

A Journey with Cancer: The Palliative Road 11/08

Why I am Writing

The news of cancer came upon me quite suddenly. My suspicion that a pulled muscle was the source of the pain in my side was quickly dispelled as results of all my tests and scans – multiple tumors in my lungs and abdomen, source uncertain – came in. The prognosis: vigorous chemotherapy may produce a partial regression.

Faced with that news and the reality of a terminal illness, the medical world most frequently offers an option: go after the cancer aggressively and hope that some new drug or procedure will appear on the market to continue your life longer, or not. Young parents, children and those who have important work unfinished often choose to go against the odds. Many have prolonged their lives significantly by this choice.

At the point of facing my reality my only question was “How do I want to live?” I wanted to know what would give me the best quality of life. Knowing the quantity of my days to be limited, I cared more about the richness of days than their number, more about spending quality time with those I love, passing along whatever treasures I have collected over the years of teaching and consulting, and living every moment to the full.

Though this was clear to me, I found that explaining it to those I love was difficult. I’ve been dubbed “The Queen of Options” by co-workers. It always seems possible to head columns with options, list advantages and disadvantages, and then make the best choice. I could clearly spell out what the chemo option would bring: the oncologist was very honest and direct. Column A could be filled in. But what does the other option mean? The word I used for Column B was “Hospice” but I have come to know that I am talking, first, about the choice for palliative care.

My purposes in writing are:

- to answer the question folks have about choice B;
- to assist those who are faced with a decision regarding treatment and their caregivers, and
- to clarify my reflections for myself and others.

It is my hope that these reflections might be of benefit to the readers.

Palliative Care

What have I learned about palliative care? The purpose of palliative care is to give a patient quality of life by managing pain. Medications can relieve symptoms, and chemo can be palliative.

My own example can illustrate the difference. The first oncologist recommended chemo the first 2 days of each week. There would be three drugs. The side effects would be neuropathy (which may or may not go away after treatment), mouth sores and diarrhea. The doctor explained that neuropathy causes tingling in the hands and feet, inability to open jars, etc., uncertainty about walking and driving and sensitivity to the cold. After three months, further tests would show if the drugs were working or not. In the meantime the cancer could be worse and then they would try something else.

I asked what would happen if I did nothing and the Doctor honestly told me, "It won't be pretty." So I asked if I were to have the treatments what would happen in the end. He honestly told me, "It won't be pretty."

He emphasized that it would be rough, that I would have to be committed and not look back.

Though saying yes seemed the brave thing to do, I just couldn't do it. Much of my life has been dedicated to teaching non-violence. Somehow I felt that the option he proposed would be similar to dropping bombs in Iraq, but inside my body. I didn't want to think of waging war, killing the bad guys or fighting cancer.

So I met with Community Leadership and my siblings. It was pretty unfair to them since I couldn't explain the second option and I told them I didn't think I could do the chemo suggested by the oncologist. At a standstill, I called a friend who works with hospice. I asked her to help me fill in the blanks for people. Though she explained about the philosophy of giving quality, relatively pain-free life, she went beyond that. She set up an appointment for me with her boss, an oncologist who is also a lung cancer specialist certified in palliative care. She explained to me that sometimes chemo can be palliative.

I collected all my test results and met with him five days later. (Is God good to me or what?) He studied all of the results and suggested a mild series of chemo. I would have two drugs the following Monday, one drug the next, a week off, a meeting with him and a repeat. I could call off the treatment at any time.

A quality of life survey was given to me. It indicated that the quality of my life was already compromised. The symptoms were keeping me from working, from normal household tasks, from walks, etc. At the end of round one I will be given another quality of life survey and will have a CT scan. The choice to repeat the series will be based on the former. If my quality improves, it will probably be because the tumors have shrunk. But the real indication of success is the quality of my life.

Hospice

There is a continuum from palliative care to hospice care. The goals of hospice are to allow a patient to die in the care of their loved ones, freed as much as possible from physical, emotional and spiritual pain. I am grateful to have chosen this path.

Attitudes that Shaped My Decision

A Slovenian friend returned recently from a trip to Ireland. She said that she was very aware while there that there is a “thin veil” between this world and the next in the land of my ancestors. It was a lovely way of explaining my Irish heritage and my family’s attitude toward death. Those that have gone before are very close. The fullness of life for which we all long is only a step away.

Wrapped intimately with my heritage is my faith. It teaches me that God’s kingdom has begun, God’s presence permeates life, and God will call us home when we have completed the role we are given to play in The Body of Christ.

There were times, and not too long ago, when I questioned my attitudes. My responsibilities as a member of the Leadership Team of the Cleveland Ursulines included consultation when end of life decisions needed to be made. I always seemed to be the voice questioning why one would choose to prolong a life of suffering. I am not a Kevorkian, I understand the role of suffering and all that it can teach us. I simply couldn’t resolve the quantity vs. quality choice any way but the latter. It made me question: Did I not value life? Was I not invested in the now, in the people in my life? There were some dark days of questioning, most likely as the disease was progressing in my own body.

Now I have clarity of the wonderful gifts life has given me of family, Ursuline Community, friends and co-workers. I am truly blessed and I want to spend my final days in gratitude.

Surprises

Of the many things for which I am grateful, the biggest at the moment is that I have been spared the depression that so often comes with this disease. I trust that, should it come, I will recognize and deal with it.

Concretely, that has meant that the struggles I would have thought would accompany learning of my condition are not present. I would have expected deep regret over all the little detours I have taken on the journey and the times my priorities weren’t straight or my commitment was lukewarm. Rather, I am experiencing a God who simply holds me, for Whom those detours speak only of my humanity and not of my heart’s desire. I feel the presence of a God who loves me, who is present in every beautiful moment and in the many people who serve and care for me in the myriad ways we call “The Body of Christ.”

Divine Providence

There are unbelievable ways that I am supported on this journey.

Though I had been belly-aching for a while, tests came back negative. When the cancer finally showed itself, I was given speedy and excellent service.

I have a 24-7 nurse available for any need that arises.

I am living with my sister, Sister Ann in a beautiful spot at a beautiful season.

The parishioners and staff could not be more supportive of Ann and me.

My family, congregation, friends and acquaintances have reached out in multiple ways to assist and support both Ann and myself. I am deeply touched that each has a unique role to play and a unique gift to give. Whether it is hands-on Reiki treatments, offer of rides, meals, treats, cards, prayers ... whatever, God provides through them in wondrous ways and I am blessed.

I am blessed by my work with women seeking to live the Ursuline Life. Their desire and dedication enriches me and the privilege of sharing this life with them inspires and focuses me.

I am truly blessed.

Courage

Many have expressed their doubts that they would have the courage to make the choice that I have made. For me, knowing that the disease is terminal, it would take more courage to choose treatment that I know will make me miserable. I respect those who have the courage to choose aggressive treatment against the odds when they have an option for years of life, or responsibilities for children and loved ones, important work unfinished, etc. It's a different kind of courage.

Many –too many to fully name - have taught me courage in different ways. Sister Marilyn J. Scott made each decision as her Parkinson's disease progressed, gracefully accepting her limitations. My brother, Kevin, refused to stop fighting cancer and won a battle which seemed impossible. My brother, Jim, has accepted his Alzheimer's with humor and grace, and speaks openly about it for the sake of others. They and so many others are shining examples of courage. The list is endless. Claim your spot on it!

The Journey Unfolds

I've already been through two and a half months of treatment. The lung tumors are responding. The abdominal tumors don't seem to be and are pressing on some vital organs, causing a bit of distress. One day I said to God, "Is THIS what I said yes to?" Then I thought about so many thousands in refugee camps who suffer dysentery without

privacy or dignity. It puts things in perspective and I am grateful for all the aids that are mine.

My oncologist tells me that I have to become “independently dependent.” Though my head tells me I can do things, my body doesn’t agree! I quickly run out of breath and out of energy. He said that now is the time that I sit and direct folks to attend to the sifting and sorting I hope to accomplish. This requires a letting go and I pray for the gift of grace-filled abandon.

As the journey unfolds I will be adding to these reflections. I began them based on questions Sisters, family and friends raised. I hope you find them helpful. I will be glad to address anything further that might concern you.

Thank you for being part of this journey with me!

“For all that has been, Thanks! To all that shall be, Yes!” Dag Hammarskjold

A Journey with Cancer: The Palliative Road Part II 12/08

The Hidden Message of Undetected Cancer

As I think about what I have learned that might be helpful for you or your loved one, this is a key point.

I’d not been feeling well for some time. Since health professionals couldn’t find the source, I decided I was just a whiner. When it was time for my six month check up I had lots of little complaints and decided that it was simply the aging process and time for me to adjust to my body so I kept my complaints to myself. (Thankfully, a week later what seemed to be sciatica got things moving in a different direction.) But such thinking will happen if all of one’s complaints seem unfounded. Like so many others, I have the type of cancer that is insidious in that it spread twice before making itself known. Since no early tests revealed a problem, I decided it was just me.

Having developed this pattern of thought it was hard for me to acknowledge the changes in my body even once they were diagnosed. Each morning, seeing my perky self in the mirror, I expected myself to function independently. I looked the best in every gathering, rested and well. To gradually confess that making tapioca was a day’s job, dusting the living room took three days or emptying the dishwasher did me in was very difficult. The saving grace for me was that my sister did not hold those expectations, saw beyond my perky demeanor and made it as OK as possible not to be a contributing member in the care of our home. I can’t underscore enough the importance of people in my life who

understood that I simply could not do what seemed like simple tasks and who helped me change my thinking to reconcile with that fact.

Even as I was adjusting my thinking, I just didn't seem able to bounce back from the third round of chemo. Simple tasks of hugging my tall relatives, or walking down eight steps to take dinner meat from the freezer were leaving me breathless and light-headed.

I found myself needing to speak with my sister of when I should move from my lovely convent in Chesterland to the Ursuline St. Angela Center, a licensed nursing facility. The move didn't seem imminent but that all changed rapidly. Somehow it seems that my body gets my head working on things...it has a certain intelligence and nudges my mind to prepare for what is next.

Though we decided nothing in our conversation, we agreed that it would be best for me to move when being alone in the house was no longer a good idea for my safety and Ann's peace of mind.

Getting on the Fast Track

The Congregation gathered to celebrate the Feast of St. Ursula on Oct. 19, 2008. I wasn't up to the crowd but thought I could take my slow walk from the convent to the Church for liturgy. Needless to say, I didn't assess that one very well! I was aided home by two men and truly crashed, finally knowing that I needed to move. "Mind over matter" was not a viable option. I stood up, my blood pressure plummeted. No contest!

The best analogy I had was that the car was out of gas and oil and the engine was burning out.

Palliative care determined that I was dehydrated and I went to the St. Angela Center for hydration the next day. On Thursday blood test revealed that the chemo had knocked my already under-active thyroid out and on Friday blood tests revealed critically low numbers which brought me to the Palliative Care Unit at Cleveland Clinic.

It wasn't until I was on my way to the hospital that I read the blood reports. Seeing "critical" raised the question for me of what was critical, my blood or me. If it was the latter, I needed to be open to let go of doing good-byes my way. By that time the analogy was that the car was out of gas, oil, transmission fluid, even windshield washer! Ann and I had a short chat about my trusting her to finish up whatever was incomplete of sorting and sifting.

The Palliative Care Unit

The call I received was, "You need to have some transfusions. Just rest up and we'll call you when you have a room." It doesn't get better than that! Sitting in an emergency

room for hours when one has no immunity is so much the normal situation today. To be treated with such service is priceless.

The Unit was quite special, the health care professionals kind, courteous and caring. Many had served in the unit for a long time and saw it as a privilege to walk this leg of the journey with those they serve.

My New Home

I returned to the St. Angela Center the following Monday and was admitted for residency on Wednesday, once again un-premeditated but clearly the next step.

Once I was living here I realized that every ounce of energy had been taken up with the simplest of things. Being here has released some energy for sharing these thoughts, planning a grand farewell, finishing up a few tasks, spending some quality time – especially with the next generations - and praying my good-byes.

Closure

It has seemed from the earliest decision for palliative care that tasks emerge and beckon me.

In 2000 I took a position in Pastoral Care for troubled children in Fall River, MA. Though everything fell in place - the position fell into my lap unbidden, a house of Sisters of Mercy invited me to live with them, the work was definitely an interest of my heart and of the Ursuline mission - it was hard to say yes to moving so far from home and community. I felt I had to be able to commit for a time so that I wasn't just one more person to abandon children whose life experience knew nothing other than broken relationships.

In 2004 I was elected to the Leadership Team of the Cleveland Ursulines. I wanted my New England good-byes to be intentional. I wanted to celebrate the many people whose lives had touched mine in those years up north: children, staff, Sisters, friends.

That's the call I am experiencing now. I hope that I have lived every day as if it were my last. I hope that I finished leadership as I did my time in New England, letting those I walked with know that they have blessed my journey and I continue with them on theirs.

Two lovely good-byes are a source of great joy and consolation to me. A sister I worked with for the last four years stopped by. We'd been trying to see one another and my energy crises were getting in the way. She told me that it's OK, that over the last four years we'd said all the important things.

And my Rhode Island friend pulled up to the bed in the last minutes of her visit and said, "There isn't anything left unsaid."

These gifts of the heart give me the freedom and peace to live the gift of the day and the blessing of the moment.

And the last days?

"It won't be pretty." Eventually I expressed this statement of the first oncologist to my palliative care nurse. At my next visit with my palliative care doctor, he explained what cancer patients can normally expect.

Usually death from cancer isn't traumatic. As the patient's energy decreases he/she could expect to become homebound. Eventually the patient will become room bound, and as energy decreases will stop eating and become bedbound. At that point it is a matter of days.

Knowing hospice's commitment to keeping the patient comfortable I haven't been concerned for myself. I just don't want anyone to experience "not pretty." I find comfort now in knowing that hospice will wrap my loved ones in their quality-sustaining cloak. I realize I have to let go and free my loved ones to do what they are comfortable doing. I trust them to do whatever is good for them to have a laughing memory!

Planning the Party

It's been exciting for me to pray about my farewell. What do I want those who follow me to remember as important about life? I use to say that I needed a two day wake because I wanted so many songs to be playing in the background! Now I have some wonderful sisters and relatives preparing a little concert of five messages to live for and by. It is my gift.

It is my hope that these reflections will be of benefit to you or a loved one. It's been a blessed journey to share them with you. Spread the good news of quality of life and death and the wonderful work of Hospice.

With Deep Gratitude

Sister Anita Whitely, OSU

A Journey with Cancer Part III

Melt-Down-Monday

As wonderful as it has been to know the gift of peace during this part of my Journey, I must admit that I was actually relieved when, at last, more than five months after diagnosis, Melt-Down-Monday came! Somehow the tears of frustration were a welcome recognition of the reality that, even when all is well, life is a journey and it has its bruises. And somehow it was a consolation to identify with that very human experience, to find myself plopped right where I belong - in the center of this fumbling human race. There is a moment when it is not only OK not to be in charge, but appropriate to feel the helplessness that tells me that my life is in the hands of Someone so much more qualified than I!

I suppose this was the first of many times when I will recognize that a physical change has taken place that won't be reversing itself. The educator in me is fascinated and challenged to see how I'll do things now, how best adjust, where to put my efforts. At this time the changes have to do with breathing. Friends will finally be able to get a word in edge-wise!

It is fascinating to walk with a many-faceted illness. I am constantly surprised by new directions, comfort where there was discomfort and challenges in different areas. I welcome the time and space to adjust, rethink and begin again!

People can be so helpful at this stage. Sometimes I need to talk it out with someone, or I really want their opinion. The greatest gift those who care can give is availability...and I don't mean physical presence. A brief check-in call or a stop at the door provides the patient with an opportunity to ask for help without feeling helpless.

As a family member or care giver you have the extra burden of figuring out what to do in the meantime to adapt to shifting needs, energy and interest. The patient's seat is a more comfortable place to be. I appreciate the openness of others to just let me work it out.

Of Rites and Rituals

As more families experience physical distance, as our lives become more diverse, the longing for a universal language seems to grow. The shrines that appear at the sites of tragedy and accidents indicate that we long for a language beyond words that will express love, loss, sadness and compassion. The many invitations we receive to engage in meaningful conversations challenge us to find a language to express the most important realities.

For my family, the strength of our continued shared faith experience was a blessing when our eldest sister, Pat, died of cancer in 2006. I recall the shock of knowing that my

family and I would be repeating those faith traditions over and over. I wondered who would be the last to say the good-byes. Being the second youngest I thought I had a great chance to be it and, even then, wanted each good-bye to be special and marked.

At the beginning of the Journey with Cancer my prayer support group engaged in a lovely prayer time. Part of the prayer was the giving of a cross, a small wooden holding cross that fits into the palm of my hand. Each of us gathered prayed for blessings for me: faith, patience, humor, compassion, peace, consolation. With each blessing prayed, the weight of the cross diminished. Friends and relatives have added their blessing prayers and the cross is a tangible sign that I walk the journey supported by men and women of faith, in the footsteps of Christ. Sisters, friends, hospital personnel, St. Angela Center staff have prayed their blessings into it as well, and the cross is my companion and reminder of the many who are walking the journey with me through prayer and support.

At Thanksgiving time I felt that I wanted to give a cross to each of my siblings. Then I realized that WE all needed to give them to one another. In a very beautiful circle we each took turns praying our blessings on each couple. What a wonderful experience! Part of the blessing was the naming of how each has been and continues to be a blessing in our lives. However our stories will unfold, we continue to faithfully carry one another in prayer, love, mutual respect and support.

Our beliefs can be communicated through the most simple means. And the gift of sharing them is invaluable.

And Now?

Now I am waiting on God's time. I've sifted and sorted, cried and thanked, forgiven and been forgiven. Shall it be just a deep breath into everlasting mystery? Will it be a gentle snipping of the last thread that binds me to this wonderful life? Whatever it may be, I am certain of one thing: each of our lives have meaning. It's not for you and me to know just what special gift God gave each of us for our day and time. It's enough to have done our best to say yes with unwavering conviction that God is at work in our world – and all is well. I am most grateful to have chosen the palliative route and I pray that my experience may prove to be of help to you or a loved one down the line.

A Journey with Cancer Part IV

Common Journey

Whether they've chosen aggressive treatment or palliative care, cancer patients often have a date they pray to see. The desire to be part of the event musters their strength to be well.

Such a date for me was January 18th when Sister Erin Zubal, graduate of our College, would be making her religious vows as an Ursuline Sister. Having worked, traveled, prayed, played, laughed and cried with Erin, I prayed to be present for that great moment.

And, as so often seems to be the case, God answered my prayer in an unexpected way!

The Thursday before the event, I fell. X-rays showed no breaks and I was confident and grateful that I would make it to the profession. Just 2 and ½ hours before the ceremony, however, I discovered that my right leg no longer worked! Later I would learn that the hip bone had fractured.

Spared a broken hip days earlier, in good health to attend the long-awaited event, I was a howling, whimpering sissy just hours before. And yet, sitting in pain was do-able. I wasn't bed bound, wasn't obviously ill, and I WAS THERE! Had my hip broken at the fall I would have been in Cleveland Clinic.

The incident made me recall how a friend of mine often says that the pictures of Saints looking pious and at peace with halos around their heads are misleading. The truth is that they, and we, are dragged to holiness kicking and screaming! God hears our prayers and answers them, but we are not in charge.

Learning Opportunities

A goal from the beginning of this Journal has been to share what I learn about Hospice and Palliative Care. At the start it seemed I'd be making a one-time decision and yet I have had to choose over and over.

When my blood counts dropped drastically I had the choice to refuse treatment, and when the injury took place I could only make a decision by looking at the same principles. It looks like Providence is using this as a learning time for all of us, offering opportunities for me to learn, discern and choose according to great guiding principles.

So far I learned that a primary objective is to *choose quality of days of life over the number* i.e. treatment will keep me alive a bit longer but I will suffer debilitating and on-going side effects. I dealt with that when I chose the less aggressive form of chemotherapy.

The questions raised by the recent break invited me to consider again the principles by which to determine a course of action.

- How do I decide whether or not to have tests to find out what is injured?
- How do I decide whether or not surgery will add to the quality of my life?
- Will treatment prolong life or prolong dying? And, again, what quality of life?

My Palliative Care nurse and Hospice friend helped me sort this out and my decision to go forward was based on these realities:

- 1) I am not actively dying. That process seems to have slowed down.
- 2) To choose not to have surgery is to choose to be dependent and in pain. My decision wouldn't hasten dying but hasten limitations and ensuing complications.

So I am post-surgery with a half total hip replacement. I'm blessed with wonderful care, great physical and occupational therapy and very little pain. Though I am faced every day with the reality that I am much more dependent, I believe I made the right decision. Everyday I get stronger and more able to do things. I can't imagine being bed-bound and totally dependent when I am feeling so well.

A reality that I am taking in is that I will probably always need someone with me if I walk. I can't trust the light-headedness that comes unpredictably. But that is a small thing.

Each day I am more aware that I know nothing of where the road is going! The Journey with its many twists and turns continues to fascinate me and the gift of life continues to thrill me.

My prayer is that I can simply say yes to the next turn in the road.

Journey's End

May, 2009

There are haunting lines in the song *Journey's End*: "Just as dawn shimmers through, I will set my course on You. And I will follow You, I will follow You to Journey's End."

In the last writing I said I didn't know where the journey was leading. Hopefully that is one thing I have always been confident about! What I couldn't have anticipated are the many curves the road has taken and the questions and lessons that awaited me at each one.

When I began to write it felt very safe. The cancer was advanced. I anticipated a quick journey along a straight path. I hadn't anticipated the ups, downs and detours or what they would teach me, not only about Hospice and Palliative Care but about myself. Having made the commitment to share this story with you, I humbly share also those lessons. It is my hope and belief that you and/or your loved one might in some way benefit from this Pilgrim's wanderings.

For each the challenges will be different. I ask you, as a loved one, to stay alert since those who know the patient can offer valuable insights as to their reactions, frustration, puzzlements and learnings.

I asked the Doctor last month if I could begin the last chapter. He said I could begin to write it because my thinking will become less clear but to leave it open to be finished at

Journey's End. In the meantime so much more has happened that it seems to warrant a Part V.

Since Part IV...

Limitations

Physical and Occupational therapy following my hip replacement went very well. Walking and doing most daily chores were not impeded by the hip replacement as much as they were from the effects of cancer. As I began to do therapy I realized how light-headed I often was, how out of focus things sometimes were. That became compounded with vertigo. So, for safety's sake, I needed someone with me to move from place to place.

The independent woman who loves to be in control of her life received a wonderful gift, then, when told I could transfer myself from bed to wheelchair, to wherever. I would need a companion to walk but, like a teen-ager with a driver's license, I had wheels. This was truly a gift! It had been hard for me to ring for help, especially during the night, even though I was constantly encouraged to do so.

I was remarking on the freedom that my wheels brought me to Father Dunson, a priest friend who has done marvelous work with young men and women who'd been child soldiers in Africa. He very matter-of-factly commented on how thrilling it is when people receive wheelchairs in Uganda and, for the first time in their lives, are off the ground. It took my breath away. I thought of the pictures we see of injured or malnourished children sitting or lying on the ground and I was given one more reason to count my blessings. It's so easy to take our privilege for granted.

In the midst of the vertigo challenge my doctor came to see me. He asked if I had been able to complete the things I wanted quality time for, i.e. giving things away, saying good-byes. I told him that I HAD done that but when God didn't take me I started some new projects that I had to close up. Being quite a perceptive man, he quickly recognized that I was doing all that I could to pull up the energy to continue to work on those things. He said that I was actually defeating my own energy by pushing to stay mentally alert. He wanted me to step back, even to disconnect my phone!!

As I began to take steps to honor his request — except for the phone — I realized the great effort it had been taking to draw up the energy. Much peace came from honoring the need to rest rather than push myself.

As a cancer patient, caregiver or loved one, I encourage you to watch for this. For those of us who spent our lives being active, having a finger in many pies at once, it is not obvious that it's OK to just be. It took backing off from my recent projects to realize that I was exhausted – and rest was a gift.

Privacy vs. Availability

I realize that I have tried to address this throughout this series and can't quite express it adequately. It has clearly been and remains an area of struggle for me.

While I was still living at St. Anselm it wasn't an issue. I had a lot of quiet and alone time and always knew when visitors would be coming.

As I anticipated moving to the St. Angela Center, I realized that there would be more people, more activity and little predictability. However, I looked forward to visiting the Sisters, family and friends who might stop in.

There is a fatigue that comes with cancer that is more profound than anything I have experienced in my life. I quickly realized that the visits drained me. I wanted to see the people, love them dearly, but felt that the well was dry and I couldn't replenish it except for uninterrupted time of quiet and rest.

The present challenge is to surrender. I love and trust those who call and come. They understand my honesty and I am simply called to speak the truth.

Lessons for You...

Though each person is different, my guess is that the energy struggle is universal. For some, being surrounded with people buoys up their energy. For others, down time replenishes it. Was the patient a one-on-one person? Was he/she energized by lots of people and conversations? Did he/she relish alone time? Thinking about this might help you to know about visiting and/or help the patient to know that it's OK to do whichever brings more serenity.

Reflection on your relationship can also be helpful in determining how much help the patient needs. I tend to be independent while there are others who appreciate all the care they can receive. With the unexpected freedom to walk some and ride some, I want to do as much for myself as I can. Those who know how independent I am understand that right away. Though I am extremely grateful for the thoughtfulness of those who want to be helpful, their efforts to do for me become frustrating. It's best to ask if the patient needs help and respect their answer, even if it doesn't seem right to you. When the time comes that more help is needed, I'll call on those who so generously offer their assistance.

The Woman in the Mirror

We had a care plan meeting a couple weeks ago with significant persons from the St. Angela Center Staff. During the meeting I had to confess that, since cancer, I have recognized that there is a person who lives inside me who has serious control freak

issues! I, of course, blamed some of this behavior on the medicines, but I promised to be a patient and let the nurses be nurses. The blessing of Palliative care is that the patient has a voice. It is time for me to remember that having that voice doesn't add RN or MD to my name and I need to let the professionals exercise their skills.

Unanswered Questions

One huge difference between treatment and Palliative Care is that the patient knows what is going on physically if the cancer is being treated in the traditional way. In Palliative Care, the symptoms I experience are being treated but there is really no need to know what the cancer is doing. I surely don't want to go through tests to find out because the cancer is not curable and I've made my choice.

I sense that I am in the minority of hospice patients in wanting to know about the progression of the disease. It's the educator in me, I guess. I'm fascinated by different symptoms as they show themselves and welcome the thoughts the nurses have about them. I want folks to know about the progression of my disease for their own peace of mind.

Give It What You've Got

If there is one thing I have learned, it is that each person has a unique gift to offer at a time like this. As I write I am aware that my circumstances are very different from so many other patients who are dependent on one or two people for the care they need. I could say that I'm blessed with an over-abundance of family, Sisters and friends who are eager to be helpful and supportive.

As people learned of my diagnosis they often would call and say, "I can't *drive/get out to the store/whatever* but please let me know if there is anything I can do for you." Each person does have something to give. When, as in my case, others are also available to care for the patient, it is best if they give in the way in which they are most comfortable.

One of our Sisters always said she was going to write a book about the people who should never be able to visit someone in the hospital. I didn't encourage her because I know that those who visit mean well. Sometimes they just don't know what to say. I'm sure the following would be included in her advice.

Knowing that your Uncle George had the same thing and died a miserable death isn't too helpful. Hearing about the troubles you are having at work isn't the most uplifting conversation — especially if those conversations haven't been part of your relationship.

When a friend/acquaintance is terminally ill is NOT the time to take on a new role. Drilling the patient on her daily routines is rather demeaning: are you eating all your food? Why are you in bed during the day? Did you take your medicine? Only the primary caregiver needs to go there.

It might also be helpful to ask yourself if you are conversing differently than if the patient were well and in his/her routines. In order to be as independent as possible and conserve energy, I am sure I am not alone in organizing my space so that most of what I need is within easy reach. Some items that I might have kept in a drawer, or on a shelf in the kitchen, bedroom or bathroom, I now keep in view and close by just to have them handy. That leaves me vulnerable to visitors' comments about what I am reading, viewing, praying, using, typing, doing, eating. I realize that I have sacrificed privacy for independence. As a patient those sorts of comments and questions make me feel that I am in a fishbowl. Though I know people mean well, such comments are one more reminder of my growing dependency.

Commenting on cards or gifts that the patient has put out is different. They are put out to be shared.

Build on the interest you share. If the patient is homebound, conversations about mutual interests can broaden the horizon. Above all, having a captive audience is not the time for religious or political debate unless that has been the pattern of your relationship. Such conversations rank up there with Uncle George's miserable death!

If you have not been a confidant, you are not the person to give spiritual care at this crucial time. I was touched and impressed when a Sister-friend who'd served as a mentor to me asked me if I am afraid to die. It was appropriate. We had shared matters of importance and she was the right person to ask that question.

Build on the relationship you have. Let the patient know that you care and are praying. Those are the biggest gifts.

And, patient, it is our job to be honest in our appreciation and about our limitations. This is our last chance to live truthfully and authentically in the moment, to express our love through honest conversation and peaceful presence.

Expectations and Reality

During the care plan meeting I noted that I find the passage of time unreal. It doesn't seem possible that this body and soul experienced the seasons of fall and winter and now spring. The perceptive women gathered at the table reflected that I had not expected to be around this long. How true! I was happy to see Christmas, surprised to see my January birthday and astounded to experience Easter 2009.

Looking back at my earliest writing, I'm aware of assumptions and expectations that were mine as this journey began. Opting for comfort and quality, I expected that the palliative route would actually be shorter than that of treatment. It is amazing to me that almost seven months beyond ending palliative chemo, I am not only still kicking but the quality of my life is better than it was when I was originally diagnosed in July!!! The reality of that is just hitting me as I write this!

I checked this question out: does the choice for Palliative Care normally extend life? My hospice friends tell me that those who choose hospice have made peace with their situation. This reduces stress and anxiety giving the patient not only a better quality of life but often prolonging one's length of days. Amazing!

I invite you, then, to add an additional learning about Palliative Care: one does not only live with quality, but at times additional days.

Happily another erroneous assumption was that the dizziness and vertigo would last. For the most part they have gone away and I am able to do limited walking on my own (with a walker) unless I am not having a good day. I was so tickled to get wheels; what a joy to have a bit more independence and to actually walk around!

The 67 Year Itch

Unrelated to cancer, except probably that it's left me in a weakened condition, I have been dealing for well over a month with a persistent rash. It loves to kick in anywhere from 1:15 to 3:30 a.m.! The experience is one that makes me look back on past conversations in which folks complained about itching. I hope I was compassionate, but I'm sure I never imagined how very annoying a rash can be. The biggest trick is to distract myself. Friends have lent me DVD's for my very early morning entertainment.

We're experimenting with different medicines. The best combo so far got me an almost normal night. The difficulty is that the medicine and the interrupted sleep leave me exhausted and I once again need to revert to the "Please Do Not Disturb; Thank You for Understanding" sign on the door.

One of the nurses explained to me that the cream I am using is a steroid which reduces swelling. She said it's probably shrinking the tumors as well. It made me laugh that an unrelated matter is extending the days of my life, as was the case with my broken hip.

What a gift these days have been!! My window looks out on a beautifully landscaped quad. There is a feeder in the tree and I am entertained by yellow finches, cardinals, blue jays, woodpeckers, sparrows, robins and morning doves.

I think of all the days that I didn't take the time to soak in the beauty and I know deep in my heart that the opportunity to live in the moment is one of the greatest gifts that cancer has given me.

Thank you again for being part of my Journey. All who read this are in my prayers. May you find beauty in each moment and peace in the decisions you make for yourself and for those you love.