DVT and PE: A Disease with Extensive Emotional Impact

*Brian Blongastainer, Patient Advocate*

A Note to the Reader: This entry is not indented to provide answers, it is meant to illustrate the emotional impact that Deep Vein Thrombosis (DVT) and Pulmonary Embolism (PE) can have on a patient’s loved ones. My wife’s story as experienced by me, her husband, serves to foster awareness of the challenges we, the loved ones, face as we try to push aside our own emotions in an effort to be supportive of the patient’s needs and fears during a time of a medical emergency.

Once the realization and the fear of death from a “silent killer” - an expression commonly used to describe DVT and PE – are introduced into your life, you can never forget how quickly and easily your life and that of your loved one can be changed or even lost. I believe that the emotions I feel – and continue to feel to this day – are experienced by others who have watched a loved one suffer from DVT or PE.

How can I forget that night? It was the late hours of the night and early hours of the morning, July 23rd and 24th, 2005. I can recall every detail of the conversations we had with the emergency room staff. Each time I think about that long night, I am quickly reminded of how lucky we are that Heidi’s life continues:

ER Doctor: *Based on the symptoms you describe, we are going to do an ultrasound to ensure you do not have any blood clots in your lungs.*

Heidi: *What could happen if I do have blood clots?*

ER Doctor: *They can be deadly.*

[Following the ultrasound]
ER Doctor: *Unfortunately, you have large, multiple blood clots in your lungs.*

Heidi: *Am I going to DIE?*

For the rest of that night, out of fear it would be Heidi’s last, we tried to fight off sleep. We both lost the battle by dozing off just as the sun was rising. We were woken by the voice of the cardiologist. It was our good fortune that the voice was that of one of the world’s experts in DVT and PE. Together with his nurse, we were assured that Heidi would survive. Life had become so surreal; we wanted to believe their calm and hopeful words, but, at the time, we could not fully do so:

Doctor: *Is there anything that I can do for you?*

Heidi: *Can you save my life?*

Doctor (in a very calm voice): *I can do that.*

We put our life’s fate in the hands of these kind and confident medical professionals as Heidi received the world’s best medical care.

Today Heidi is healthy, but since the diagnosis the emotional scars of that fateful night and ensuing months remain with us. I keep thinking back to the ominous comment of the ER doctor, “You will die.” I recall the conversation between Heidi and the doctor administering the echocardiogram. What would have happened if we had not gone to the hospital that evening? His reply: “I am glad you did.” Those five simple but chilling words said it all.

I recall those many nights in the months following Heidi’s diagnosis. Still to this day I wake up and watch my wife breathe –reassuring myself that she is still alive. My fear for Heidi’s condition has even led me to spend a morning in the ER, positive that I, myself, was plagued by DVT. Despite assurance otherwise, on occasion I still must convince myself that a pain in my calf is not a blood clot.

While dealing with my own emotions and fear, I need to be there for Heidi. I continue to struggle with how best to support my wife and her emotional needs. Together, we attend a PE Support Group where we hear and learn from other patients about the myriad of ways each developed DVT and PE. Paradoxically, while gaining support from other victims of this “silent killer”, my fears for Heidi (and myself) increase. I know that I am not alone in this continuous emotional rollercoaster.

It has been four years since that long, fateful night in the ER and I am still wondering how I can best support my wife each time she complains of the slightest calf pain or shortness of breath. Now an “expert” in DVT and PE, I mentally eliminate any potential risk: surgery/trauma, genetic, immobility, etc. I
push aside my own fear of blood clots, as I try to calm down and reassure my wife.

Heidi is now pregnant and back on prophylaxis treatment, daily shots of Lovenox. I can only imagine the pain she must experience with each shot. At the same time I silently monitor her compliance in the routine. As Heidi’s scheduled cesarean section and transition from this low molecular weight heparin draw near, my fears increase that a new trauma to her system will lead to another blood clot.

And so you see, while the physical or medical consequences of DVT/PE are great, the emotional impact of this potentially devastating disease reaches beyond the patient. This “silent killer” results in an emotional rollercoaster for the patient and all those that love them.