

Experiencing Cancer

-by Judge Anne Wallace

So, you have just discovered that a friend, colleague, family member – in short someone you care about – has just been diagnosed with cancer. What should you say? How can you help? I have had cancer. From having “been there” and from speaking to many others who have faced this challenge, I am offering some thoughts on how friends can help.

These thoughts are prefaced by a caution and it is this - however you decide to help, always keep in mind the personality of the person you are trying to help. Are they extroverted and like to talk? Or are they a private person? Just because they have this disease does not give anyone the right to cross previously-set personal boundaries. It is important, above all, to respect who they have always been and treat them in that same way.

The Initial Diagnosis

In October 2002, I experienced a pain under my arm. I thought nothing of it. Life was going so well and I felt great. When I still noticed it a couple of days later, I felt around and to my dismay found a hard lump, the size of pea. I convinced myself it was nothing. but arranged to go to my G.P. anyway. It wasn't until mid-January that I got the news. I had breast cancer and needed surgery, then chemo, then radiation.

The diagnosis hit me like a tsunami – a huge wave that knocked me completely off my feet and I no longer knew which way was up. Should I fight against it or should I go with the flow? How could this be happening to happy and healthy me? Although no two people who receive such a diagnosis will react in exactly the same way, everyone feels shocked. So it is important to realize that immediately after diagnosis is not the time to try to be rational and logical with the person. For those closest to them, it is a time to just be there with them, tell them you care and you are sorry they have to deal with this.

If you have just heard the news of the diagnosis and want to get in touch, give the person some breathing room at first and send a card. Include a note that you've heard about the situation, you care and will be in touch in a short while. As my tsunami analogy is meant to point out, everything is overwhelming at first. Knowing people care – and

that they know what is happening – is important. Responding to many people, or sometimes even a few, may be too hard.

If you are close to the person diagnosed (let's call them the diagnosee) and want to take on a big role, the best thing you can do for your friend is volunteer to be their "point person". As word gets out about the situation, people will start calling your friend who, along with their family, will be in the position of repeating over and over again the hard facts.

So if you feel you can take it on, tell your friend you are willing to be the person that will send e-mails and take calls for them, passing along the information he or she would like people to know. If a good friend can take on this task, it takes a huge load off both the diagnosee and his/her family.

The most efficient way to take on this task is by getting an email list from the diagnosee of all the people with whom your friend would like to keep in touch. It is important to assure your friend that you will pass on only what she/he would like you to share and you MUST stick to that commitment.

Also let the diagnosee know that it is fine for her or him to forward e-mails or phone calls to you for reply. Encourage the diagnosee to leave a message on their telephone answering machine with your phone and to contact you for information. Once things settle down, the telephone situation won't be necessary. But in the beginning this can be such a big help.

Being there for treatment

I didn't realize until I was the patient how different cancer treatment is for each person. Chances are your friend won't have known that either. How a person is treated depends on the type of cancer and the stage to which it has developed when it is discovered. Not every person has surgery or chemo or radiation. Some have all three, some two, some only one. Each treatment plan is based on what the oncologist thinks is best for that particular patient.

If chemo treatment in addition to or instead of surgery is needed, the patient will have an initial meeting with an oncologist. In or near the bigger centers, this takes place at the cancer clinic. In my own experience (and I have found to be true of quite a few fellow cancer travellers), the first walk through those clinic doors is hugely emotional. "What am I doing here?" seems to be the overwhelming

first thought. Sometimes this is the first time that the reality of actually having cancer really sinks in. The diagnosee needs someone with them for emotional support on the first trip to the clinic.

Then there is the meeting itself. Current medical thinking is that it is best for the patient to participate in the decisions about treatment. Therefore the patient will be given several options for treatment. In presenting the options, the doctor talks about mortality rates. Anyone who hadn't considered that this disease might be fatal will not be able to avoid that possibility after this meeting starts.

The oncologist will tell the diagnosee about the relative chances of being alive 5 years later and 10 years later, for each treatment option. The bluntness of receiving this information when it relates to your own life is not exaggerated when described as "brutal".

No one should go to this meeting on their own. And the person accompanying the patient should take a pen and pad of paper and record as much as they can of what the doctor says. Taking a tape recorder isn't a bad idea – there will be a lot of information. It will all seem a blur to the patient when they walk out the door but once the fog lifts, they will probably want to know everything the oncologist said. Recording what took place is vital.

How you can help with chemo

I don't know what I thought about chemo previously but whatever it was, it was a vague and I thought it was a "one treatment for everyone" thing. Not so.

Most patients who receive chemo do so by intravenous injection but some take pills. Intravenous chemo is almost always received at the cancer clinic in a big room with other patients there as well. Sometimes this takes one or two hours but sometimes it can take up to eight. Some patients receive chemo once a week, some less frequently. The number of chemo treatments varies from patient to patient, as do the type of side effects and their severity.

Going to the first treatment is scary. The fact is that your friend is going into uncharted territory in which they never expected to find themselves. For most people it helps to have someone familiar accompanying them, being positive and upbeat.

After the first treatment, the day before scheduled chemo or the morning of, your friend has to have a blood test to make sure they can

have chemo. The doctor must be sure their white blood count has recovered sufficiently from the last chemo in order to take the next one. This is very stressful and can be a strangely conflicted time for a patient. Because it is unpleasant, there may be some irrational sense of hope of not having to have chemo. But at the same time, the diagnosee does really want to be able to get take every treatment on schedule so they can get the whole thing over with.

If you want to be a support, it really helps to know when the patient will be going for the blood test. If it turns out your friend can not have the treatment, there is a tremendous disappointment that things are delayed. Being available to go for coffee, be a listening ear or a shoulder to cry on or just a source of distraction is really valuable.

If chemo is going ahead, company in the chemo room is usually really appreciated. It can be boring. Offering to come along with playing cards, or a lunch or just to talk may be very welcome. If you suspect your friend is declining your offer to go with them because they feel badly about taking up your time, drop by the chemo room to say hi about a half hour after the time for chemo is scheduled to start and see how they feel then. If they seem uncomfortable to see you, just stay for a minute or two to say hello and leave.

However, your friend might be really glad to see you. Perhaps he/she just felt too proud or uncomfortable to accept your offer. (and after all, when it comes to judges, we are an especially proud lot!) One of the most memorable lines I heard the year I was getting treatment was "It is better to give than receive – and it is easier too." Just keep this in mind.

Apart from being company at the clinic, be aware that chemo treatment is not something that a body gets used to and therefore gets easier. It's the opposite – the body gets more worn down with each treatment and it gets tougher and tougher. And the course of treatments takes a long time for the patient, no matter how long it actually takes. A friend's support and encouragement, especially over the long haul, is a real gift.

Radiation

Like other treatment, whether radiation is required at all or how much is prescribed varies for each situation. Once started, the patient receives the treatment every day, usually for some weeks. The more positive aspects of this treatment is that it takes only a few minutes to receive each time and it is usually easy to tolerate. But like chemo, it

gets harder as the regime progresses and it enormously saps the patient's energy as the treatments go on.

I am so busy but I do want to help . . .

There are many things people can do to help along the way.

If your friend has kids, the possibilities are abundant. Driving kids to and from school, sports, lessons etc. can be a godsend, especially when radiation has drained your energy. Just taking the kids out for awhile on the weekend so your friend can nap can really help. Once again, the pride factor can pop up. So just doing it, rather than asking "Would you like me to" can be good.

Delivering a meal all ready to eat just at dinner time, especially if your friend has children to care for, is wonderful. Again - an organizer/point person to oversee meals is the best plan. They can find out about any allergies or strong dislikes and pass that info along to those bringing meals and they can co-ordinate so only one meal arrives each night.

Another alternative is preparing a main course that can be stored in the freezer and heated up on "a bad day". Make sure to label the dish with what is in it and what is required (temperature and time) to heat it up.

As well home baked snacks, like muffins and cookies, are a great treat. They can always be frozen for the future too.

Important Tip: Be sure to put the food in dishes that don't need to be returned! I think I still have some people's dishes, it got to be such a task trying to figure out which one belonged to whom.

If cooking isn't your thing, there may be take out places that serve good, ready to serve meals which you could deliver at a time when your friend is struggling.

What not to do = phone your friend and ask "What can I do to help?" Chances are very strong that the person either can't think of what will help or doesn't feel comfortable asking for specific help. If you are particularly close to the person, you will know the things that your friend will be fretting about - the house isn't tidy or clean, the laundry isn't done, the lawn hasn't been cut.

To quote Nike's famous slogan – "Just do it". That is, just do what your friend usually takes care of but can not. If you are not close to the person but want to help, ask someone who is close to your friend what would be most appreciated and make arrangements, for instance send a gift certificate for a house-cleaning service.

In closing . . .

I read part of a PhD thesis written by a student who had had cancer. They described getting the diagnosis as going "from the land of the well to the land of the ill" , that it felt like there was an invisible wall between the two, and the sick person feels like they are looking at a world in which they used to live quite comfortably but in which they no longer seem to fit. That description really struck a chord with me. I felt exactly that way.

Accordingly, my friends who mostly just treated me the way they had always treated me made me feel so much better. Those who looked at me sadly and treated me with kid gloves only made me feel worse about the situation.

So treat your friend as you have always treated him or her. Let them know you are concerned about their health issue but don't make all your conversations about their disease. Talk about what you always talked about – sports, fashion, kids, spouses. Don't let the cancer take over.

It should go without saying but it happened to me so I am going to mention this. Don't talk about people who died from cancer or who have had their cancer come back. It is devastating to hear this when your are trying to be positive. Do talk about people you know who had cancer 20 or more years ago and are doing great!

And my strongest advice is to not be worried about what to say or afraid of saying the wrong thing. If you feel very unsure, just tell your friend that – "I am not sure what to say", then move on.

Whatever you do, don't avoid the person because of the cancer. Find a way in which you are comfortable communicating – with an e-mail (finally someone who might appreciate receiving internet jokes!), a card, a phone call, a visit or a chance to get out of the house. Remember, your friend doesn't have leprosy – only cancer!