



LAW OFFICES OF AVIV S. BLIWAS, LLC

MEDICAID PLANNING, ELDER LAW and ESTATE PLANNING

Protecting Families' Life Savings from Nursing Home Costs

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Diary of a Caregiver-Part 2

When I left you last, I had made the decision to return home and care for my mother (and later made a decision to remain and care for dad). The day after I flew home from California, those decisions were still ahead of me. I knew nothing at that point. I went to the hospital to visit my mom and met her doctors for the first time. These were her oncologists. They came in to examine her and run tests. Then they asked me to step into the hall. In the hallway of Harrisburg Hospital is where they explained to me that my mother's breast cancer had metastasized to her brain. That it was very aggressive. They informed me that if they did nothing, my mother had 2 months to live. Even if they did one or a combination of treatment options, my mother was going to die. That was certain. The only question was when.



Now, remember the setting, these doctors are telling me this outside of the presence of my mother. I'm all by myself. No one else is there from the hospital—no social workers, no clergy of any sort, absolutely no one to help me digest and process this.

Mom's deterioration was rapid, despite undergoing several of the treatment options. It never seemed to slow. I never seemed to be able to get a handle on her new level of needs before they would fall again. And no one was telling me what to expect so that I could try to anticipate needs and get things in place ahead of time.

So I simply dealt with the most urgent things as they came up. My days were spent taking my mom to her doctors appointments of which there were sometimes several in a day, preparing all her meals, making sure she was taking her medication

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WHAT'S NEW WITH US

Well, quite a bit since I took a brief hiatus from newsletter writing for the last few months! Sorry about that. Between the holidays and all this confounded snow, it really put me behind! But I'm slowly catching up and that means getting back to my monthly newsletter schedule!

I managed to escape the snow and ice a few times, I visited some family friends down in the Florida Keys over Christmas and then made it out to California during January for business but managed to visit some family and friends while I was out there. (PS- I happened to arrive in LA right before the Grammy's and the driver who picked me up from the airport thought I was there for the Grammy's, I couldn't decide whether that was a compliment or an insult).

February marked birthdays in my office. Both Augusta and I had celebrations!

Jennette had a theater debut at Open Stage and Augusta and I took a night to take in the show which we both really enjoyed.



Being goofy at Alcatraz Island.

Diary of a Caregiver (continued from cover)

(half of which she certainly didn't need and no one told me—let's be honest did mom really need her cholesterol medication at that point? Or would her quality of life have been ever so slightly improved if I could cut the number of pills down so she didn't have to take 10 in a sitting?)

I tried bringing in hospice care since that seemed the best route. But at that time, my mom wasn't ready. And since the doctors were not talking to her directly, they were only telling me, that the end was inevitable, I'm not sure she even knew at that point that the best route was hospice, or maybe she did but wasn't yet ready to accept it. I'll never know because the doctors certainly never told her.

I remember driving her back from an appointment one day and asking her what she would like for a funeral. She told me she didn't feel it was time to talk about that yet. I said "Mom, the doctors said you only have 2 months to live. If you don't tell me now, you

aren't going to be able to tell me." Mom looked at me and said, "I didn't know that, no one told me." Maybe they told her and she was confused at the time, which being in a hospital and sick can do. But I certainly never saw anyone talk to her.

Later, when visiting nurses came in, they would try to communicate with me about my mom's prognosis, literally behind her back. While her back was turned they would try to mouth things at me. Why? This was my mom's life. She had a right to have input on the decisions if she could.

My mothers oncologist was equally unhelpful. When we went to see him, he suggested a round of chemo. Why? To treat the cancer in her back. When I asked him point blank, if this chemo would stop or slow her death, he admitted it would not. When I asked if treating that cancer with chemo would ease any pain, he admitted the cancer in her back was likely not causing her any pain (and I never saw any sign that it was). This doctor had my mom convinced she should do this chemo. It was only because I put my foot down

and said no, that I was not going to let my mom's last couple months be a round of fruitless chemo that would literally accomplish nothing, that the idea died.

My dad's doctors were a different experience. I felt fairly confident that they communicated with me and him. Of course, by this point I was a pro and knew how to stand my ground, how to ask questions, what questions to ask—how to insist that I be a part of decisions.

But I believe the biggest problem was the complete lack of communication with each other. Since my dad's doctors all worked for the same medical facility, I assumed that there were charts and records with all my dad's info and that these doctors were communicating about my dad's illnesses. And it's true what they say about assuming. I happened to tell dad's oncologist that he was in the hospital on one of his frequent visits for pneumonia and persistent infection. This was probably his 4th or 5th trip back to the hospital from rehab. The oncologist told me this was the first he'd heard my dad was even in the hospital. There is no mechanism, even within the same medical facility, for a doctor who has a patient actively under their care, to be alerted if that patient is admitted to the same hospital unless it is for a problem directly related to the disease that doctor is treating.

The problem was, this doctor had an injection to

boost dad's white blood cells to help fight some of these infections. If I had known I needed to call this doctor every time something was wrong with dad (or if the hospital had a system to do it automatically), it could be that the last infection that killed my dad would not have happened. I have no way of knowing.

So what did I learn from all this that I'm telling you? I think the biggest takeaway from all of this, is that you can't do it all. You can't be expected to coordinate with the dozen specialist doctors you will inevitably be dealing with when someone is in ill health and keep it all straight and take care of your loved one and manage all their affairs and manage your life! You just can't do it. And you shouldn't try. You will make a mistake, you're only human. Something will get missed. Something will slip through a crack. You need help. I don't care if this is the help of family members, friends, or professionals who you pay to be medical advocates (yes there are such things!) but get some help. Because even though no one cares as much as you or can do it better than you, when you're too tired, stressed, and overwhelmed, then yes—there are people that do it better than you. I'll never know if trying to do it all myself hurt my parents or precipitated their deaths, but I promise you I will always wonder.

THEATRE SCORNER

by *Jennette Harrison*



In mid-February I was cast in a show at Open Stage of Harrisburg called Clybourne Park. It is a Pulitzer Prize and Tony Award winning show by Bruce Norris. As my first professional acting experience it was incredible and I hope to do more shows at Open Stage Harrisburg in the future. A promotional

picture of cast member Valerie Ray Smith and me was even posted on Pennlive.com in the Entertainment section during opening weekend. I worked with many amazing people in the cast and crew. I am confident I will have the chance to work with them all again.

In fact, I was asked back to do a show in June, but because of a scheduled vacation at the end of the month, I am not available to do it. The show is called *Stories from Home: Dauphin County* and I encourage you all to see it. The show is comprised of original work based on stories of the various neighborhoods in the Harrisburg area. It

is running at Open Stage of Harrisburg from June 7-29, 2014. I will be catching this opening weekend.

June is also time for Shakespeare in the Park. Gamut Theatre Group's Harrisburg Shakespeare Company is currently running *Antony & Cleopatra* at Harrisburg's Reservoir Park. The show is FREE and runs May 30-June 14. Food will be available from local eateries: Uptown Spice Grill, Manna Café and Dog on Good Dogs. I have to admit I haven't been to a Shakespeare in the Park show. I'm not a fan of sitting out in the hot sun for hours, but I will check it out this year. If you plan on checking it out, the show starts at 7:30pm each night (May 30-31, June 4-7, and June 11-14). Also, bring a lawn chair or a blanket!

Other shows in the region in June 2014:

Oyster Mill Playhouse

717-737-6768
Jeeves in Bloom
June 6-22, 2014

Ephrata Performing

Arts Center
(717) 733-7966
Agnes of God
June 12-22, 2014

Little Theatre of Mechanicsburg

(717)766-0535
Reefer Madness
June 6, 7, 12, 13, 14, 20, 21

Gretna Theatre

717-964-3627
Camelot
June 19-29, 2014

Calendar

May 26th – Memorial Day, office closed

May 28th – Book club hosted at Aviv's house, the book is "Packing for Mars" by Mary Roach

June 10th – Greater Federated Women's Club hosting Change Purse and a purse drive to raise money and awareness for victims of sex trafficking

June 15th – Fathers Day

June 17th – Jewish Family Services board meeting

June 24th – speaking to the JCC Senior Adult Club on Long Term Care planning

July 4th – Fourth of July, office closed



Josie "helping" rake leaves in November