Caregiving for Someone You Love In Chronic Pain

Transcript highlights from Facebook chat on March 18, 2014

Funny...insightful....very helpful. That's how PainPathways would describe Peter Rosenberger - author, advocate and founder of Standing With Hope.

Working with more than sixty physicians, twelve hospitals, $9 million in medical bills, and seven insurance companies through his wife’s seventy-eight operations and multiple amputations... Peter Rosenberger has learned a few things about the America’s healthcare system. Living with a chronic crisis and being married to someone with extreme pain and disability has also taught him a few things about perseverance, love and relationships.

Peter Rosenberger

Welcome! Thank you for joining us today for “Caregiving for Someone You Love In Chronic Pain.”

Hi, This is Peter Rosenberger,
Great to be with you all this evening. Caring for someone in chronic pain is not easy, and quite truthfully …not for the fainthearted. By coming together in this format, we strengthen each other. That said, let’s jump into this ...my wife's car [accident]....this is where her journey of pain started.

Right off the bat, let me state that I didn't cause this wreck, nor did I cause her pain. I try to care for her to the best of my abilities...but I can't solve what this wreck did to her. Sometimes, I feel that all I can do is watch it happen...often times from lonely vantage points like long hospital corridors. That said, let's take some questions, thoughts, comments...and you know what...you can even vent. It's all good.

Barby: How much are you doing on your own as a caregiver vs having professional aides take care of your wife with such a busy schedule you are on?

Peter: It varies. I've been a caregiver for 28 years, and until the last year, I did virtually all of it myself other than a little bit of part time help. In the last four months, I've added some part time help. Gracie had five additional operations from 12/12- through 4/13 (bringing her total to 78 over 30 years). Little much for one person, so I welcome any help I can get.

Barby: Are you still able to maintain a healthy physical relationship or have you had to change it drastically or cut it out due to her physical pain, how do you handle that aspect of the relationship?

Peter: Barby, you go right into the deep end of the pool, don't you!? 
With someone in the level of pain my wife has, "Not tonight, dear I have a headache"...is taken to WHOLE 'nother level. We've taken the trapeze out of the bedroom and have to work around a few things. This is a family show...so we will leave it there. That said, pain and medication can be a real challenge for EVERY aspect of the relationship.

Linda: I'm grateful for the help I receive from my caregiver, but how can I communicate my needs without being too demanding or without hurting feelings? It seems to be a fine line, especially if you (or they) are in it for the long haul.

Peter: Great question, Linda: Starting with "I want to be sensitive and not demanding" is always a good place to begin. The elephant in the room is always, "the person in pain has extraordinary needs." There is no use denying it...so launching into any dialogue about your extra needs with a candid conversation is a healthy place to start. That said, those needs are like mowing the grass...they are tasks that need to be done on a regular basis. Sometimes you can hire people for those tasks, sometimes you can't. But doing a task for someone...doesn't mean you are deepening the relationship with someone.

I cannot expect my wife to understand that my doing the dishes every night replaces my spending time with her as a person. I have to carry a lot of extra tasks...and when she sees that and is candid about it, it only strengthens the relationship for me.

Ken: Have you been able to or considered teaming up with any organizations to spread awareness about your wife's chronic pain condition?

Peter: No, not really. She doesn't really want to spend a lot of time doing that. She's been in pain since Reagan's first term, so it's wrapped into her life. In fact, of all the interviews we've done on TV and so forth, I don't know that she's ever talked about it much. She's not in the public eye much now, but when she is, she focuses on what we do at Standing With Hope, and other components of her life.

She delved into in her book Gracie—Standing With Hope, and let that speak for her regarding this.

Alex: How can people outside the caregiving situation best support the caregiver?

Peter: Great question, Alex: There are many ways that folks can help. Few are easy. Caregivers by definition are high functioning multi-tasking, problem solving, crisis management type of folks. Face it, y'all, we can be control freaks.

But control is an illusion. Here's an article I recently wrote about this. I can go deeper, but probably not in this forum. http://caregiverswithhope.com/prying-hands-wheelchair/
Alex: And if there is a family member who is "helping," but is really interfering, how do you stifle them without being ungracious?

Peter: Say what you mean. Mean what you say. Don't say it mean. Some people don't like boundaries. That's not your problem. Your challenge is to maintain the boundaries. If there is blow back from them, you can allow it to be messy until such time as they grow up.

Carol: How do you keep your irritation level down when both of you are having a particularly bad day and you're not feeling funny?

Peter: I only feel funny after eating cheap Mexican food.

The way I keep my irritation is to start with The Three "W's": Wait - Water - Walk.

   Wait a few minutes before saying anything. You don't have to apologize for things you don't say. Sometimes you have to bite your tongue and learn to like the taste of blood.

   Water. Drink to think. It hydrates your brain, keeps your mouth shut, and buys you a few minutes to gather your thoughts.

   Walk. Change your physical state. Walking bleeds off stress, and gets oxygen to your body faster...calming you down, etc...

By the way, it ain't like I got this down perfect. It's progress not perfection!

As we wind down, just know that it is not easy to care for someone in pain. Imagine if you are walking barefoot on hot gravel, while carrying a couple of hundred pounds on your shoulder. You would probably not be the most gentle in how you responded to people would you? That loved one's life is kind of like that. Their pain is a huge weight they have to carry, and quite truthfully, it sucks.

I can't change that. But I can learn to hold my tongue, and be a bit more compassionate. That doesn't mean I enable or capitulate...but my heart can stay tender.

I can learn to make amends a bit faster, and most importantly: I can learn to see the heart...not the chart.

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Romance and Disability
caregiverswithhope.com

Caregiver, Author, and Radio Host Peter Rosenberger shares from three decades of experience as a caregiving spouse.
Ken: As a caregiver have you ever had a difference of opinion than your doctor for treatment options and how did you handle it?

Peter: I've had differences of opinions on many occasions...and won a few. The challenge for me is to keep my opinion out of the mix for the most part...unless I feel the doctor is way off (which has happened on more than one occasion). That's when I pull out my Dr. Rosenberger title (I tell them I am a cranial proctologist - specializing in extracting heads from...)

Gracie has to drive her own health needs. It's her body. I can advocate for her, but I have found it best to stay out from between her and her physicians. I am the historian of the group and know pretty much every procedure and event, but I serve as support.

Ken: Where can I purchase Gracie's book.

Peter: Here's a quick link: http://www.standingwithhope.com/store/books/gracie/

PainPathways: Don't forget that in every issue of PainPathways magazine, we feature a caregiver's story. You can read it in the print issue or through the digital edition. And you can quickly search our website on "caregiver" and find many articles: www.painpathways.org/?s=caregiver

PainPathways: Hi everyone! This is Amy North, editor of PainPathways magazine. On behalf of Dr. Richard Rauck, we'd like to thank Peter Rosenberger and all those who participated in tonight's chat! We are excited to be offering this great forum for information and inspiration. Have a good night everyone!

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