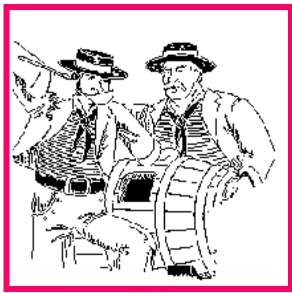
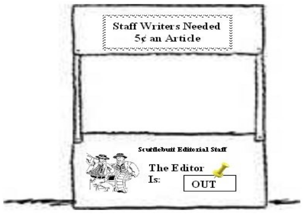


Scuttlebutt

January 23, 2017 Volume-2, Issue-2

Rocky Mountain Cancer Center of Boulder, CO, Kidney Center of Lafayette and Longmont



Editorial Comment

I have always wondered what newspaper reporters thought about what their readership thought about the articles, were they able to accept the idea of them writing to an unknown audience and never hearing back on what the readers thought about the subject being written about. Maybe they didn't care what anyone thought, and I assume that is because they were paid by the word, not on how good the article was, just a word count. Well in this area I have to admit I am a curious person because I always look for feedback, which motivates me to continue or I guess you can say it also moves me to stop all together. Well life is what it is, a scale of pros and cons, but if I don't get a chance to read any of it, I will continue walking the shaky limb that hangs over the limbo of my existence.

A Guide to Advance Directive Documents

(Final Installment)

Please be aware that what follows is just information that I was able to get from system and should not be taken as advice. As you probably know not every situation is the same but individually different. Now if you have any questions about your particular situation, please consult the appropriate qualified professional health care practitioner, attorney, or estate planner.

Low-cost legal assistance is sometimes available. Consult the Colorado Bar Association Web site at www.cobar.org (click on "The Public" and "Legal Assistance Programs"). You will also find more information about advance directive documents and the Colorado-specific forms can be found under Links and Resources at www.irisproject.net.

CPR Directive

♦ A CPR (cardiopulmonary resuscitation) directive allows you to direct in advance that no one should give you CPR if your heart or your breathing stops.
♦ CPR directives are almost always used by people who are severely or terminally ill or elderly. For them, the trauma involved inCPR is likely to do more harm than good, but emergency personnel are required to perform CPR unless a directive tells them not to.
♦ A CPR directive is not the same as a DNR order. A DNR order is doctor's order made for everely ill patients in health care facilities, including nursing homes. The DNR does not require the patient's consxent, and it expires when the patient leaves the facility.
♦ The Colorado CPR directive (or "blue form") must be signed by both individual (or the indidual's MDPOA agent or "proxy"—see below) and his/her physician.
♦ Other forms, such as those particular to a health care facility or created by individuals, are valid and should bed signed by a physician to avoid any question about their validity. However, emergency personnel should honor any directive, made by the principal or his or her agent, to refuse CPR.
♦ The CPR directive form does NOT have to be "original" nor do the signatures have to be "original." Photocopies, scans, and faxes are valid.
♦ CPR directives must also be immediately visible to emergency personnel. Keep the form in an easy-top-get to place, like the front of the fridge. For more active folks with CPR directives, a wallet card or special CPR directive bracelet or necklace can be obtained.
♦ For more information on CPR directives, ask your doctor or visit the Colorado Department at http://www.ccdphe.state.co.us/ern/Operations/AdvanceDirectives/index.html.

Medical Proxy for Decision Making

In Colorado, no one is given automatic authority to decision making for another adult, and health care providers cannot make decisions for patients except in an emergency.

If you have not appointed an agent, and if you are unable to make or express your deci-

Continued on Pg-2

Advance Directive Documents

Continued from Pg-1

sions for yourself, a “proxy” is needed.

Your spouse or partner, parent, adult child, grandchild, brother or sister, close friend, or other “interested party” may be chosen as your proxy by the group.

Like your agent, your proxy should act according to your wishes and values, so the proxy should be the one who knows your medical treatment wishes the best.

Proxies selected in this way cannot refuse artificial nutrition and hydration for you.

If the group can’t agree on who the proxy should be, then guardianship needs to be pursued through the courts.

Medical Orders For Scope of Treatment (MOST)

Colorado has approved the MOST process and you can view it on line, searching for ‘Medical Orders for Scope of Treatment (MOST).’

The MOST form is a one-page, two-sided form that gets all a person’s key choices for life-sustaining treatments in one place. It includes CPR, general scope of treatment, antibiotics, artificial nutrition and hydration.

Persons may refuse treatment, request full treatment, or specify limitations.

The standardized form can be easily and quickly understood by patients, health care providers, and emergency personnel.

It is primarily intended to be used by the chronically or seriously ill person in frequent contract with health care providers, or already residing in a nursing facility.

The MOST is completed by person or his or her agent in conversation with a health care provider, then signed by the person/agent and a physician, advanced practice nurse, or physician’s assistant. The physician/APN/PA signature translates patient preferences into medical orders.

The MOST “travels” with the person and is honored everywhere: hospital, clinic, day surgery, long-term care facility, ALR, hospice, or at home. This avoids delays, duplicated conversations, and confusion about decisions.

A section on the back prompts patients and providers to regularly review, confirm, or update choices based on changing conditions.

The original is brightly colored for easy identification, but photocopies, faxes, and electronic scans are also valid.

Completion of a MOST does not replace or invalidate prior directives. The MOST overrules other advance directives only when they directly conflict.

A Word About Advance Care Planning for Children with a Serious Illness

Persons under the age of 18 cannot legally sign advance directive documents; their parents or legal guardians are responsible for their medical decisions. When a baby, child, or teen faces serious illness, parents and health care providers can develop an advance care plan. Older children and especially teens can have a voice in putting together the plan.

The plan outlines in writing the parents’/child’s preferences for care in case of an emergency situation or in cases where all treatment options have been explored. If you are caring for a seriously ill child, here’s what to do:

(1) Request a family conference with your physician and primary nurse. You may also want to include a social worker, spiritual advisor, or close family friend. (2) Discuss with your doctor/nurse their plan of care for your child, including palliative care for pain and symptoms, and emotional/psychological/spiritual support. (3) Discuss whether a Colorado CPR Directive might be appropriate for your child in case of an emergency. (4) If appropriate, talk over choices and likely results with your child and include him or her in your decisions. As parents, you have the final say, but even young children can benefit from being included in the decision making.

Caregiver

In the last issue of Scuttlebutt I wrote about my wife being my caregiver and I told the story of when I went into the hospital with medical problems, which resulted in me being ordered by doctors to undergo dialysis treatments. Now of course from that point forward my wife was my caregiver as it related to me undergoing dialysis or any other medical treatment, but that is not the beginning of my wife filling the position of a caregiver for me.

Now I would like to speak of another time that my wife filled this demanding and thankless position in my life. Going back to the 1980's when I was diagnosed at having PTSD, which in my case had to do with me suffering from sleep disorders. These disorders involved me having nightmares, when I could get to sleep, but the hardest part of the disorder for me was to just close my eyes and force myself to relax and get some sleep. So from the 1980's, which has been a burden for me before but from that time forward, as well, it has stayed with me up too, even today. Before an Army Psychiatrist at Fizsimmons diagnosed me with PTSD, oddly enough I knew the doctor when he was a Lance Corporal in the Marine Corps, where we were stationed together in the same command. So as you might have guessed, our conversations and discussions regarding my problems were easy for me to discuss with him, he had similar problems.

Now, it was recommended by the doctor that I pursue writing as a means of therapy, and yes my wife was involved in my efforts to clear my mind so that I could get some normal sleep. So writing became a way of life for me, when the nightmares came in the dark, or when I was afraid to close my eyes, I forced myself to get up and write. I would write about almost anything, and my wife lost a lot of sleep because she stayed up with me and kept me focused on my writing and she reminded me of how life was for me before we got married, maybe I will write about that one day.

This poem is the product of one night of no sleep and it does paint a pretty clear picture of what I was going through –

Dark Mysteries

From a sound sleep, I awoke in the middle of the night,
Feeling lost, my mind was racing with a sense of fright,
Unsure of where, I felt something was very wrong,
Unable to move, I lay frozen, knowing that I did not belong.

The air around me smelled of rain, it was heavy and wet,
My muscles felt like they were knotted, I was covered in sweat,
Surrounded by the jungle's nightly noises, so loud and very clear,
Each sound reinforcing my sense of not belonging and fear.

Each breathe taken, tasted of a jungle's rotting and putrid air,
My senses searched, looking for the what, when and the where,
Yet, all I knew, for me, that this threat and danger were real,
With an iron grip, panic seized my heart, with a fear I could feel.

My flesh crawled, as my surroundings closed in upon my head,
I wondered if I had been buried, because they thought I was dead,
Could I take a chance and call out for someone to save me,
Or should I just lie still and wait on the unknown, to see what would be.

To my left I heard a soft sound, which I had heard many times before,
As I listened, the jungle around me changed to things I had ignored,
The noise I had heard was the soft breathing of my sleeping wife,
Again, unknown, she had saved me from the dark mysteries in my life.

Scuttlebutt

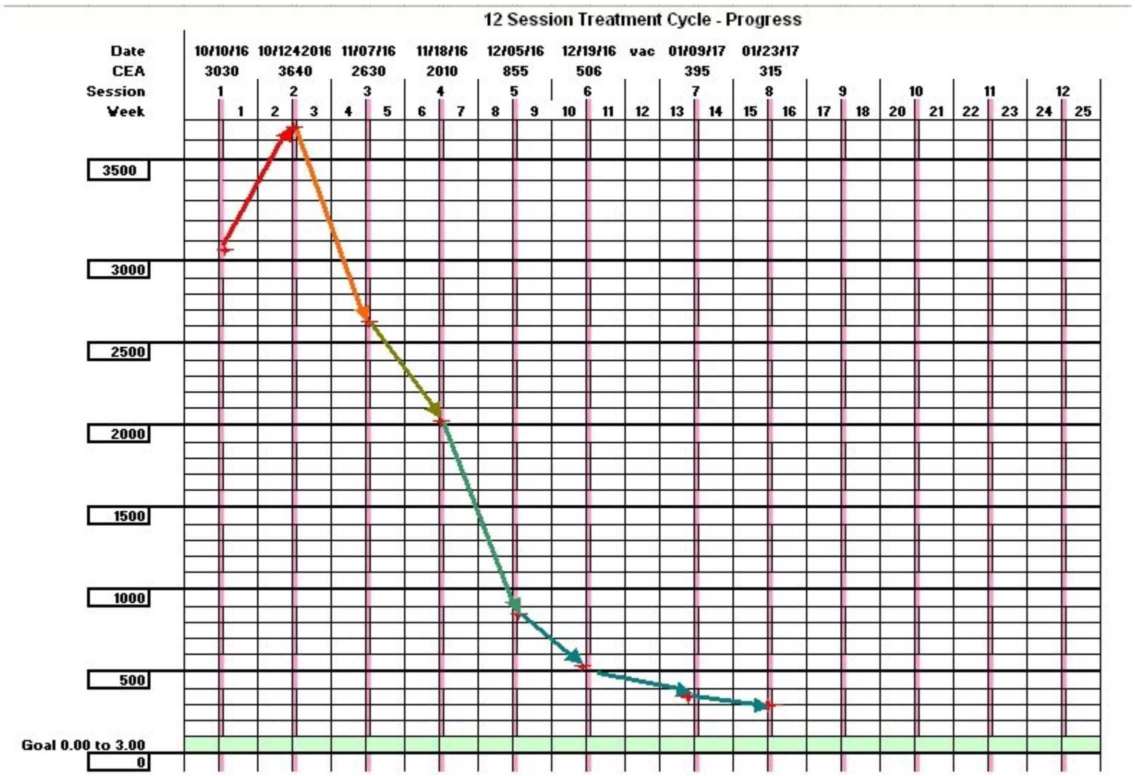
Volume-2, Issue-1

Cancer and Me

Well that title pretty much states it all, there is the cancer the passenger and then there is me the transporter of it. I say that because it is with me all the time. So as I pointed out in previous issues, I go in for chemo infusion treatment every other Monday, the last one before this one was January 9th, and now here it is January 23rd another treatment has come upon me. Of course the difference with my chemo treatment is that they draw blood for labs every other Monday, each time and for dialysis, labs are only drawn once a mouth. So my lab through the Cancer Center I have to say is probably more up-to-date regarding my medical situation, because the exactness comes down to having labs twice as many times as it is done every other week rather than once a month.

As the patient, it is important for me to track my labs, not just the Tumor Marker, which I will admit is probably the primary mover for me to continue Chemo. However, the labs also reflect other things that are important in maintaining my health. I also monitor the count for my White Blood Cells, which is important when the chemo you are receiving is pretty depleting my immune system; and of course the Red Blood Cells which determines whether I have to have an Epo shot or not that helps the body make the red blood cells with the help of iron. Now where my energy is concern I keep track of my platelet count as well, and should it falls out of the boundary established (150 to 400) it could cause the doctors to cancel or reschedule my chemo treatment.

Well enough of me talking about my labs, lets go and see what my Tumor Marker is for this most recent lab test –



Since my weeks vacation from my chemo treatment, I have been expecting to see my marker numbers bounce back with a higher numbers. I am a realists, I hope for the best and plan for the worst, so what my marker count is, kind of tells the story as to where I am in my treatment cycle, I dropped 80 points from last time.

Dialysis and Me

I was thinking of comparing my cancer burden with my dialysis treatments, but since I don't think there is a commonality in either of these that someone could legitimately compare. So I think I will just share my thoughts on the dialysis treatments that I receive and my stays in the Kidney Center clinic. As everyone might know, I changed clinic, leaving a clinic where communications between everyone working or receiving treatment seemed to be something that the patients enjoyed and made them comfortable in a place where dread might be waiting just around the corner.

For myself, I was comfortable in the other clinic, everyone had a ready chuckle to share, but now I am surrounded by people who seemed to have had their faces froze in place, covered with a serious note and frowns. Being a person who suffers from depression and loneliness, the lack of human contact is something that just makes my stay there that much more uncomfortable, as if it wasn't already unbearable point of existence for me.

A few weeks back I made an agreement with my family that I would go back to having three dialysis treatments a week, but since my stay in this clinic I have been so depressed and lonely, I have thoughts of quitting dialysis treatment all together running through my mind. So being whom I am, I made it a point to speak with my family about what has been bothering me and actually the only thing I was released from was undergoing three treatment sessions a week. Which means that I could consider going back to just two sessions a week rather than the three I have been doing these past few weeks. For me only having two sessions a week was not detrimental to my health situation, since my labs continued to be as good as they were when I did the three. So if you have not guessed, I am strongly moving towards only having two sessions a week, now I will probably hear all the horror stories of the dos and don'ts but since the monsters did not come out of closet the last time, I personally don't expect them to visit me this time.

So as I write this, at the top of my mind is the thought of just quitting dialysis altogether and I can hear the arguments of the adverse effect on my health, yes the argument plays for me most of the time, because believe it or not, I have heard it all before. Pros and cons, like an old song being sung everyday, but that does not make them right, first of all everyone is different and each is subject to things that another person isn't and visa versa, but none of that answers my own argument regarding the yes or no of it all. Still only going two days a week is another point of view entirely; still since I'm on the Tuesday, Thursday, and Saturday cycle, which day would I find beneficial to give up. Now if it was Saturday, I would have Friday through Monday off, which equals four full days

Dialysis Clinic - Customer Service

It was back in December 24, 2016, Volume 1, Issue 5, I wrote about the Dialysis Clinic as a community and the smoothness on how it operates. Of all the things I mentioned in that article I neglected to comment on Customer Service, it is a very important commodity that the staff of any clinic must have, it is something that the staff bring with them when they apply for any position within the clinic, where it requires that they as individuals deal with patients.

The primary functions of the Nurses and PCT job consist of the medical fundamentals, which they are instructed in and require learning how to perform their medical duties as it deals with putting patients on the machine to receive their dialysis treatment, along with taking them off. This primary is done in a manner that the patient's safety is the priority concern. Now those are the how- to in doing the job, but something that is not taught per say; it is Customer Service, this is basically the relationship between patient and staff, it is an important interacts with any of the patients in

Dialysis Clinic - Customer Service, continued on Pg-6

Dialysis Clinic - Customer Service, continued from Pg-5

the clinic. If it is done right, it creates a comfort level between the patient and the treatment they are receiving.

Now my experience in the world, dealing with people, I have found that Customer Service is something taught to the child by the parents, it is very difficult for an employer to teach an employee how to practice good Customer Service. Of course it can emphasize by management on how to treat the customer as they provide the service for such things as selling in retail or in a restaurant, where they wait on them as a customer ordering food. A waitress, who relies on tips to make extra money, uses Customer Service as a means to insure that their customers are satisfied and happy with the service they received.

Now in closing, the two things about Customer Service, which comes to be that there is nothing more valuable between a patient/customer and the customer service provider than a warm cheery smile and a heartfelt sincere greeting.

Clinic Review

Since I have started publishing this newsletter, I have a lot of time to observe what and who is around me in the clinic, dialysis and chemo, and in my observation, I noticed that patients in either of the clinic have more than one ailment. I know for myself, I carry around three separate problems, and one I have had for sometime, Post Traumatic Stress Disorder, End-Stage Renal, and now more recently cancer. Of course I am not the only patient carrying many ills on their shoulders, I met a person at the cancer center who was suffering from MS, plus arthritis, not to mention problems with her heart. I have noticed that a lot of patients who suffering from End-Stage Renal Failure also are diabetic, which could lead to the patient loosing legs and their eye sight.

The truth of it all, most patients could use a caregiver or a companion that they could interact with on a daily basis. Maybe this topic would best be a continuation of Volume 1, Issue 5, dated December 24th where I wrote about The Dialysis Clinic Community, where I suggested that patients get to know the people sitting to their left and right of them in the clinic. Life is so much easier to cope with when you have a friend or companion who understands what you are going through; just as it would be for them to have you as a companion.

I think this is a topic that I will explore further in future issues.

Notices & Tips

Notice:
This is the last newsletter hand delivered to the Lafayette Clinic, future copies can be obtained by visiting my web site -
http://ron-wicker.weebly.com//scuttlebutt/html

Dialysis from the sharp end of the needle

tracking industry news and trends, in advocacy, reimbursement, politics and the provision of dialysis

http://

http://www.dialysispatients.org/site/PageServer
http://www.facebook.com/pages/Dialysis-Patient-Citizens/213958433375

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Scuttlebutt

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