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Season's Greetings

Editorial Comments

As I was putting this issue together and gathering what materials I needed to complete this issue, I came across some old records of mine, which gave me information about when I was a patient at his facility back in 2008. Yes my being here is the second time for me having been a patient here. I think I mentioned this in Issue #2, when I provided some history of my life on dialysis.

Now believe it or not, I had approached the facility management, at the time (2008), about creating a facility's newsletter; my request was approved but to tell you the truth, I could not get anyone involved, so the idea died on the view, so to speak. You know I had had hoped that interested professionals would submit articles that dealt with their field of endeavor, such as,

dietician, social worker, etc. As it was I only received one article and it was from the dietician at the time, which I thought was very suitable to be posted in the newsletter. Since it wasn't posted before and the information is still applicable to a dialysis patient's health, therefore, I will be posting it in this issue.

I'll be posting a series of articles that will be dealing with Advance Care Planning, which I am currently reviewing for the Scuttlebutt issues. Now these articles will be focused on selecting a Health Care Agent, plus other items such as A Guide to Advance Directive Documents. Now any, if anyone has any questions regarding this area, they should be directed to the Social Worker for answers or assistance.

Your Plate and You

Phosphorus is a mineral found in many foods, especially protein foods. Your dietitian tells you that you must eat protein foods to stay healthy, and there is no way to avoid eating them. Phosphorus has a partner mineral called calcium, which is also found in many foods, mostly dairy products. The kidneys would normally control the amount of these two minerals in the blood. When kidneys are no longer working properly, imbalance can and more then likely will occur.

An imbalance in phosphorus leads to mineral deposits in the joints, skin, eyes, heart, and blood vessels. This "**calcification**" causes pain and itchiness. When Phosphorus is high in the blood, Calcium is usually low. The



body then takes calcium from the bones to replace the calcium in the blood. Over time the bones can become weak and brittle; I imagine you have heard of brittle bone disease.

There are three main ways to control phosphorus, 1) Consistent dialysis, 2) The Plate/food, and 3) The sponge/binders. Consistent dialysis is necessary for the proper cleaning of your blood, but it only removes some of the phosphorus from your blood. Most of the phosphorus that enters the body is through food. Therefore diet/food or the Plate is a key component in controlling the phosphorus.

The next step is to Rate the Plate at every meal and snack. The more meat, eggs or

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cheese at a meal the more binders/Sponge are needed to soak it up. Binders are Renagel/Renvela, PhosLo, Fosrenol, and Tums. Phosphorus binders are like sponges in that they soak up the phosphorus while it is still in the stomach. Bound phosphorus cannot enter the blood and is passed out of the body in the stool.

Since binding takes place in the stomach, it is important to have the binders in the stomach at the same time as the food. Then the binder can soak up the phosphorus from the food. If the binder is forgotten or taken a half hour after the meal, the phosphorus in the food will still get into the blood.

Besides taking the binder at the right time, it is also important to take the right number of binders, 1) the larger the meal, the more binders are needed. Just like the more water spilled the more sponges are needed, 2) the higher the phosphorus content in the meal the more binders are needed. **Plan ahead for when you eat out, by keeping your binders with you at all times.**

The Dialysis Clinic Community

The Dialysis Clinic can only be called a community, because we are a gathering of people from many walks of life, all coming together at this location for reasons that are related; some to provide the medical treatment prescribed by the doctors that provide service at this clinic, while the majority of us are here to reap the benefits of the treatment provided. Now having said that, let me move forward to talk about our community, something we belong to, regardless of whether we are active members or those that just sit quietly on the sidelines.

I'm working on my 14th year of getting dialysis treatments, and in that time I have been a patient at a number of clinics, which I have covered in Issue 2, (21st of November), so I will not clutter this issue with what I have already wrote about. Still, having been to other clinic, as a patient and just a visitor to see how each one was operated...I still visit other clinics to meet with people I know who work or are patients at these clinic.

My first time in any clinic, once I enter the treatment area, it is my habit to just stop and listen to the ambient of the working floor, to weigh how the clinic breaths so to speak. If the working floor is quiet and you can hear a pin drop, that clinic is not for me. What I need is a clinic that is alive and full of life, one where

the patients and staff take the time to know each other, so a comfort level is created. I remember my first time in the Lafayette Clinic; it was like coming home, because as soon as I was allowed in the treatment area, as a visitor, the on duty Patient Care Technicians greeted me. Thinking about the PCT staff, I remembered I had a picture of them, which was taken during the first few months of my being a patient here at this facility (2008); and I decided to share it with you –



L to R: Cathy (Nurse), Myrna (Social Worker), Louie (PCT)



Back row, L to R: Ramona (Manager), Terri (Nurse), Louie (PCT), Nick (Bio-Med), Bill (PCT), Laura (PCT), Heidi (PCT- Nurse Now), Rosemary (Receptionist)
Front row, L to R: Kim (PCT), Unknown (PCT), Myrna (Social Worker)

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The Dialysis Clinic Community, continued from pg-2

The Dialysis Clinic is more of a community than anything else, it is a place where people gathered, and the people here are not just patients who visit the clinic to undergo dialysis treatments. No, that is not all the people that come here, because we have the back bones of the Clinic, the Staff Workers, such as the Clinic's Manager, Social Worker, Dietician, Bio-Med(FTM), Nurses and Receptionist and of course the Patient Care Technicians...and on a regular basis we have Doctors that provide the patients the medical guidance necessary to insure that their treatment are in their best interest.

Since I described the clinic as a community, this kind of implies that everyone should talk to each other and the possibility that friendships can be forged amongst those that come in at their scheduled time. Now I don't know that any friendships are actually forged, because as I see it, people tend to take their individual chairs and fall asleep or watch TV, and they kind of ignore their neighbors in whatever pod they might be assigned.

In the Lafayette Clinic, there are 24 chairs or positions where patients can receive their scheduled treatment, which could run for three and a half hours to four plus hours. Now on Monday, Wednesday, and Friday, the clinic's operation consist of three shifts, from five in the morning until the last patient is removed from their chair, which would be around eight in the evening. What makes the clinic run smoothly is the Management Staff, plus the always and ever-present Patient Care Techs.

I didn't cover the other days when I described the operations above, and to do that, you must know that the clinic also has scheduled treatment times on Tuesday, Thursday, and Saturday, of course the hours of operation are reduced and they begin at eight-thirty in the morning until the last patient leaves around three or four in the afternoon, with only two shifts during these days. The staff might be reduced in there numbers, however it is still a smoothly run clinic.

I may have deviated from my original purpose in entitling this article 'The Dialysis Community,' because as I view the interrelationships within the clinic, I feel we have lost the human element, with all the people coming and going without a hi, hello, or by your leave. Nobody appears to be taking an interest in his or her fellow patients, or for that matter the people who give them excellent service in putting them on and/or taking them off of the dialysis machine. In short no one seems to know anyone, they tend to judge their fellow patients at a distance, by how they look, never making the effort to get to know just who they might be. I guess I have said enough about the lack of communications between people; so in closing let me leave you with this closing thought – **Who is the person sitting to your left and/or right?**

The Christmas Question

The Holidays are quickly coming and will be speeding off without a backward glance at the people who were idling through the holiday days, waiting for the glory and pleasure of the holidays to arrive so they could enjoy the moments of seasonal merriment, and for the most part, once the gifts are exchanged, the joy of of the day kind of dwindles away, leaving the people with a memory of the holiday as just a day of gift giving. After the holiday has past, what can they look forward to but many empty days, filled with a countdown of the next time the holiday will visit with them, a year away.

But what if the purpose or value of this Christmas holidays is, for example something that just comes down to the gift giving? So does that mean we only reap the benefit of the day in our receiving; with maybe a small token of pleasure we might derive in the giving? I hope not, I personally have taken the Christmas Spirit into my heart and I exercise its strong spirit, feeling the power of it everyday, and I hope each of you do the same thing. Because giving is what we should be doing all the time, yes giving without the need for thanks or to expect anything in return.

Advance Care Planning

I'm not one who makes New Years Resolutions, but the first of the year is as good of a time to review things that are important, especially those who are suffering from medical problems. Even now I find it hard to believe that it has come, yes 2017 is here. When I was young, I guess you can imagine how long ago that was for me, but hearing the year 2017 in any context was like hearing people talking about a date somewhere way far into the future, which could only be referring to a sci-fi year, but here it is almost 2017, it is the now.

Well I'm not young anymore, as I imagine you aren't either, nor can I say that my health is all that great, which tells me that other things, need to be considered. Of course I imagine that others like myself who are undergoing dialysis treatments or other medical procedures such as Chemo for cancer should consider looking into what I am suggesting here. Yes you want to know what I am suggesting, well it all comes down to you and your health, how you are treated and what voice you will have when you no longer have a voice to express your wants and needs; not to mention who will speak for you when you aren't able to do so for yourself, and for this to all happen, you need to set things into motion now; now because later will be too late to have your voice heard. Where does this all begin, right here –

Steps for Advance Care Planning:

- **Step 1: Consider the Issues**
- **Step 2: Introduce the Conversation with family and friends**
- **Step 3: Explore Personal Beliefs and Values**
- **Step 4: Define end-of-life Wishes**
- **Step 5: Document Wishes**

Considering the steps listed above, each is a step that needs to be taken as you weigh and consider the items listed below. Now these items you need to consider, you will find that they might be beneficial to your well-being and I will cover each one in upcoming issues. Each of these topics listed below calls for you to determine who your health care agent will be; and this posting deals solely with the need to choose such an agent for yourself.

Medical Durable Power of Attorney
Living Will
CPR Directive
Medical Proxy for Decision Making
Medical Orders for Scope of Treatment (MOST)
Five Wishes

When you take the time to consider an agent, it is important that they should be someone who –

- is willing and available (preferably not for instance, living in another state),
- knows your values and life goals and your preferences for life-sustaining treatment,
- will honor and follow your wishes,
- is able to make difficult choices, usually under stress, and
- has the time and commitment to serve as your agent for however long is necessary.

Remember, your agent need not be your spouse or someone closely related to you. In fact those closest to you might have the hardest time serving as decision maker for you, because his or her own feelings or values might get in the way. (If you pick your spouse and later divorce or legally separate, your spouse will be disqualified to serve.)

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Your agent can be a family member or friend or even a legal or religious advisor. It is also a good idea to choose an alternate agent, in case your first choice is unavailable, unwilling, or unable to serve when needed.

Now you as the person who is making this decision, you can decide whether you want the agent's authority to begin right away or only after it has been determined that cannot make your own choices. * It can be very difficult to deal with, even over the course of a single day. If you trust your agent (and you should) an immediate power of attorney avoids having to go through this process.

**Note:*

A physician or other health care professional with special training usually make this determination.

Above all, be sure to talk to the people you want as your agent and alternate(s) before you officially appoint them. Make sure they understand your wishes and agree to serve. And give them each a copy of all your advance directives, especially the Medical durable Power of Attorney.

If your choice for an agent is not a family member, be sure your family members know about your choice and how to contact the agent and alternates(s). If possible, it would be a good idea for you and your agent to talk with your primary doctor about the kinds of medical decisions that might be likely and the options available. Additionally, if a family member is not chosen it could very upset them but don't let this deter you from selecting the person who would provide you the service you will require, family ruffled feathers will take care of themselves.

Your agent and your doctor should have a copy of the MDPOA form and any written advance directives you have completed.

What's Involved in Being a Health Care Agent?

Picking a Health Care Agent is not an easy task, but no matter whom you might choose to be your agent, they will more than likely wonder what will be required of them as your agent.

In Colorado, unlike many other states, when an adult is unable to make his or her own medical decisions, **no one has automatic authority to step in.** Health care providers may naturally turn to a spouse for medical decisions, but spouses have no more legal authority make such decisions than do adult children, siblings, or even close friends.

To make any medical decision for any other adult in Colorado, you must be officially designated as that person's "health care agent" or selected as the decision maker through the "proxy process." Health care agents are appointed through a document called a Medical Durable Power of Attorney (MDPOAO, which is signed by one competent adult (the "principal") granting authority to another (the "agent") to make medical decisions.

If you are appointed as a 'health care agent,' you agree to make medical decisions for someone else (the 'principal') when that person cannot. Your responsibility might be temporary, for example, if the principal is severely ill or injured vbut then gets better; or it might be long term, if the principal has a permanent disability or chronic or terminal illness.

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The health care agent has all the rights of the principal to talk to doctors and other health care professionals, to look at medical records, and to make treatment decisions. Typically, the health care agent does NOT have the power to handle the principal's financial affairs. Health care agents may not be paid for their service, and their powers end at the principal's death.

If you agree to be a health care agent,

- Your job is to make medical decisions in line with the principal's values, goals, and preferences.
- You must put aside your own values, goals, and preferences and speak for the principal you should talk over in detail what the principal would wish for in a lot of different circumstances. (The Five Wishes, www.aginwithdignity.org, and Caring Conversations, www.practicaibioethics.org, booklets can help you ask the right questions and think about the kinds of choices that might be needed.)
- You must, as much as possible, continue to consult the principal about decisions and follow his or her expressed preferences.
- Be sure you understand whether your powers are immediate or only begin when the principal has lost the ability to make decisions. As noted above, when someone is seriously ill, their capacity to make decisions can vary a great deal, even over the course of a single day. An immediate grant of powers is helpful – but remember, you are only the decision maker when the principal cannot be!
- You must be willing to talk to many health care providers, especially doctors, and go with the principal to appointments in health care facilities or at the principal's home.
- You must learn everything you can about the person's condition, treatment options, prospects for recovery, and – if needed – end-of-life choices, such as when to withdraw or withhold certain treatments or when to arrange for palliative or hospice care.

Depending on the circumstances, the job of a health care agent can be very demanding, requiring a lot of time and commitment. . But the job has many rewards, including the knowledge that you are safeguarding the desires and dignity of someone you know and care for.

If your needs are more immediate than the scheduled posting of the rest of this topic, please contact the Social Worker to get assistance for your health care needs.



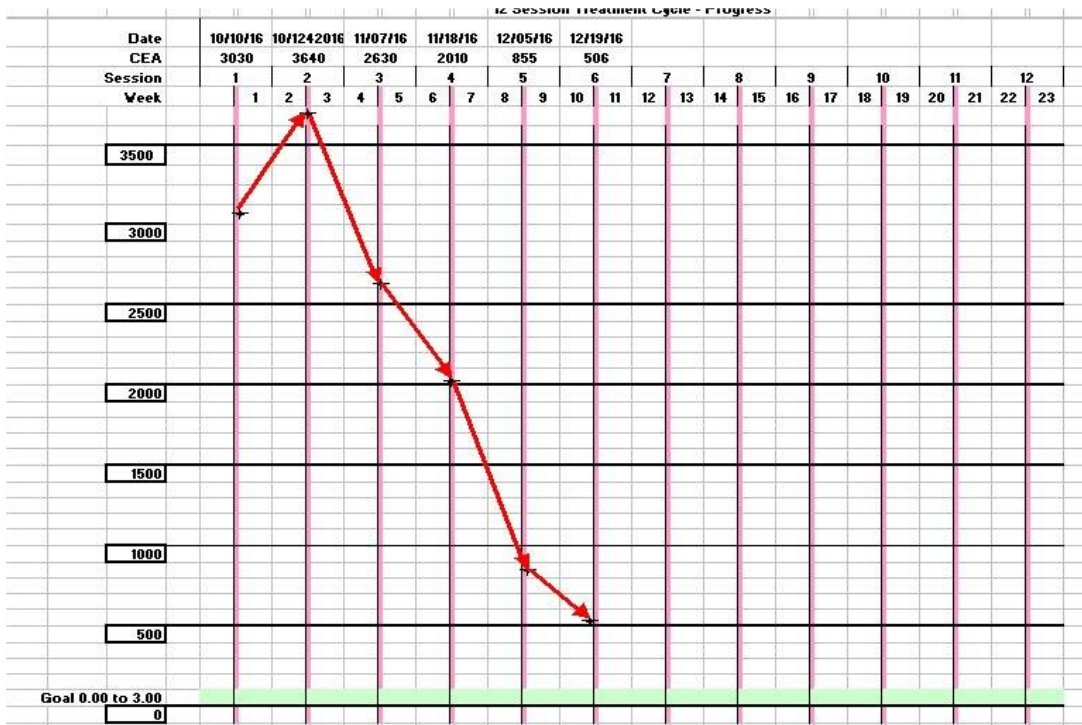
Some more Good Chemo News

Now if you remember in previous issues I posted a bar graft to show my progress on Chemo, it was I will admit a wee bit crude, well I hope you do, well anyway I created a new bar graft to illustrate a more realistic view of my progress on Chemo. See bar graft on next page.

I have to remember that the original forecast of my life expectation was very gloomy and dire, sighting that if I did nothing it would be a matter of months, but if I had the cancer treated I could look for maybe three and a half years of life. Now that original forecast was based on the original Tumor Markers seen below.

Some more Good Chemo News, continued from pg-6

on the bar graft, but that has changed with the continuing lowering of the markers as my treatments went forward. Now in all of this, me being a person with an open mind, who always 'plan for the worst but hopes for the best,' I could only deduce that my markers were telling me something positive, as it shows the numbers going down, which indicated for me that my life expectation could be extended outward, furthering into a possible future down a road that I was not able to see an end for and that is where I must leave my thinking looking forward.



Notices & Tips



Information sites online that would provide you some good information.

The following websites offer additional information to help you understand kidney disease and dialysis, transplantation, dialysis industry news and other opportunities available for dialysis patients.

General Pre-Dialysis and Dialysis Education

- <http://www.lifeoptions.org/> (pre-dialysis and dialysis education)
- <http://www.kidneyschool.org/> (pre-dialysis and dialysis education)
- <http://www.davita.com/> (pre-dialysis and dialysis info)
- <http://www.kidney.org/> National Kidney Foundation; kidney disease, research
- <http://www.kidneytrust.org/> The Kidney TRUST - Chronic Kidney Disease education and testing

Notice

Next publishing of the Scuttlebutt will be in the second week of January 2017; if you have an item or article that you would like included please use the contact information shown at the bottom right of this page.



For those of you who might be interested in getting your future copies of Scuttlebutt online, please go to the link provided below:

<http://ron-wicker.weebly.com/scuttlebutt/html>

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