

**Interview with Leah de Roulet, MSW
Oncology Social Worker
By Howard (Jack) West, MD
February, 2009**

Dr. West: Hello and welcome to the first GRACEcast on the topic of social work. My name is Dr. Jack West and I'm a medical oncologist in Seattle. I also serve as President & CEO of GRACE, the Global Resource for Advancing Cancer Education. And I'm fortunate to be here today with Leah de Roulet, who is an extraordinary oncology social worker here at Swedish, semi-retired at this point after previously serving as the leader of our social work group. And she actually won the prestigious Lane Adams Quality of Life Award from the American Cancer Society for her role here.

A transcript as well as a pdf file with copies of figures associated with this program are available at www.cancergrace.org/GRACEcasts.

Let's just start with what an oncology social worker is particularly trained to manage as compared with other social workers. What topics, what knowledge base do you have compared with other social workers in the health care field?

Ms. de Roulet: Well, I have worked in oncology and hospice for over 25 years and so I've had a lot of on the job training and I think most oncology social workers actually do most of their learning in on the job training. But all of us in health care are trained in medical social work, so in that study base, we study people's reactions to disease, to chronic illness, to grief, to adaptation to treatment, basic treatments for various diseases and that sort of thing. And then social workers tend to gravitate toward the specialty they are most comfortable with. And I gravitated to cancer. I found it extremely, intellectually stimulating; I'm constantly learning every day. And it's very wonderful to be able to help people at a point of crisis in their life when they're diagnosed with cancer and feel like their whole world is turning, completely falling apart.

Dr. West: Yeah, I imagine the stakes are very high. How prevalent are oncology social workers? Are they professionals who you can expect to find at most oncology offices? Or are they really largely available at just the larger cancer centers?

Ms. de Roulet: I would say they're largely available only at the larger cancer centers because most of the smaller oncology offices really can't afford the overhead of having a social worker available to them. And we don't generally charge for our services and so consequently we're not revenue producers in anyway. And it takes a large cancer center to be able to support that overhead.

Dr. West: Unfortunately it's not rare for someone to be diagnosed with cancer and have poor or no insurance coverage. What are some of the options for them to explore for getting appropriate care?

Ms. de Roulet: Well, if a person has no insurance and they are somewhere around the poverty level for one or two people, they can apply for in Washington State, it's called the Department of Social and Health Services and get medical coupons that cover their health care. Otherwise, they have to go to another plan.

Sometimes people go on COBRA if they need to stop working; that's very expensive for most people. It can run as high as \$800 a month, and most people really can't afford that. If they don't have insurance to begin with, they're not going to be able to afford a COBRA plan. The other option would be to find out what other plans your state might have. In Washington State we have a program for high risk populations, populations which are most likely going to be denied by insurance companies because they already have a diagnosis of a disease that's clearly going to cost you a lot of money. And we also have a program called Basic Health which is on a sliding fee scale for people who don't meet the welfare criteria but can afford to pay something for their insurance. And these are Washington State programs, but most states also have similar programs like that because they recognize that it's going to be very difficult for people with no insurance to pay for any kind of cancer care.

Dr. West: Do you have any particular recommendations for oral therapies, which are sometimes poorly covered even by people who consider themselves pretty well insured?

Ms. de Roulet: Yes. I think if somebody is on Medicare and many of our older patients are, *uh*, they often have a very high co-pay on these oral medications. For instance, Tamoxifen, which is a breast cancer anti-estrogen drug that's used in post-menopausal women, costs approximately \$100 for the co-pay. And the very expensive other oral medications like, there's a form of a 5-FU which is a commonly used chemotherapy, can cost as much as \$300 for the co-pay. So I think the best thing for people to do would be to try to work with their oncology office to look at the patient assistance programs from the drug manufacturer who is manufacturing the drug that the doctor wants to prescribe. And most of these will not cover a person if they have insurance. Some will, but many of them won't.

And so then you sort of have to look at other patient assistance forms. And there are a number of large organizations in the United States, the Health Well Foundation, Cancer Care.... Most of them are situated in New York and they are nationally-based organizations, and they offer co-pay assistance or just money that can help somebody pay for a month or two months of a co-pay.

Dr. West: What are some of the emotions you typically discuss with a patient who's just been diagnosed with cancer? And perhaps you can discuss whether there's differences in how you approach a patient who is being treated potentially in a curative setting versus someone who has been diagnosed with an incurable cancer.

Ms. de Roulet: I think the most frequent diagnosis emotion that comes up after the diagnosis is simply shock. What they often say is I've never been sick a day in my life, except for a cold once in a while. How did this happen to me? So they're questioning how this happened. They don't know what caused it and even if they're potentially curable. So people feel very vulnerable. They're clearly grieving about their state of lost health and they're scared. They're really scared. So those are the most common ones on diagnosis.

And if somebody is diagnosed with, say, Stage IV disease which would be probably incurable. They certainly can be treated. I think that's what I try and foster in patients is the hope that whatever treatment that they will receive will give them some time and hopefully good quality time. And I try and keep that hope alive because it works for me to do that, otherwise I would be falling apart a lot of the

time. And for the patient to have some hope because I think hope is really an important consideration that we can provide time and quality of life to patients even if they're not curable.

Dr. West: Can you tell us a bit about the concept of the Gratitude Journal that you introduced as a post on the website a while back?

Ms. de Roulet: Yes. I think what it does is forces people and if you recall I think I said at the end the day you should keep a journal and you should write down three to five things that you are grateful for today. And most people find that even in their worst days there are things they can find to be grateful for. And usually they are very simple things, it's like seeing the first crocus or daffodil come up in the spring or planting a tree and being able to see that tree leaf out or maybe even bear fruit. And of course nature is a very strong one in general. Just the beautiful sunset or a beautiful sunrise or like today it's a beautiful day in Seattle. The sun is shining. Its cold, but it's beautiful. So, just trying to allow people to experience some joy and some gratitude for whatever time they might have and what they can enjoy out of life is the most, is the basic concept of the Gratitude Journal. And I think once people get used to doing that, the gratitude itself helps to enhance their quality of life.

Dr. West: I'm just thinking of the concept that if you smile a lot, it makes you happier actually.

Ms. de Roulet: Yeah, I think that's probably true and it makes other people happy. And so there's this back and forth reaction that goes on.

Dr. West: You've written about the concept of "Scanxiety", or anxiety around scans and surveillance of a cancer. *Uh* Can you talk a bit about that and *and* how you talk with patient who are *uh* really debilitated by that?

Ms. de Roulet: It's so common; everybody has it. Especially for patients who are considered to be in remission but they're on surveillance. And even that word is kind of scary, if you think about it. And they get particularly anxious around the time of another scan that's either going to tell them they're still in remission or they're not in remission and their disease has recurred and they may have to undergo treatment again. I try to focus on the "what ifs." If there is a recurrence what's the worst possible thing that can happen? You're going to go on treatment again: right. And it will probably not be the same treatment although if you responded well to the first treatment and you were in remission for 18 months, you may go back on that same treatment. And you already know what that's like. So that's not going to be a big unknown for you. And often I think that it's the fear of a new treatment, what the symptoms are going to be and all of this scares people quite a bit. And, you know, I just try to normalize this. It is normal to be frightened. It's normal to worry about whether there is a recurrence and to worry about whether it's going to be a different treatment and it's going to be harder than the one you had before.

Dr. West: Leah, thank you so much for taking the time. I really appreciate it.

Ms. de Roulet: Thank you. I always enjoy it.