



Looking Back,
Walking Forward

by Jen Bernhards

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This booklet was especially written for teenagers who have a chronic health problem so that they can help themselves, family and friends deal with their health concern. Even though there is only one person physically living with a certain problem, everyone who cares about that person is affected.

I was diagnosed with brain cancer two years ago and as a young adult, there are things I wish I would have known that would have been helpful and comforting. While I appreciated the advice, encouragement and empathy from my friends, I found that I trusted comments from those who “had been there.” My friends could only imagine what it would be like. They could say the right things, but they weren’t talking from experience and so their words didn’t have as much credence.

I have written down some personal experiences that illustrate valuable lessons I have learned over the past two years. While many of these situations deal particularly with cancer-related issues, I believe and hope that there are topics in the following pages that are useful to everyone.

What I needed and wanted to hear from my friends and family after being diagnosed with cancer may be different than what other people need and want. However, I do think that everyone needs to know that people love them and will be there to support them. Here are some lessons learned that may provide some insight into what it's like being a young adult living with cancer...

Closeness

Even though no one knew what lay ahead, hearing that people loved me, that they were there for me, that everything would be okay, and just being physically close to each other is how my family initially reacted to the news of my diagnosis—and I appreciated it all. While I was in the hospital, my parents took turns sleeping on a cot in my room so that if I got upset in the middle of the night, someone (who wasn't there to 'stick' or 'poke' me) was there for me.

In those first weeks, my family's continued affection, verbal support and always being near me helped me more than I can ever explain.

I'm Still Me

I had brain surgery in the fall of 2002 and after spending a week in the hospital, I was sent home to rest before I started chemotherapy and radiation treatments. As I started to understand what was happening to me, I slowly began to crave a little more personal space and independence.

I suddenly realized that since I had been home from the hospital, my parents always greeted me in the mornings with a stop-watch and we'd take my pulse while I was still in bed. I would rate my pain on a scale from 1-10, I'd report any headaches or neck aches, and then I would eat breakfast. I wasn't in the hospital anymore, but I felt like my parents had assumed the roles of my doctors—only they weren't in white coats and they were nice enough to wait for me to wake up on my own!

They seemed to focus on my illness, and not on me as a person. You have to work to convince your parents that you're not their patient. To get my point across, I'd ask them to think "Is this a question you'd normally ask me?"

Coaching Your Friends

My parents' and friends' reactions to my illness were varied. My parents constantly worried; some of my friends only emailed me because they didn't know what to say in person, and others tried really hard to make me laugh and never said or brought up anything serious when speaking to me. I wanted to laugh and have humor in my life, but I also wanted a balance, and the ability to discuss regular and non-superficial topics.

One of the most ironic things I have learned is that even though I was the patient—I was the one who had to tell people how I wanted to be treated. It didn't seem fair or make sense that it was my responsibility to ask people to treat me a certain way...didn't I have enough to deal with already?

Yet, that was the role I needed to play in order to be happy, and it made things easier for those around me because they didn't have to try and guess or assume how to treat me.

Getting Back to Normal

There was a point when I needed to be treated as “normal.” It was often a lose-lose situation: if people didn’t show concern or ask about my health it could potentially be upsetting because it would seem like they didn’t care. There is a fine line though between inquiring about one’s health and showing too much concern or pity.

For example, with my closest friends, we agreed that they wouldn’t always ask me or bother me about how I was feeling because they didn’t want to annoy me. If I really needed to talk about something or if I was in pain, I would go to them and they would be there for support. This worked out very well for us—and they also periodically asked me if I wanted to talk about anything to make sure I knew they were still well aware of my situation.

Every Word Counts

My family members and friends started asking me “how are you doing?” —instead of “how are you feeling?”

There is a huge difference between doing and feeling...and a lot of times, you wouldn't want to know the answer to how I was feeling while on chemo—don't ask me that question unless you're prepared to hear about me feeling exhausted, nauseous and constipated.

Frequently Asked Questions

I think people always “meant well” and had good intentions, but sometimes asked questions that I didn’t know how to answer or they said things that made me feel uncomfortable. Since you know you’re going to be asked, it might help to have some answers ready ahead of time. Here are some examples:

“How are you?”

This is a simple open-ended question that gives the patient the power to decide how to answer. If someone close to me asked this and if I wanted to talk, then I’d reply, “Well, honestly I feel...” ; or if I didn’t want to talk about it, I’d say, “Actually, I’m really tired right now...” I could also always take the easy way out and reply, “Good, how are you?” even if it wasn’t necessarily true. And finally, if I happened to be in a bad mood when someone asked this, I would explain how wonderful I was, that chemo was fabulous and that I highly recommended it.

Special note:

There is a difference between “How are you?” and
“How arrrree youuuu?”

The first is a question; the second is a statement. In the second case, the person may as well be saying: “Ohhh, you poor thing, you look horrible, how are you able to be out in public?” or something along those lines. It is nice to know that people understand you’re going through a hard time; however, I have not met anyone with this disease who wants or needs anyone’s pity.

“You look soooo good!”

Hearing this usually made me cringe, no matter who it came from... Did this mean that I looked terrible the last time they saw me? Or that they were expecting me to look bad? It was especially annoying when I knew very well that I didn't look “soooooooo good.”

After a night of four hours of sleep, I went to the public library to return some books. I had acne on my cheeks (that were swollen thanks to steroids) and I was very aware of and a little embarrassed by my appearance. Most of my hair had fallen out, so I had a scarf wrapped around my head, and since I didn't have a great appetite, I felt like my head was rather disproportionate compared to my body. I ran into an elderly woman who lived a few houses down from my family and after we said hello she said, “You look soooo good, sweetie!” I muttered “Thanks” while wondering whether she was merely trying to be pleasant and boost my self-esteem, or if she just had bad eyesight.

“Let me know what you need, or if I can do anything to help...”

I was usually flattered and grateful that people wanted to help me, but what people sometimes fail to realize is that there are *a lot* of things a person ‘needs’ when they haven’t slept soundly, or can’t keep food down, or aren’t able to go outside, or have plumbing issues that involve needs that have not been met.

It was hard to say what I needed, and usually just knowing that people were genuinely there for me was the most helpful thing anyone could have done.

While most people are sincere, I learned that sometimes people say “Let me know if I can help” because they don’t know what else to say, and it seems like a shallow offer. One way I knew if people genuinely wanted to help was when they had some ideas of their own, “Let me know if you need anything, I could bring you some hot tea, or go for a walk with you, or we could watch a video, etc...” and gave examples that they were willing to do whatever I needed.

“Your hair...it looks, oh wow, something’s different...I mean, it looks really great...”

(Awkward stare/pause)

I heard this remark when I began wearing my wig and though some people take hair loss in stride, losing my hair was very traumatic for me personally. I think hair loss is also something that gets brushed off because it doesn’t physically hurt and usually grows back. The biggest reason I took it to heart was because it created a constant reminder— to me and the rest of the world— that something was very wrong inside my body and I was not well. (Plus it’s abnormal for people under 20 to be bald!) A positive way to look at this situation is to think that the radiation or chemo is working really well when it makes your hair come out.

I have curly hair and the wig I purchased had stick-straight hair, so I was very self-conscious about wearing a wig, and preferred that people not bring up my new ‘look.’ Then a few months went by and I got used to my wig, and started to gain some confidence. (I had also tapered off steroids so my face was its normal size, too.) I didn’t avoid mirrors anymore and I felt healthier just seeing my face with hair around it!

Everyone reacts differently to hair loss, and unless the patient specifically brings it up, my advice is to avoid anything that has to do with this personal topic.

“You’re gonna fight this thing and beat it and be so much stronger when you’ve defeated this disease, etc...”

Who wants to be told that they are “fighting” or “beating” something inside of them? I was—and I still am—*living* with cancer. Some find phrases like this encouraging, but I don’t like the violent connotation associated with this phrase. More so, it seemed like people would tell me this as if I didn’t know I was facing something difficult and so I assumed they felt that I needed encouragement.

I still wonder if the people who told me this were saying it more for their own benefit than mine— like they needed to tell themselves out loud that I will ‘beat’ this.

Special note:

When I did have doubts or questions, I preferred to ask someone close to me for reassurance that everything would work out. I guess there were times when I appreciated hearing and being reminded that, “You know this will all be over soon” or something along those lines. Being bombarded with, “You’ll get through this, just keep on fighting hard and don’t stop! Never give up...” had a negative effect on me and made me wonder if the people telling me had doubts about my actually getting through it.

“God only chooses the strong people” or “God is just testing you.”

This is a delicate topic, and for me personally, the God I believe in does not strike people down with cancer, nor test people by giving them an illness. I ignore these kinds of statements.

“Everything happens for a reason.”

This doesn't really help coming from a friend who is in great health. I also think the cliché “everything happens for a reason” is a trite rationalization for why bad things happen to good people. If we look hard enough though, we can always learn and grow from everything that happens to us in life—good or bad.

“Think of the people who are worse off than you” and “At least you can still _____” (enter anything that I could still do—eat, walk, talk, drive, etc...)

I had already thought about those scenarios, therefore comments of this nature insulted me.

So, what *do* you say?? Here are a few phrases I would suggest:

“(Name of person), I can’t imagine what you’re going through, and I don’t even know what to say, or how best I can be here for you. I am so sorry you have to go through this.”

“It’s difficult for me to know what to do or say, but I want to be there for you”

“I’ve been thinking of (or praying for) you” and a simple greeting like “Hello” is a good start, or a hug is also nice coming from someone you’re close to. (Some people aren’t ‘huggers’ though.)

**You ultimately can’t go wrong though when you speak from your heart.*

Do's and Don'ts

Do get outside to get fresh air if you can

Do think positively

Do go with your gut feelings and ask your doctors any questions you may have

Do tell yourself that you are strong

Do things that make you laugh and that you enjoy

Do try to learn from this experience

Do ask for specific things like grocery shopping—for people trying to help parents

Do find people who you can relate to (support groups online—no harm in trying)

Do remind yourself about all the things you have to be thankful for

Do understand that it's okay to sometimes be jealous of your friends who have 'normal lives'

Do whatever makes you happy

Don't give yourself a hard time if you cry and feel sorry for yourself every once and a while

Don't feel guilty if writing bad words or thoughts in a journal makes you feel better

Don't forget that you are in charge

Don't ever lose hope

Always remember that people care about you.
That includes nurses, doctors, family members and
friends. Everyone wants to help and wants you to get
better even if it sometimes doesn't seem that way!





Jen graduated from the University of Virginia in May 2004 with an English and Psychology double major. She currently lives in Northern Virginia and is still being seen at the University's Cancer Center