



Interview with Leah de Roulet, Part II
by Dr. Howard (Jack) West
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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 the President and CEO of GRACE, the Global Resource for Advancing Cancer Education.

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.

How do you approach a patient who is living alone who may not have close friends or family nearby and its starting to reach a point where it may not be safe or feasible for them to stay at home for much longer? We do see that a fair bit in clinical practice.

Ms. de Roulet: We do. And that's a hard one because most people really want to retain their independence for as long as they can. So we start with small things, perhaps wearing a Life Alert button, that's what it's called here in Washington State. There are a number of these systems available nationwide. It's a small pendant that somebody wears around their neck and if they get into trouble, if they fall or whatever, they press this button and it rings into a center which calls, there are three people on the calling list. The first one might be the landlord or somebody close to them. The second one might be a family member or a neighbor or a close friend. And then the third call is to 911 or emergency assistance wherever they're living.

And that is very inexpensive, it's around \$30 a month and it offers a lot of security because I think one of the things patients as they get weaker are concerned about is falling in their home, not being able to call anybody. That's a terrifying feeling. And so we encourage people to wear this pendant all the time when they're in the house alone, because it does give them the security of knowing that they have the power to summon help.

Dr. West: How about the issue of trying to get someone into a more supportive environment before its an emergency situation?

Ms. de Roulet: That's a tough one because, first of all there's the cost of that. So whether we're talking about assisted living or a skilled nursing facility or an adult family home, they're all very expensive. And most people are resistant to the idea of doing that unless they are absolutely forced to do that. And sometimes what happens is the patient will come into the hospital because they've had an acute episode of something, and the physician will need to tell the patient, "I really don't want you to go home. I want you to spend some time perhaps in a skilled nursing facility where you'll get rehab assistance" and so on, if the physician believes that will help, or we'll talk to them about no longer living alone. Period.

Just moving into an assisted living or one of these other facilities and the cost of these is really very overwhelming for most people because Medicare, as you know, doesn't cover any custodial care, what we would call custodial care. If a patient does have welfare, they're totally covered. It's actually the best insurance you can get. But a lot of people are reluctant to go into their savings if they have them, or cash out an IRA or do the kinds of things that they might have to do if they had to pay for this kind of care them self. And I think it definitely needs to be sort of a joint effort between the physician and the social worker who has a relationship with the patient to try to help them make this awareness that this is coming.

Dr. West: What are some of the other additional challenges you face when you have a patient in one place and family members a good distance away?

Ms. de Roulet: That's very difficult because often what happens is that the family members don't realize that perhaps the patient is going into a downward spiral, and some of this can be emotional.

We see a lot of depression in people who are not doing well with their treatment, so they become almost reclusive and the family members want people to get them to engage in life because they don't understand what's happening. If the patient goes into the hospital and it's clearly a terminal situation, the family members will all converge in the hospital at that time. Most of the time, I rarely see people in agreement, like adult children never agree about what should happen to mom or dad unless the parent has a clear Durable Power of Attorney for medical treatment and perhaps a physician's orders for life-sustaining treatment. It's sometimes called the DNR -- do not resuscitate.

The first line of attack with that is always the physician, because the physician needs to be able to tell the patient, "I want to know what your wishes are in the event that something should go wrong." And then the patient and the physician talk about it. It's in the medical record. But you need to fill out the form that states it because, let's say for instance that the emergency services come or the ambulance comes or whatever, and you don't want to be resuscitated if something happens. Unless you have that form in writing on your refrigerator door with a magnet, then they're going to do what they are trained to do which is to resuscitate, to get you to the hospital, to get you on oxygen, to do whatever they can to make sure that you survive whatever emergency it is.

Dr. West: That can be a real challenge for say family members, because it's certainly harder to take someone off of a ventilator than to never start that.

Ms. de Roulet: Absolutely. I think that is one of the most difficult decisions family members have to make. And that's when we often see the conflict between adult children who come in at such a time when the parent has been in an emergency situation and brought to the hospital.

Dr. West: And I think it's much better to deal with these things proactively before it becomes that emergency. First of all, because I believe studies have been done that show doctors are not good at predicting what their patients will want and I imagine that it must be hard for family members to opt out of something even when they think it might not be a great choice for fear of not having done enough.

Ms. de Roulet: Absolutely. I think the time to do these things is not when the situation is bad. It's when you are well, it's sort of like ensuring that whatever you believe about what you want to have happen regardless of the cause of the death whether it's cancer, an automobile accident or anything like that, heart disease, that you have discussed this and there are clear instructions, and you have a Durable Power of Attorney done for health care decisions if you are unable to do that yourself.

But I just want to throw in that I have no intention of dying in the near future but I've had a Will, a Durable Power of Attorney, and discussed the executor of this Durable Power of Attorney, my oldest son, exactly what I want and don't want. So I have no fear that he will not do what I want. I know he will.

Dr. West: Well and I think the fact that it's called a Living Will implies what you're supposed to do, that you should not wait until you're imminently dying to make a will. Everyone should have that.

Ms. de Roulet: Exactly.

Dr. West: In the same way ideally if you have these discussions and it doesn't imply that there's the specter, this looming threat of dying very soon, it would take away some of the stigma of it.

Ms. de Roulet: It definitely does. And I find it's difficult to get people to think about, though there are many patients who have thought about it and have already done it even before they were diagnosed. And that's really good. If they haven't done it, it's often something people keep putting off because they're so afraid. Particularly with cancer treatment, they're always waiting for the other shoe to drop, whether it has or not.

And the idea of facing your own mortality and making these instructions is so much more frightening at that point, than it is when you're relatively well and are thinking clearly about what you may want.

And the other part of that is, if things are going badly, often people are on pain medications and things that sort of cloud their mind and they're not really making decisions they would have made had their minds been totally clear.

Dr. West: How do you approach a situation in which a patient and their spouse or another family member is in a very different place about the limitations and the reality of a prognosis, particularly, say, a patient denies the mounting difficulty and the increasingly limited options for treatment, but the family doesn't know how to handle what they perceive as denial at this point.

Ms. de Roulet: You know, I'm a firm believer in the concept that wherever somebody is in their process of coming to grips with what's happening is where they need to be. You know, denial is a very functional defense mechanism. And the reason people are in denial is because they need that time to come to grips with this. And it's okay.

So I often try to just talk with the family about not forcing the patient to accept this reality because they're not ready. Otherwise, they wouldn't be in denial. They'd be talking about it. So helping the family to understand that that isn't necessary, that just allow the patient to be where they're at and they will know as scans perhaps

progressively get worse because most physicians are very open with their patients about what's happened or the need to change treatments, or whatever. And eventually patients come to grips with that at some point or another. I've seen very few patients who didn't.

I have seen a lot of family members where they're more in denial than the patient is. So it's a reverse situation. The patient is aware and wants to talk about the fact that they maybe getting to the end of their life and the family member doesn't want to talk about it.

Dr. West: I imagine it must be especially challenging in the situation in which the patient themselves feels the need to put on a brave face and protect their spouse, their children from negative information.

Ms. de Roulet: Absolutely. Its very hard. And family members often use this, what I call *false cheeriness* thing with patients, which also puts up a barrier to real communication about this. For both of them, let's say the husband and wife or the parent and children, there's really no way to reach the kind of closeness, intimacy and communication ease that you want if you have to do this false cheeriness thing.

And so at some point usually in my relationship with the patient, I'm able to broach that with either the family or the patient and the physician, because believe it or not, you know, physicians are human. They don't want to lose patients. They don't want to see their patients suffer in any way. So that can be a difficult thing, but I also believe that patients themselves generally know when things are going bad, though they may deny it initially.

But if I ask somebody what do you think is happening with you, and the patient says to me I think I'm dying, and I've had patients say that, but the doctor hasn't said anything yet, I'll just validate that and say I think really that patients know at some deep level. And this is usually after a series of increasingly bad scans or changes of chemotherapy, one chemotherapy doesn't work and two months later you're on another one and then you're on another one. They know, and they know how they feel.

Dr. West: And you bring up the issue of patients perhaps feeling like they need to do certain things to please their doctor who may want them to continue on a treatment and have their own feelings about not giving up.

Ms. de Roulet: That's also very common. I think the relationship between the doctor and the patient is extremely important, and it's an extremely emotional one. I think there are some physicians that I've worked

with over the years who have great difficulty in just allowing their patients to make these decisions or being honest enough to say, "This is really bad, and I'm not sure we have any really good treatment options anymore." That sort of thing.

The patient does try to please their doctors and continue to take treatment because they care, also they don't want to fail their physicians, and they've gone through a journey together. And it's a hard thing -- it's a hard thing for everybody.

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

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