

## Voices of warriors - Patients

Soulla - Along this journey, I have found peace

Johnny - "On the wings of death" - communications with the list

### Advice for caregivers from stage IV patients

Trisha - What can you do for me? Well, I'll tell you!

Lester - Advice to caregivers

Soulla:

Hi guys,

So here I am in mad preparation to die. Since being told about 2 weeks ago that the cancer has spread to meninges, I've been frantic tying up loose notes. Sure, I was getting ready to go but time has taken another quantum leap. Now it's coming up to me like a freight train. I have come to terms with my own death.

The hard part is letting go of the girls, not because I can't let go, but because, as a single mom, it's been me and them always. We are close, they are still young (10, 11 and 18 years). It's not fair on them. That said, all the plans, all the thoughts..... it ain't going to happen.

I have been so frantic sharing ideas, wishes, crying, laughing and holding. I have never experienced such joy or such sadness and grief.

It's been wild. For years I have "made do". Always budgeting, always cutting corners and always putting the girls needs above mine. Absolutely no regrets though, no bitterness. Having said that, I had just sold my house and moved into a rental that I thought would carry me through for a few years. Oh well. Anyway, I've just spent the better part of a week buying "stuff". Nothing fancy, but stuff that really embodies who I am, things I have always put to the side as "nice to haves" but not absolutely necessary. Little bits and pieces to make the home feel like me. I've been pretty practical about stuff all my life. Now I'm going all out with candles, soft pillows, warm colors, filling the house and garden with color and flowers, scented oils. I'm having a blast. If someone saw what I was doing they would probably think I was pregnant or something. I feel like I am nestling. I know harder times are to come when I will be house bound, so if I'm going to spend so much time here, I want a) to feel good about my environment b) and probably more importantly, I want to go leaving the girls with a "home" set up that epitomizes who I really am inside. They are absolutely thrilled with what is happening and all are glowing with how the house is coming along. We snuggle so much, hug so much. I feel like a big momma bird with her little chicks. It's great! We've also spent some time fixing up their rooms. They already like their furniture, but we went out and bought new covers for their rooms, nice lighting, nice rugs. What a blast! My ex tells them (doesn't

like to share with me for some reason) that he will take over the house as is for a while. It's a conversation I intend to have with him soon to nail that sucker down (as much as I can - dying wishes and all that)

Note - this is an email with random thoughts and paths. The steroids don't help, but so much is going on in my mind at the same time. So forgive me.

Damn, idiotic, moronic..... I'm frigging dying. All my life I have worked hard to be who I am. And damned proud of it. My parents were uneducated. My mother was 10 years old when she was taken out of school (in a little village in Cyprus) to look after her younger siblings. My father worked from the age of about 12. We moved to the UK because of my fathers ill health. The words warmth, love, nurturing are not words that spring to mind when I think of my upbringing. My brothers and I worked hard to get ourselves through college. I worked and have never asked for a penny from anyone from the age of around 13. I also brought up 3 beautiful girls, have a nice home (no mansion) and a little money. I made sure warmth, nurturing, love, empathy, humanity are all words that surround me and my girls. Sure I would have liked to have enough money to put them all through college. But that ain't going to happen and now it's their fathers turn to take over.

The second part of my journey is a more spiritual one. Lots of talks with god. I'm not a "religious" person per se. But am finding comfort with god. I have always believed in god, it's the dogma that goes with it that I struggle with.

Along this journey, I have found peace. I am happy with my life. Lots I didn't do, but lots I did. And when I think back I can say with certainty that I was true to myself always. I maintained my integrity. I never went out to hurt anyone emotionally, physically, spiritually. As a teenager I knew I wanted to be a mom. And I have been a damned good one. I knew I wanted to change the life of at least one person. Not only have I created 3 that I know will go out and do good but also spent time teaching children, some of whom had difficult lives and for those, I made sure they received the specialized help and guidance they needed. I made a difference in people's lives, if only briefly.

I have been so overwhelmed by the love I have received these few weeks. My friends have, until now been cooking for me. Driving me (seeing double isn't conducive to driving). Popping by with gifts, flowers. Friday I was taken for a manicure & pedicure. Saturday they threw a hair cutting ceremony where they took turns cutting a lock of my hair for keepsakes (I'm going to loose it anyone with the radiation). The girls then took turns to spray my hair all sorts of colors and cut. It was so fun. I then had a hairdresser tidy it up (the girls decided a mohawk would be good, which was so silly).

I feel so loved, so happy. Sure, there are times when I wake up with a huge weight on my mind and I just ball my eyes out with grief. But being surrounded with so much love and caring. What could I ask for more?

I have a transition group of close friends to help with the girls when I'm gone. Three wonderful women that epitomize either who I am, who I want to be or who are strongest to be able to guide these girls through the tough times. They can look at them and know who I am. My friends can

share insights about me and things that happen. Continue the spirit in me. I will always be with the girls, in their hearts, minds and souls. They know that, but when they need a hug. When they need to talk about their mom, when they need the nurturing of a woman. Talk about their first date, what to do when their periods start. They will have my wonderful earth angels to guide them, and I will guide through the heavens. Please say a prayer for my angels. I pray that you all have people so dear to your hearts near you now and always.

Anyway ladies and gents. Sorry if I bored you or whatever. I just wanted to share. I haven't seen too much written by people about the process of dying. Finally, I would like to extend to each and everyone of you my deepest and sincerest thanks for being there for me always. You have guided me, challenged me, made me laugh, made me cry, but always been there for me when I needed you. Thank you. I hope to be able to continue posting from time to time and pray I can. I hope my thoughts help others through some of their pain.

Wishing good things for each and everyone of you, now and forever. Hoping our paths continue to cross (although under better circumstances).

Love ya

Soulla

n.b - disclaimer, I ain't giving up the fight. I'm doing whole brain rads, looking into getting on Termodor, maybe throw in some thalidomide. Doing TM therapy to bring down the copper level in my blood (antiangiogenesis stuff, Univ. Michigan study going on good results). I ain't gone yet, so your prayers are all still needed.

Soulla to Wendy:

By all means, share this post. I hope my post wasn't too harsh? My intent was to communicate the joy and extreme of emotions. No anger, no bitterness. Life is what it is. We can choose to be bitter about it and spread negativity or choose to take a good hard look and say, that's what is, what have I learned, how can I share in that learning and put it to good use. Yeah, sounds naive and simplistic and maybe even a cop out. I don't see it that way. You can change some stuff and I've worked hard to do that when I can. My health I have always taken good care of (eat healthy, organic foods, off red meat, don't drink, exercise my mind and body), but yet my health failed. I will never know, I didn't do anything wrong for it to happen, but the reality is I have no control, so I'm not going to be bitter or angry.

In life we are driven either by love or fear. Once we recognize that, we can better take a grip (yeah, another over simplification of life). If we let Love take over, it gives us strength, solace and security. If we allow fear to take over, we are wracked with pain, anguish and all the other not so nice stuff. So what are we afraid of? Losing control? Submitting to others power? Once you face the fears and what's the worst

that can happen.... oh dear, you're going to die, then there is nothing else to worry about. I am going to die, that sucks it's painful, but it's going to happen so I'm going to make the most of it.

Good luck to you Wendy with whatever endeavor you have and with your health.

I find it admirable that you are doing what you are doing. You seem to have

taken the positive attitude about this and want to share in that great knowledge

As you traverse this myriad of feelings, enlightenment and quest for life.

Cancer is about life, not death.

All my love

Soulla

I met Soulla through a breast cancer list, and she gave me permission to quote her message to the list as well as her private correspondence with me, and to use them on this site. Wendy Sheridan

From: Susan Date: Fri Dec 14 2001 - 22:46:48 EST

It is with both sadness and happiness that I share with you all the passing of Soulla. Soulla was my best friend and I'm going to miss her. I am happy for all of the beauty that surrounded Soulla as she went through life and for all of the lives that she impacted in a positive way.

namaste

susan

Johnny

Nov. 11, 2001

Hello. My name is Johnny. I am 59. Will be 60 soon. Self employed. Pathology report in. I have small cell, high grade invasive as hell bladder tumor. Had surgery (transurethral resection with fulgation) last week. Cancer has invaded the bladder wall and muscle. The cancer has made its way outside of the bladder to one lymph node along side the bladder in pelvic region, right side.

I don't feel quite like I used to, but I am not sick nor in pain, as yet. I seem rather lethargic these days. I lack a certain amount of gusto and vitality. I suspect I am depressed. I have had 3 bad days wherein what I strongly suspected to be the case was, in fact, officially confirmed by the URO, pathology reports, ct's, ultrasound, blood lab analysis, chest x-rays, urinalysis, cystoscopy, etc.

Do I want to live? Yes. Am I suicidal? No. But there is no cure for this cancer. Detection came too late. There are few treatments with no guarantees, and they all SUCK. They come with lousy odds that only an extremely desperate gambling man would consider playing. On top of that, these poorest of poor odds bring sufferings, complications, indignities, pains, sicknesses, messes. Shall the remaining days of my life be measured within such a sink hole of horror? What about my offspring? Must they see me in this pitiful state? Must they wait on me hand and foot, wait on me to die and set them free from the pain of standing by, watching helplessly the father of their very blood, die?

When I was 15 I went through that. I watched and stood by as my dad took two years to slowly fade away in a hospital bed, paralyzed, unable to come home, a victim of the system and structure of the medical bureaucracy. When he needed family the most, family often was not there. I did not cope well with this, ran from it, bleeding to this day from wounds which never healed. He had a brain tumor. They operated once, gave him an extra year, a year filled with sorrow, suffering, anguish, pain, helplessness, fear, all the while longing for what would never be again, praying to his God for the mercy of death. For what did he suffer and spend his last year in a hospital bed, forlorn and forsaken?

My philosophy has always been for quality, not longevity. That philosophy is now up against the ultimate test. How will it fare? Will I change my leanings? Should I? Should I dare to blaze a trail for a wee bit longer, or should I let the natural course walk along that wall of death as it will? It is inevitable, you know? I tend to consider getting it over with, not prolonging what surely could be a lingering nightmare for me and my sons and few friends. Those last lingering months that maybe a radical cystectomy or chemo, or radiation might extend to you may not be worth living at all when your ill, drowsy most of the time, unable to engage or enjoy those for whom you care on an alert basis, stupefied by pain killing narcotics. What's the point of this suffering? What's the point of this prolonging when you can't do much of anything but endure pain, when you no longer even care to do anything but lie there, fading in and out? What's the point of this extended time? I don't want the ones I care about to have to live through this out of the selfishness to cling to a futile life that has run its course. I really don't relish living longer than I need to if it means prolonging a horror.

I am already over four grand in debt in the space of just three weeks. And what did I buy? A prognosis of imminent death? A surgical procedure that promises only short term relief? I remain terminal. Money spent is not meant to change that fact. (I do pee a little more freely these days, however, but for how long?).

I have been reading everything written at this site for the past 30 days. You are all an amazing group of fighters. I come asking to hear what you have to say to me, 'the fatalist'? Let me see what you see, hear how you feel. I have some almost impossible decisions to make about my life and death. It is my hope that each of you continue to grow in the strength you have found. May you help me to find mine in these hardest of times, for I falter. May we be sheltered in the consideration of each other. May we rest in life and peace.

Johnny

From Wendy

Dear Johnny,

Thank you for your post, which is one of the most brutally honest, soul baring messages I've ever read on a cancer list. You're facing some terrible circumstances and decisions, as well as carrying baggage from having seen your father suffer

That's something we have in common. My father got sick in 1963 at age 36, I was 7. His cancer was very advanced, he was given 6 wks to live. But his desire to survive stretched it into 18 months of agony as a guinea pig for early chemotherapy trials. Then my sister in 1997 was given 18 months right off the bat, put on a clinical trial for high dose chemo/stem cell transplant for inflammatory breast cancer. It was horrendous and she suffered before she died in '98 at age 47. Another sister gets bladder cancer in '98.

As a cancer warrior myself, I don't know how far I would be willing to go to extend my life, I suppose the variables are many. I do find it comforting that I live in a country where euthanasia is legal.

I belong to a Buddhist community, last night we discussed "The Eternity of Life":

iKarma doesn't stop just because someone dies. The causes you make now will reverberate into the future whether you're here or not.

" At the same time, because the life of the family members of the deceased are connected at the level of Buddhahood, if we, as survivors, become happier and happier, that is an indication of the happiness of the person who passed away. "

I feel lucky that I have an outlet which enables me to pray for my sister's future happiness and freedom from disease in her next life. Same for my father and the other family members I have lost to cancer. 3 within 4 years, 3 more of us fighting. You said, "I really don't relish living longer than I need to if it means prolonging a horror." It's a horror if you feel it as a horror. I didn't ever think of my sister as a horror when she was dying, I only felt my heart expanding with love till near the breaking point. Consider the following:

"In a sense our practice is ultimately for having the right life condition and the right mind at time of death. Living our life to the fullest brings about the most peaceful death. In the way we live, we die."

You need to do some 'attitude adjustment' if you're going to ensure that you not only (please forgive my religious overtones here) break a karmic chain, but die with dignity and leave your son and loved ones with good memories.

You have to decide which path is the best one for you. Even if you ultimately decide not to opt for any treatment, you can find a way to live out your life in a state that is more desirable than "enduring pain, when

you no longer even care to do anything but lie there, fading in and out?"  
 It doesn't have to be that bad! My sister once said to me when it was clear that treatment didn't work: I'm afraid to live and afraid to die. I think it's safe to say that this feeling is universal in the respect that we all feel it sometimes. We are all going to die. When Lester groaned about the 50-50 stats yesterday, I had to think of my sister being given a 1 in 5 chance of making 2 years, and a 1 in 15% chance of seeing 5. "50-50" is all anybody really has, anyway, cancer or no. So my best advice to you is to focus on embracing the rest of your life, every moment we experience on this earth is a precious jewel, and every experience gives us an opportunity to grow (and karmically advance). This may sound all well and good to you, while you envision the worst case scenarios, but I feel that the best thing we can do for ourselves and our families is to strive towards happiness, express our love more. It's our fate that we are the only animals who ponder death; I try to envision a peaceful death with as few regrets as possible with the least amount of trauma to my poor family, what's left of us.

Would you consider anti depressant? Lots of us do it. What better reason than helping us to deal with something as horrific as cancer and being faced with mortality and all kinds of other life-rocking realizations.

You wrote:

"There are few treatments with no guarantees, and they all SUCK. Shall the remaining days of my life be measured within such a sink hole of horror? What about my offspring? Must they see me in this pitiful state?"

Ouch, John I can feel your despair. How desperate to live are you? A "sink hole of horror" is not a good way to look forward to the next phase of your life. Action is needed, research and knowledge so that you can come to some kind of treatment compromise. Palliation is a valid goal. My treatment is palliative but I'm still here 2 years later. I've read of hormonal treatments being used for advanced bladder cancer and I can testify that the side effects are minimal. There are interesting things going on in clinical trials, with low toxicity such as TKI inhibitors, even Herceptin is used. Chemo has helped people on this list, against their expectations and much to their relief.

About the pitiful state, we are as pitiful as we make ourselves. It's a feeling within, not without. Those who love us don't see us that way, I experienced recently how my sister's death helped our family grow in many ways. First we fell apart, then we reassembled. Stronger, and with faith we didn't have before.

"Must they wait on me hand and foot , wait on me to die and set them free from the pain of standing by, watching helplessly the father of their very blood , die? When I was 15 I went through that. I watched and stood by as my dad took two years to slowly fade away in a hospital bed, paralyzed, unable to come home.. "

Of course your mind delves into these reaches, but sooner or later you must leave some room for survival mode to kick in. Sorry to remind you, but you aren't dying you're living. I recognize something in you...you're dealing with family karma too. I called it 'baggage' at the start of this post. In Buddhism it's believed that something like cancer, especially one that is apparently being passed down from generation to generation, is actually an opportunity presenting itself to \*change\* your (bad) karma, and in doing so, your family's karma.

Be careful not to project your experience onto your sons. Do it differently than your father so that they won't suffer as you did.

The bottom line is that the treatment is palliative. The true 'art of oncology' comes into play- which the way I see- it is a balancing act between real benefit vs. sacrifice of quality of life. These are some of the issues your doctor and you need to get clear on and the sooner the better.

Please do some inquiring about financial assistance. I don't have much knowledge about this, but there are some links to get you further here: [financial resources](#) Maybe your sons could help. We need all the help we can get when faced with a huge crisis like you are. I hope that you allow others to support you at this time.

Best Regards,

Wendy

Date:1/12/02 11:21:02 PM Eastern Standard Time

From: johnnyhigh

I'm three chemo treatments into this thing now. I have a bad cancer...small cell...malignant...invasive...grade three at least...i will get scanned in a couple of weeks to see how much response is occurring...i am hoping to buy myself a little time...maybe one or two years...but i tell you, i have days when i believe this is going to take me relatively soon and i am preparing for death as best i can. And since we all have to die anyway, no matter what the results of our last cysto, I think this is a good course of action to take, as long as you don't forget to live while you are preparing to die.

Right now, I'm trying to carry on and live. This chemo, though, puts me down at times, and I feel so tired, and I fear I don't have what it takes for a long hard fight. But I have a crack at it, and I am grateful for that. I am 59 and in good health otherwise. I am a good candidate for chemo and a fight. I just really don't know where my breaking point will be, when I will just say...let it take its course...i have no idea...one day at a time...i made today, and i intend to get up tomorrow and try it again. looking back. i'm looking straight ahead. god help me be strong enough to finish the task at hand.



Johnny

From: Karen

How we choose to die, to end our lives, is at least as creative an act as how we choose to live it.

On Sun, 13 Jan 2002 13:42:18 EST Ray writes:

Johnny, thanks for sharing not only the history of your condition, but your heartfelt thoughts as you battle cancer each day This is one guy who feels he has gotten to know someone else in the bladder cancer family a little better today. May God give you strength to live each day to the fullest. As you said, we all will meet death one way or another...our paths to that journey's end are perhaps a little better defined. As such our preparation for death takes on a strong sense of importance and urgency.

I am rooting for you to have good scan results in a couple of weeks. May God give you strength for the battle one day at a time.

God bless...Ray

Sun, 13 Jan 2002 09:50:28 -0500

John,

Wow! I see quite a change in your letters over the past few months. It has been very powerful for me to observe that! I don't know if you remember, but I had lymph node spread as well. You are so right, it is just a crap shoot, none of us knows who will have a complete response to chemo and who won't. I understand your thoughts and I thought what you wrote was quite honest and thought provoking. I suppose that is all any of us can do. Fight as long as we can, then stop.

I remember when I went through chemo there were days that I actually thought that when I laid my head down, that I would not wake up. And then when I did wake up, I was surprised, if not a tad bit disappointed. I was suffering and I wanted it to end. I was actually grateful that half of me is a paraplegic, because then my whole body didn't hurt.

A friend of mine that I met in my support group died in October. She had early stage lung cancer. It was caught early and they thought they could cure her. She went through a 9 month chemo hell and then the cancer came back. She decided at that moment, that was her breaking point and she refused all treatment. She lived 3 more months.

I sure do wish you the best John and thanks for your thought provoking letters.

Lea

FROM: johnnyhigh 03/05/02 04:55PM >>>

CONTAINING AN UPDATE ON MY "growing condition", I can only say:  
thank

You Janet, Frannie, Charles, Lester, Hildegard, Pat, Anne, Paul, Wendy, Roni and Ben, Peter, Barbara, Karen, Kathy K., LaNette, Crilly, Marti, Capt. Mike, Carole, and any and all others who privately made room for me in their hearts, minds, spirits. Everyone should be so fortunate as to have such a caring response from so many beautiful people.

Let me clear up what seems to be one slight misunderstanding. I did not mean to convey the impression that I would not be talking to my sons. I meant to say that I wanted one son to tell the other two about the prognosis, because I was choking up so badly and he could carry the ball for me, which he did. It only concerned telling them the news that I have three months to live. (I thought that only happened in movies!)

The boys are, well, they are Italian boys, what can I say? They are Hanging out with me, not bawling their eyes out. That is as it should be. I'm around, and I'm a talker. We are an open bunch of street guys around here, no airs, no frills, no errors. Us guys have a way of being close and making contact without being overtly emotional or dramatic about it. After all, us men have stiff upper lips and broad shoulders for others to lean on. We don't lean on each other (but we do, we just know how to pretend not to).

The liver is riddled and I am fatigued every day. Little energy remains to do or say. It will progressively worsen. The best I can do is write as one ordinary human to another. However paltry, I must learn to cherish it and elevate it to the extraordinary by recognizing how strange it is to be alive at all, how mysterious it is to be an animal that can invent, utilize, manipulate symbols. How precious and exquisite is the language of human life. How rich and deep the unfathomable ordinary mind. How remarkable that we speak to death, as if an old friend. How revealing that, at the end, it smiles and shakes your hand, and says: "See, I'm not so bad after all, am I? Am I not just what the Doctor ordered?"

Johnny

Wed, 6 Mar 2002 10:39:24 -0500 (EST)

from: Crilly

My aunt went to Egypt five years ago, and while there, she died. She was part of a tour group that was visiting the more memorable and extraordinary locales in this ancient country. Inside one of the great pyramids, she had an asthma attack, probably brought on by the horses and camels that had been transporting them. Before she died, she waited nearly 30 minutes for transport to a local medical clinic. While on route, her breathing and heart stopped. Upon reaching the clinic, she was examined and then moved to a back room to await transportation to the morgue.

After nearly an hour, she came back. She says that when she "died", she had the experience of entering a huge hall in which many people were standing in a circle, holding hands. They were praying and chanting. She knew that she was dying when she realized that they were praying for her. She recognized some of those standing in the circle as members of her tour group. Then she moved away. She remembers moving towards a light that was filled with the most loving and joyous feeling imaginable. At that moment, she knew that she had nothing to fear from death and that

what awaited her was the purest, most genuine love and acceptance that she had ever experienced.

However, she also remembers feeling as if it were not yet her time to go. That's when she decided to return to her body. Though this experience had a profound impact on her in many ways, the most telling has been the complete ending of any fear of death whatsoever. She knows now, unambiguously, that death is a door into a state of profound love and joy.

I have no particular opinion about the "true" nature of her experience one way or the other. However, for some reason, it has been very reassuring to me as I face the uncertainties of BC and my own existence.

I hope it can be reassuring to you as well, Johnny.

Crilly

Subject: [CAFE] OPEN LETTER TO LIST MEMBER FROM JOHNNY M., CLOSING UP FOR THE NIGHT March 7, 2002

Dear People:

Know that your letters in response to mine spill a torrent of tears from my eyes, tears of joy, satisfaction, gratefulness, tears wet with the beauty of sincere intent of words sent. I lock them up within me, a treasure chest of humanity. How blessed am I to know and be touched by such genuine goodness, I know that I am not alone, that you walk with me, and we breathe our last breaths together. I look to encounter the beauty of death as it comes to be, knowing I am in good company, safe as safe can be.

Today I changed my business voice mail greeting to meet my special occasion. This is what I say now when would-be clients call me:

Hello. This is John M. I regret to inform you that Cash Financial has ceased operations. I have cancer and the prognosis is terminal. If it is necessary to speak with me regarding any unfinished business, you may leave your name, number, and your message and I will return your call. To all my former and current clients in good standing, you are welcome to use your business relationship with Cash Financial Services as a credit reference if you seek another cash advance company for your payday loans. With the utmost sincerity, I thank you for your patronage and wish you God-speed in your life and in your well-being. Thank you.

I should say this marks a rather back door ending to what once was a front door beginning. Appropriately inauspicious, wouldn't you say?

John died on March 23, 2002, this was his last message to the group.

## What Can You Do For Me? Well, I'll Tell You!

By Trisha Tester

I am a metastatic breast cancer patient. Although this means that I am almost certainly going to die of this disease (barring a miracle), I am not a victim. I don't like that word, and I would prefer that you never use that word around me. I am a regular person, who happened to be standing in the wrong place at the wrong time, and I got whacked with the cancer stick. I have noticed that people don't always know what to say to me any more, or what to do to help. Most people are loving, caring souls who really do want to help, but really have no clue what I need. To try to help you help me, I have made a list. Please keep in mind that this is purely a subjective list. I have tried to include other viewpoints, but I don't want you to think that all things work for all people. We are wonderfully, excitingly unique human beings. And so, of course, our needs will be different. You will have to judge which suggestions you feel would be appropriate, and what you would be comfortable with.

1. If I want to talk to you about what life will be like after I am dead, DO NOT under any circumstances give me that fake, terrified, cheerful smile and say "Oh don't talk like that. You will be fine." There is every likelihood that I will not be fine, and it is very comforting to me to know that you will tell stories of me to your children (and my children!!), and will always hold me in your heart. It is incredibly comforting to hear that you will include my children, who are much too young to lose their mother, in your life in a much greater way than now, while I am still here for them. You can not depress me, by acknowledging that death is probable, or even imminent. I am all too aware of it. As a matter of fact, if you put on that fake cheer, all you are telling me is that you are not able to be "there" for me for my needs. If that is the case (and I won't fault you if it is), don't even try to pretend. Just give me a quick hug (there is nothing about me that is contagious), and tell me you care, and skedaddle. I don't have the time to waste on fair weather friends.
2. Don't give me the standard offer, "If there's anything I can do for you, please don't hesitate to give me a call." Most of us are used to being strong and capable people, who have taken care of ourselves (and usually others) for decades. It is very uncomfortable to be in a position of not being able to do for ourselves. I would suggest that you drop in for a visit, pick up a broom, and sweep. Ask me if I have any plans for dinner, and just start making it. I won't ask you to do these things. I am not used to asking for help. I am not good at it. If it is an emergency, I will call out for help. But if it is the little day to day nonsense that piles up until it feels like it is going to consume me, I will probably not ask for your help (but I will be eternally grateful if you just come and do it). Be assertive. (But never mean!)
3. Talk about old times often. This has come as a surprise to many people when I have suggested it to them. They say "But Aunt Nellie will think that I think she is about to die if I talk about old times." HELLO!! She is about to die. I am about to die (although I hope it is prolonged by long periods of relative wellness). And I love reminiscing. It helps me to remember fabulous times in my life that I may have forgotten. It brings me a smile. It helps me to remember that even if my life is

cut much shorter than planned, that it has still been a good life. It gives me a better sense of wholeness.

4. (Actually, corollary to 3.) Take some time to organize the photos into albums. I don't know a person alive (well, maybe one) who is really on top of their photos. Put everything else aside, and devote however much time it takes. Get the photos in albums, with captions, and stories. If you have a videocam, just set it up and let it go. If you just have a tape recorder, that would be great too. Not only will your loved one have a superb walk down memory lane, generations to come will bless you. If I had only done this with my mother.....
5. Don't ever, ever feel guilty for enjoying life. When you find yourself having a great time, and you happen to think of me, do not feel bad - not even for a microsecond. Life is short. For all of us, whether we live to be 10 or 105. Enjoy the hell out of it. I would if I were in your shoes. Heck, I do now. My favorite cliché du jour: Your life is a bag of coins to be spent any way you choose. But you can only spend it once. (Spend it wisely, my friends.)
6. Don't be afraid to be afraid. If you are paralyzed with fear (and believe me, I have been there - as has my family!) it's ok to tell me that you are afraid that I am going to die. I am afraid too. Sharing that fear really does in some way make it easier to handle. Denying it seems very very false. I need real. I have no use for false. Once we have shared the fear, amazingly enough, we can set it in back of us again and move on. If we don't do that, it will block our paths at every turn.
7. Chances are that my bills are a pile of unorganized paperwork in a box somewhere. Cancer is an incredibly overwhelmingly expensive proposition. All the charges are mindboggling, and intricate. Insurance companies (in my experience) are incompetent and potentially fraudulent bozos who screw up all the time. I don't know if they could really be that incompetent, or if perhaps they are encouraged to be so, hoping that you will throw up your hands in confusion and pay some of the things that they "forgot" to pay. At any rate, I would be enormously grateful if you would come by some day, without judgement as to what kind of a mess I have made of the pile, and help me straighten it out. Maybe make a few phone calls. Maybe write a few letters. You wouldn't believe what a difference it would make.
8. Say, "I love you" a lot. Depending on who you are, that may come out as "You are the funniest person I have ever met," or "In the history of mankind, there will never be another person as \_\_\_\_\_ as you," or simply "I love you". But this is your chance. Don't blow it. After a certain point, there is no going back for makeup credit.
9. Be very conservative in what perfumes/colognes you wear. Chemotherapy often makes for incredibly sensitive olfactory senses. Perfumes can be overwhelming and nauseating. And by the same token, be especially sensitive if you are a smoker. (Unless the patient is a smoker - I wouldn't know about that situation.) If you do have to smoke, please go outside. Even if I say it is OK. And hang out outside for an extra 5 or 10 minutes to air out. You wouldn't believe how much vile aroma clings to you.
10. Make plans, not offers. Instead of asking if I want to do lunch sometime, ask me if next Tuesday is free. Then tell me, "Great! I will be by

to pick you up at 11 so we can go out to lunch. Maybe we could do a little window-shopping if you are up to it." Of course, you will have to be flexible, in case Tuesday is one of those days that I feel like I have been run over by a Mack truck...

11. When you ask me how I am, please remember that I am much more than my disease. I know that people ask out of concern, but I get a little tired of reciting disease progression/regression, treatment updates, symptoms, etc. Remember that we really did have things we used to talk about BEFORE I got whacked. Those things are still important to me.
12. Please be aware that "looking good" has NOTHING TO DO WITH IT. Don't worry - I even do it myself - tell my friends how good they look as if it meant that the cancer must be under control... No such luck. Until the very very end stages, cancer itself frequently doesn't cause any distress at all. Usually doesn't hurt. Often you can't even feel it (which is why so many of them go undetected for so long.) The treatments, on the other hand, can make you want to die, even when they are saving or (at least prolonging) your life. This doesn't mean I want you to stop telling me I look good. I just want you to realize that it really doesn't mean diddly-squat.
13. I need you to realize that this experience has changed me in several ways. I am still the person I have always been, but I am different, too. For one thing, I am tired. You know how tired you are when you are sick? Imagine having that be your new "normal". Be sensitive to my need to rest often. And don't expect me to be able to go as long or as fast as I used to do. I also don't have the memory I used to. Treatment has taken things from me that I will never get back. Now I feel like I am slogging through marshmallow goop, both physically AND mentally. Another change is in attitude. Some things just don't seem important to me any more. (Hopefully, I don't yell at my kids quite as much.) And other things have become more important. For example, I talk to strangers more often now. When I have something to say, I say it! Don't be surprised if I start dancing in the aisle at the grocery store. It can be a little disconcerting. If I embarrass you, you are free to walk away and pretend you don't know me. But please don't try to limit me. Let me spend the rest of my life doing exactly what I want to do!
14. Don't try to shelter me from the harsh events that happen around me. I have been omitted from too many events, because people well-meaningly felt that I had "enough to handle". Well, I am still alive. Even though I am fighting a war with this disease, I don't want to be shut out of the lives around me. Which includes sharing your pains as well as your joys. My body is failing me, but my spirit wants to support you in whatever way I can, for as long as I can. I don't need protection from truth.
15. Go to the doctor's appointments with me. Sometimes my poor "chemo brain" drops important information. It is very companionable to have someone with me in the various waiting rooms (maybe someday doctors will operate in a timely fashion.....nah, never mind -it'll never happen!). And it's great to have someone to talk to during an infusion drip. It is a good idea to have a pre-written list of questions. Again, a tape recorder can come in handy. And if the doctor is a little short or brusque, dig your heels in and be assertive. Help me to remember that although I am but one file in the doctor's toppling stack of workload, I am the single most qualified protector of MY LIFE. I have every right to as much of the doctor's time as I need. He (in my case she) certainly keeps me waiting long enough!

16. (Actually, corollary to 14.) If I don't like the doctor's advice, or manner, remind me that there are plenty of doctors out there, and I deserve a second (or third....) opinion. Cancer treatment - especially for metastatic disease, is not even close to refined yet. There is so much "art" and doctor's judgement to it, that I should never be coerced into a treatment I don't feel right about.
17. Respect my decision. There may come a time in this journey that I decide to lay down beside the road and stop fighting. If I make this choice, I know that you will be disappointed and dismayed. Maybe even furious. Please remember that it is my battle, and my decision. I know that you love me. I know that you want me to fight. But if that day ever comes, please understand that there is simply no more fight left. I promise you that I will never ever make that decision lightly.
18. If I am walking around bald from chemo, take the plunge. Shave your head! You would be surprised how refreshing it is to stick your head under a faucet on a hot summer day... Don't worry. I will not be in the least surprised if you "pass" on this suggestion. I can say in all honesty, I doubt if I would do it for you!

I hope that these suggestions help you to understand what is TRULY helpful, in dealing with a friend or loved one who is battling a life-threatening illness. Of course, the most important thing you can do is to just be there. Listen. Perhaps your heart will hear what needs to be said or done. Bless you for caring, and may there be miracles enough for all of us!

#### Lester's Advice to Caregivers:

It's a management situation. Out in the work world, it's management's job to see to it that workers can get their jobs done with the least amount of upset & discord. For End of Life Care Givers, everything should be done to eliminate the nuisance things. Basically this will mean total catering to the patients needs, wants, even demands. Coddle & Pamper are the key words. Never argue. Disagree or refuse ONLY if and when absolutely necessary and that means ABSOLUTELY. Even if something in any other kind of situation may be a no-no, "what difference will it make if I do it here?" should be a question. Personal needs are critically important but the patient may not want to be cleaned up. "Go away! Leave me alone! Don't bother me!" should be so honored.

Shaving, especially with an electric shaver and its vibrations, could be painful, plus probable razor burn if pre-shave lotion is not used. The screen on any electric razor could start to break down, sucking in and shaving off pimples etc., plus leave long scratches on the face. (These have happened to me in years past and I wasn't even sick, let alone terminal) A blade razor could be dangerous even with a slight cut in some cases, plus painful as it scrapes across one's face.

For some reason, certain patients such as those with leukemia can't stand even a light sheet touching them and will throw off pajamas, etc., as well as blankets, etc. If there are bed rails, the sheets should be draped and worked up even at the foot of the bed so nothing touches the patient.

