

On giving care

Resources for caregivers listed below

For those who would like to know what our loved ones with advanced cancer really want, read what stage IV breast cancer warrior Trisha Tester has to say; What You Can Do For Me; Well, I'll Tell You.

When somebody you love gets a cancer diagnosis, it's like the roof caving in. However, a cancer diagnosis is not a death sentence. It's part of life.

Encourage your loved one to learn all they can about their illness and options. However, some people do not want to be exposed to the terrifying and conflicting information out there; if so, respect that attitude and spare them the gory details unless they expressly ask.

Never second guess someone's choice of treatment. Once the path is chosen, support it.

Too many times people internalize their anger, try to spare us their fears and frustrations, while they are worrying just as much about us as we are about them. When it comes to talking; follow their lead. Don't push. Be a good listener if and when your loved one chooses to confide their feelings, and don't feel like you have to come up with any clear answers or good advice; sometimes it's not what is needed or wanted, and just listening will suffice. There's a lot to be said for 'companionable silence', and sometimes the message is best expressed with a hand squeeze or a hug. Just 'being there' is everything.

Find support for yourself. You can't hold someone up when you yourself are collapsing. Join an email group, a local support group, or counsellor, it helps. Many times such groups are more supportive than friends and family.

Finding a good doctor is the most important, as well as the most difficult part of a cancer journey. Check the limit on second, third and fourth opinions. If you aren't careful the insurance company might tell you you have reached your limit on consults. Please refer to Newly Diagnosed, for some tips on choosing a path and finding a doctor .

If the unthinkable happens, and the time comes when a person is too tired to fight, there are two very important things to remember;

Don't force them to continue, support them at this difficult crossroad. As Dr. Bernie Seigel points out in his book, 'Love, Medicine and Miracles', sometimes they need our permission. This is the true test of love.

My friend Wendy has asked me to contribute my tips on giving care. First...Chicken Soup;

1 whole chicken or quarters of legs, breasts, 4-5 lbs

2 onions, with skin on (this adds to the golden color)

3 stalks of celery, whole

5 carrots, whole

2 scraped parsnips, (I love this so I usually put more)

bunch of dill

bunch of parsley

salt, pepper

Chicken in pot, cover with water. Bring to a boil and skim off the brown

stuff (that is the technical word). When all is skimmed off add

vegetables. I usually put the greenery in cheesecloth.
Cook for

approximately 1 1/2 hours, until chicken pulls away from bone.
I love

the veggies so I usually add more. I "pull" pieces of chicken from
the

bone and add it to the soup when serving.

The following is most especially from the perspective of a spousal caregiver.

I would like to first mention that the caregiver is suffering along with the patient. Although most people I have met believe this, there exists great anger from some patients who believe they are the ones who are suffering with the effects of the disease, and they are the ones who are dying while the caregiver lives on. The caregiver is the one who assumes every role in the household along with the taking care of a loved one who is very ill, both mentally, due to the stress of the illness, as well as physically. The caregiver is expected to do everything to make the patient comfortable, both in mind and body, and to give up your life to be at the beck and call of the patient. You are expected to be loving, and always the understanding spouse with unlimited patience. You have to be a psychologist and nurse and hold back the nausea when initially faced with the realities of the surgery and a stoma and a life of hooking up to the urine bags. In some cases (if the prostate is removed) you have to face a life without sex or a completely different way of loving each other. You have to do all the lugging and housework and assume all the responsibilities. And through all this everyone expects you to be well kempt, well dressed to put a happy face forward so as not to upset the patient.

If the above sounds sarcastic and callous, I don't mean it that way,

I am trying to impart a picture of the role the caretaker is thrust into. Louis and I have a very open relationship and he is well aware of my role and took care of me in the best way he could during these past few months when he was 'laid out'. He would recognize and give credence to what I was going through, and not always 'feeling sorry for himself.' This is what kept me going and gave me strength.

When Louis would be upset watching me doing a chore that he used to do and would tell me about how badly he feels and that I shouldn't be doing this job, I would say, "yes you are right, but there is no choice and this is what has to be now."

I always accompanied Louis to the doctor and to chemo. I saw other patients who were alone, for whatever reason and maybe their significant other works or could not be there, but I saw this as important. I always came to the doctor with a list of questions. Which is another part of the role of the caregiver.

Sometimes the patient cannot think clearly, not to say the caregiver can, but I found that the caregiver is the one to do the research and write the list of questions for the doctors. I believe decisions about a course of treatment has to be shared by the patient and caregiver. If the patient is too ill or not of the mind to do the research and to ask, ask, ask, then the caregiver has to gather any and all information. This is also 'my life' we are dealing with. Yes...I will go on if Louis dies but not as I was before.

Louis is a wonderful patient and we have a very open relationship where everything is discussed and accepted, even if it is hurting...we talk, calmly. Even about death, which makes me want to scream and I tell him and we cry. But it is a catharsis when we can do this with each other. I know how terrible it must be for other patients whose caregivers don't want to discuss the negative or who don't have a great relationship.

Most people will call and say, "Is there anything I can do?" A better question would be, "What can I do?" The caregiver has to learn to delegate and relegate some chores to someone else. Shopping, baby-sitting. Sometimes the thought of going to a store was too much for me. How can I shop and be next to a crowd of people who are laughing and the checker in the market says, "have a nice day?" No I am not having a nice day! You don't know how sick my husband is and how we are suffering. But there must be time for the caregiver to get out. Do lunch, go to a movie, buy a new hat, or whatever.

Many people do not know what to say to a person with the Big C (and this is said in a whisper). I found that if you 'allow' people to help you, it helps them and in turn helps you. Loved ones, friends and family truly want to do something and we need to outright tell them what to do. We also found that if we talk openly with people about cancer it eventually becomes easier for them to relate to us, and vice-versa.

The most important part of being a caregiver is to allow the patient to talk about life and death and not try to get him to think of other things that are 'more pleasant'. Faced with a life threatening illness makes one think of many issues such as last wishes, wills and getting things in order. All of a sudden the garage becomes important with an eye to cleaning it up. The caregiver must validate the patient's feelings and fears, to hopefully help them to feel less alone and misunderstood.

Be aware of the clues he/she sends out and act accordingly. It is okay to cry and to tell him this sucks but we will fight together. Yes, I would rather be back to where we were a year ago, but this is our reality and we have to go through it, because we can't go around it.

When Louis tells me that he hates the stoma and the urine bag, I say, "Me too but this is what we have to live with." The important word is live.

Edith Grey

For WebCafe's Nurse Sharon McMullen's story of her mother's bladder cancer diagnosis, [click here](#)

Resources for Caregivers

Taking

Time "Support for People With Cancer and the People Who Care About Them" National Institutes of Health, National Cancer Institute. An excellent online brochure.

The Fifth

Dimension: Supportive Cancer Care <http://www.cancersupportivecare.com/>

Information on psychosocial support, nutrition, exercise, fatigue, anemia, pain control, sleep disorders & management, sexuality, intimacy & communications, lymphedema, diversions, creativity and coping, spirituality and chaplaincy, program planning for the "End Of Life". From Cancer Supportive Care by Ernest H. Rosenbaum, MD & Isadora R. Rosenbaum, MA

Home

Care Guide to Advanced Cancer from the American College of Physicians, an online book, downloadable for free. For family, friends, and hospice workers caring for persons with advanced cancer at home, when quality of life is the primary goal http://www.acponline.org/public/h_care/index.

Hospice Net <http://www.hospicenet.org>

Useful site for those who choose palliative care. Information about hospices around the US, pain control; help for caregivers, bereavement.

Growthhouse

<http://www.growthhouse.org>

Award winning site for life-threatening illness and end of life issues. Public education resource about hospice and home care, palliative care, pain management, death with dignity, bereavement, and related end of life topics." Bookstore and public chat rooms.

National Cancer Institute's support and resources for caregivers, patients

and professionals: http://cancernet.nci.nih.gov/support_resources.html

Oncolink Information and support for family members and loved ones of cancer patients who are accepting the challenge of being the caregivers outside of the hospital setting.

For relationship and family issues, advice can be found here;

<http://christie.man.ac.uk/cancerlink/relationships/intro.htm>