## Health (Http://Www.Philly.Com/Health)

— <u>Diagnosis: Cancer (http://www.philly.com/philly/blogs/diagnosis-cancer)</u>

## Survivors' advice: 11 things never to say to a friend with cancer

Updated: DECEMBER 14, 2016 — 4:51 PM EST



L - R: Laurel Felsenfeld, Claire Snyman, Dan Duffy and Renata K. Louwers

## by **STAFF REPORTS**

The next time you wonder whether it's okay to ask a friend how their cancer treatment is going, consider the story of testicular cancer survivor Dan Duffy and his buddy Chris.

"One day while sitting in the car waiting for a mutual friend, he started asking me questions," writes Dan, a contributor to Philly.com's "Diagnosis: Cancer" (http://www.philly.com/philly/blogs/diagnosis-cancer) blog. "Some were serious, some were seriously flawed. They included:

"How did you get it?"

"So, how bad does it get?"

"Do you just puke constantly?"

"Since it's testicular cancer, just say you're having sex with your girlfriend ... Can you give it to her, like an STD?"

Was Dan offended? Not at all. Chris, he knew, was just being Chris.

"It taught me that while I appreciated my friends' genuine concern, every now and again, I needed someone who just didn't like me more, or differently, because I was sick," Dan wrote. He's healthy now, and reports that Chris can still be kind of a jerk. "And I still love him."

It's the holiday season, when friends and family who may not have seen each other for a while are gathering. "How's it going?" seems a safe enough question. But what if someone in your circle is dealing with a health crisis?

We asked the experts - survivors and caregivers who have written for our "Diagnosis: Cancer" blog. They were unanimous on one point: The worst thing you can do is ignore another person's pain. Saying something well-meaning but kind of stupid is not great, but it's better than walking away.

Still, it's hard to know what to say to someone who is struggling. So our experts offered up some well-meaning comments they wished they'd never heard -- and suggested some words they would have found more helpful.

- "You are so brave." Cancer patients don't want pity or to be labeled. They are the same people they always were. Let them know you are their friend and if they want to talk about the illness you are there to listen. And if they want to avoid the illness, you are there to talk about other things.
- -- Renata K. Louwers (http://www.philly.com/philly/health/Her-husband-dying-of-cancer-she-struggled-to-fill-his-opioid-prescriptions.html)

• "Wow, you are looking so well; you can hardly tell you have cancer." The real battles can lie behind the mask that the person wears, even after recovery – the 'invisible' challenges that are taking place every day that may not visible, such as extreme fatigue, cognitive challenges and pain. Try this instead: Let them know you are always around for a chat, a coffee, or a walk especially when they are having a tough day or just want a change of scenery. This acknowledges that they may have challenges that aren't obvious.



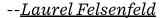
(http://www.philly.com/philly/blogs/diagnosiscancer/Struggling-to-find-a-new-normal.html)



• "I don't know how you do it." My first husband endured metastatic bladder cancer that included significant pain and numerous hospitalizations. Most frustrating was when someone would marvel at what we faced. My response was, "What exactly are our options? We all deal each day with the life and circumstances in front of us." I know it was a well-meaning comment but it was utterly unhelpful and a reminder of just how awful our life appeared to observers.

-- R.K.L.

• "It's good you can put that all behind you." When I run into people that I haven't seen in a long time who hear of my cancer diagnosis ..... (there is) a distinctive look of surprise and curiosity followed by an exclamation of "How are you?!" When I respond, "I'm good now, it's been four years of remission" I usually get, "Another year and you'll be cured," or, "It's good you can put that all behind you now." I wish that were true—high grade soft tissue sarcoma cancer is only controllable, not curable. The risk of recurrence is lifetime and so there's a lifetime of being scanned for tumors at regularly scheduled intervals. It's not worth my time to try to explain this, because inevitably the response involves the inspirational story of someone who had some other kind of cancer ... and when I ask how this person is doing, the answer is: "Oh, he died!"



(http://www.philly.com/philly/blogs/diagnosis-cancer/How-I-got-over-my-cancer-scanxiety-and-got-my-gratitude-back.html)



• "At least it's not [fill in the name of some other disease]." This can feel insensitive to the person receiving it and demeans what they are going through. Cancer and tumors affect the lives of every person whose bodies they invade, no matter the type, form or degree of aggressiveness. Try this instead: "I can't begin to understand how your condition is affecting your life. Would you mind telling me more about it so I can understand better?"

-- *C.S.* 

## • "God doesn't give you more than you can bear."

Platitudes, niceties, etc. only serve to make the speaker feel less awkward, invariably making everything more awkward. There is only one thing you should ever say: "I will be here in any way you need me in any way I can, and every few days I'm going to ask if you need something specific, like a cleaning or a meal. Take me up on it or don't, but I'm not offering out of pity; I'm offering out of love."



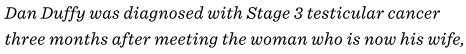
-- <u>Dan Duffy</u>

(http://www.philly.com/philly/blogs/diagnosiscancer/Post-chemotherapy-and-adjusting-to-a-new-normal.html)

- "I know how you feel, I sometimes feel like that too." The physical and emotional experiences accompanying any disease condition are unique to each individual; no one else can fully understand them. Try this instead: "That sounds tough. Tell me about it and how I can help out." It can be hard for people to ask for help, but if you know more about their symptoms, you can get creative.
- -- C.S.
- "You're doing a really great job." This is often said to caregivers. Caregivers don't want praise; they want practical help. Ask about specific, routine tasks such as groceries, laundry, etc. and how you might be able to help. Offer up specific days and times when you could help. Don't make the caregiver ask.
- -- R.K.L.
- "My uncle's second wife's cousin had cancer and did this raw diet and she's doing great!": Give the patient and caregiver credit for being smart enough to decide upon a treatment plan. If they specifically ask your opinion, then offer it. Otherwise, keep your so-called cancer cures to yourself.
- -- R.K.L.

• Running away. The worst of the worst was when a couple of my friends simply went away. One disappeared entirely and I have not spoken to him since. Another friend had the decency to call me when I was almost finished with my treatment. He told me he was sick with sorrow for not having the courage to face it like I did .... When you don't know what to say, talk about what you would have talked about before your friend or loved one got sick. Life doesn't stop.

-- D.D.





and the mother of their two boys. "I have dedicated myself to telling my own story, and helping people tell their stories, so that no one feels they have to go through cancer alone," writes Duffy, whose day job is video producing.

Laurel Felsenfeld is a registered nurse care manager empowering families overwhelmed by the care of aging, ill or injured loved ones to navigate the health care system and become effective advocates. She is certified as a case manager and holistic cancer care educator and uses her 30 years of professional experience and personal cancer journey to mentor others living with cancer. She can be reached at kickncancersass@gmail.com (mailto:kickncancersass@gmail.com).

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**Published:** December 13, 2016 − 1:38 PM EST | **Updated:** December 14, 2016 − 4:51 PM EST

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