects of the United States in the last 60 years, we know that the risks of smoking were not previously fully understood, and that both the media and tobacco companies promoted the "glamour" of smoking. The post World War II era saw smoking as a part of one's affluent lifestyle. We also now have a better understanding of addictions. Tobacco addiction is a very difficult addiction to overcome. Sheer will-power alone may not be enough to overcome tobacco addiction.

Still, whether one has smoked or not, no one deserves or asks to get lung cancer. The impact of stigma has far reaching effects. British researchers interviewed 45 lung cancer patients between the ages of 40 and 90. Most of the patients felt that others were holding them responsible for getting sick because of the link between smoking and lung cancer. But even lung cancer patients who never smoked, or who quit decades before, felt this stigma, University of Oxford researchers reported. The negative feelings caused some patients to conceal their illness, which hampered their ability to get support from others. Others in the study worried about being denied care because of the perception that they caused their own illness.



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Many people with cancer feel isolated and some feel shame, however these feelings are stronger among people with lung cancer. “It is a special stigma. The whole thing has been tainted by the smoking thing”, says Jimmie Holland, MD, professor and vice chair of psychiatry at Memorial-Sloan Kettering Cancer Center in New York.

Other effects from this stigma have to do with support and research. Treatment and support services lag behind those of many other cancers. In 2007 the National Institutes of Health provided \$572.4 million for breast cancer research, but only \$226.9 million for research on lung cancer, although lung cancer remains the number one killer in the United States. Despite lung cancer causing one in three cancer deaths, lung cancer received less than 5% of the National Cancer Institute budget in 2007. Lung cancer received no funding from the Department of Defense or Centers for Disease Control, both of which funded breast cancer research at \$2.07 billion and \$201 million respectively in 2007. The reason that so much more is known about breast cancer and why treatment has been so effective is largely because of the money put into it and the enormous advocacy efforts behind breast cancer awareness and research.

Gregory Otterson, MD, medical director of Thoracic Oncology at Ohio State University Comprehensive Cancer Center-Arthur G. James Cancer Hospital states: “With lung cancer, the stigma persists, and there is the perception that you ‘brought this on yourself’. That same argument was made about HIV, and it’s now obvious that it is inappropriate. Look what happened with AIDs”.

Susan Sontag, author, in her books *Illness as Metaphor* (1977) and *Illness as Metaphor and AIDs and Its Metaphors* (2001) writes about the assumptions and fantasies attached to diseases that we have yet to understand. She references diseases such as cancer, AIDs, and in earlier times, tuberculosis and epilepsy, and describes how people often responded with fear about things we had yet to fully understand. She contends that illness is *not* a metaphor, and that the most truthful way of regarding illness – and the healthiest way of being ill- is to resist such metaphoric thinking. “ Nothing is more punitive than to give a disease a meaning- being invariably a moralistic one. Any disease whose causality is murky, and for which treatment is ineffectual, tends to be awash in significance.” (Sontag, 2001)

It is important to remember that the stigma associated with all cancers has lessened considerably in the past 40 years, as we have come to understand and more effectively treat, many cancers. We now talk about cancer openly, versus keeping a “conspiracy of silence”. In most cases, we no longer isolate the people who have the disease. While lung cancer unfortunately continues to carry some stigma, that too, is changing, as the medical and lay public have more information, greater awareness, and more exposure to the disease. Advocacy efforts and support services are growing. The visibility of people with lung cancer who are willing to publicly discuss it and advocate on behalf of more research, also helps.

Ask for help from your medical providers. An oncology social worker in your hospital or clinic can tell you about local support groups and educational resources. If you are someone who is currently smoking, and you would like to try to quit, ask about smoking cessation resources in your area. Remember that you are not alone.

If you are a family member or friend of someone with lung cancer, try to remember that lung cancer, like any cancer, is a challenging disease with many psychological and social challenges. Your loved one needs your understanding and support. Ask how you can best help them during this challenging time. Sometimes the more practical things can be most helpful. Can you bring a meal, or transport your



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friend to doctor's appointment? Do the children need extra help? Many things, great and small, can help the person with cancer.

In conclusion, lung cancer continues to be a serious, life-threatening illness. Additionally, there continues to be stigma about the disease, and toward the people who have it.

It will be important to continue advocacy efforts and awareness about the disease, the needs of patients, and the need for further research. People dealing with lung cancer need and deserve support and understanding. Again, if you are a patient, please remember that you are not alone. There is help available.

## REFERENCES:

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Susan Hedlund, LCSW, has been a social worker in the health care field for twenty eight years and has extensive experience working with individuals and families facing life threatening illness and loss. She is currently the Director of Social Services for Hospice and Palliative Care of Washington County in Portland Oregon, and is on the faculty of the School of Medicine at Oregon Health & Sciences University, as well as the Graduate School of Social Work at Portland State University. She was previously the Director of Counseling at Cancer Care Resources, and the Clinical Manager of Social Work at OHSU.

She is a past president of the National Association of Oncology Social Work, and received their Leadership Award in 1999, and the national American Cancer Society Quality of Life Award in 2009. She received the Compassion Award from Breast Friends, a breast cancer advocacy group in 2009. She speaks nationally and internationally, and publishes on topics related to coping with illness, end of life issues, and loss. Additionally she served on the Oregon State Task Force to Improve the Care of Terminally Ill Oregonians, the Oregon Partnership for Cancer Control, is a Senior Scholar for the Center for Ethics at OHSU and co-founded the Well Arts Institute, a non-profit program for arts in health care settings. She is the past chair of the Health Specialty Practice Section for NASW nationally.