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AMY DILBECK

TOPICS DISCUSSED:

BODY IMAGE; DATING AND NEW RELATIONSHIPS; FINDING MEANING; PHYSICAL REHABILITATION; TELLING OTHERS YOU ARE A SURVIVOR

I became a cancer survivor on March 14, 1996, when I was diagnosed with osteosarcoma a month before my sixteenth birthday. Osteosarcoma is a very rare and very aggressive form of bone cancer. My life changed drastically within the period of about a week.

I had limb-salvage surgery, where they replaced all the bone that had been affected by cancer with metal. The biggest physical challenge was relearning how to walk and run and move my body. The muscles that maybe were used for one thing are a little bit different after surgery, so you're having to modify what's happening within your own body and think about movement in terms of the small processes that come together to make one big movement.

I couldn't look at my scar for two or three weeks after my surgery. I think because it felt like it wasn't part of my body yet. After I decided that it was okay and that I was going to embrace it on certain terms, it wasn't long after that I started being pretty flamboyant about it in public and wearing skirts and shorts and seeing it as something that made me different and special, not different and weird.

I went from swimming competitively and cheerleading to not being able to do anything on my own. I think that loss of control either makes you want to fight a lot harder to get back or it makes you give up. You have to make the choice. I honestly think that so much about survivorship is just being focused on what you are doing and moving forward in that, and being stubborn and wanting something and working for it really hard.

After my surgery, I started going to physical therapy about three times a week for two to three months. Then my life was so busy that I didn't go back much more. Once I had gotten to the place where my muscles were starting to remember how to work, I decided that the best way for me to be motivated to get better was to do things that I like to do anyway. So I would take a walk around the block with my dog, and I would think about the way that my muscles were moving and focus on walking a certain way. I would go to cheerleading practice in high school, and I started swimming again for my swim team, focusing again on using the muscles. In remembering what I was living for and wanting to do those things again, I think that became an important part of my physical recovery.

One of the most important things for me in learning how to deal with my new body and my new scar was understanding that sharing with other people is going to make it easier. Because in order to be accepted for who you are, people have to understand who you are and if you are not willing to share that with people, then how do you expect them to know? My policy was always to tell anybody that wanted to hear and be as open as possible about what was going on in my life.

It's only probably been in the last couple of years that I've decided that I don't have to tell everyone the whole story, and that some people really don't care to know. That realization came when my good friend finally said, "Amy, you don't have to tell everybody that you had cancer. You can just say, I had knee surgery, and that's enough if you don't feel like talking about it." I had expressed to her how draining it could be for me to have to give so much to people when they asked me about what was going on. That was something that was really freeing for me. I understood that it was important to be open, but it's also important to choose when you want to be open.

Emotionally, a lot of things changed. I think that your friendships in high school change, because a lot of people don't understand what's going on. So instead of dealing with it, they either try to ignore it or ignore you. And both of those can be pretty hurtful. I think at the same time, though, there's a lot of people that will surprise you with how incredible and thoughtful and consistent they can be in your life.

For my family, emotionally, things changed in many ways. My mom and dad became really focused on me. I have a little brother and sister, and I know that that was hard for them. My sister said that, for probably a year, nobody asked about her. They said, "Hi, Kathy, how's your sister?" My brother was little enough that he didn't understand a lot of what was going on. Now he says that he wished people had told him more. People thought that they didn't understand and didn't need to know, but instead they imagined things that were probably much worse than what was going on.

With my parents, there's a huge sense of connectedness. They give as much, if not more, to your treatment and your recovery. Even after treatment, that emotional connection is very strong. I know my mom will probably always be more protective of me than she is with my brother or my sister. Every year when I go back for my checkups, my mom is the one who can't sleep for a week. And then, as soon as we get out of there with an okay and good scans, you can just see her kind of relax. I think that she doesn't want to make me nervous, so she tries to hide things from me. They still say funny things to me like, "Honey, you are a cancer survivor and you are different. So if you get tired at work, you tell them that you need to go take a nap." Who else's parents in the world tell them that they don't need to work too hard? It's kind of surreal.

I think there is the tendency upon the part of those who interact with a survivor to want to baby the survivor. It's an interesting balance, because there are times when we need help, but there are times when we don't want help. I maybe should not move heavy boxes, but I may want to feel control over that issue. I may want to walk around the block by myself even when it may not be the best choice for me. It may not always be the best decision, but it's an important part of empowering that person and giving them a little control over their life. I think the issue is just to be aware that survivors still know what they want and they still want to assert control and have a part in the making of their own decisions.

What was hardest for me about entering the job field was trying to differentiate between who I was as a cancer survivor and who I was just as me. Whether I wanted to pursue some sort of field that would be able to incorporate those two things, or whether I wanted to be in some place totally different where I never interacted with people on the level of being a survivor. The more I thought about it, the more I realized it would be really healthy for me to find some closure in the area of survivorship by helping other people who are going through the same thing and hopefully offering some sort of guidance and insight. What to look forward to, what to look out for and all those things.

I think that, as survivors, we can all feel pressure because you've been saved, so to speak. You've been granted another chance at life; you are expected to live something better or special or differ-

ent or more or higher than other people. But I think that, as I come farther in my journey of survivorship, I learn more that it's okay just to be me.

When I finished treatment, there were a lot of different emotional and psychological things that started happening. For one, you are used to being the center of attention. There begins to be a sense that everything you do is the most important thing in the world to everyone around you. And once you get off treatment, you have to let go of a lot of things that have been consistent and have made you feel supported for the time you've been in treatment. It's hard to let go of chemo, of your nurses, of your routine, because your life has been dependent on those things.

It begins to be about how you redefine yourself as a person, drawing on all those things that you've experienced and making yourself into the new person that you want to be. I think survivorship is process of the journey; about being open with yourself and learning about yourself, and taking all your experiences and putting it together with who you are to make yourself even more incredible than you were before.

My name is Amy Dilbeck, I'm 23 years old, and I'm a bone cancer survivor.

TOM BOLEN

TOPICS DISCUSSED:

AFTEREFFECTS OF CANCER TREATMENT; BODY IMAGE; MEETING OTHER SURVIVORS

It was really quite unremarkable. Got up one morning and noticed a large lump in my neck. I thought, "Gee, that wasn't there yesterday. That's unusual." Of course, most everybody knows you have lymph glands in your neck and when you get a cold, sometimes they swell. But this particular one seemed a little large.

I live in Kotzebue, Alaska. Kotzebue is a town that is about 49 miles north of the Arctic Circle. We are about 550 miles north of Anchorage, which is, of course, the biggest city in Alaska. That's really where the most medical expertise in the state is in Anchorage.

The first problem that I ran into was that they couldn't diagnose me in Kotzebue. I ended up having to go to Anchorage. I saw an ENT who was able to confirm that I did have base of tongue cancer. The lump was actually a secondary site. The cancer had metastasized to my lymph nodes. Had that not happened, I might have gone for another year or more without knowing that I had cancer. The primary tumor had not caused me any symptoms. I had no difficulty swallowing. I had no sore throat. There was no sign that there was anything going on at the primary tumor site. I was really fortunate that it did move and show up there, which ended up causing me to have my diagnosis done and only have a Stage 2 primary tumor.

I came back to Kotzebue after my diagnosis, and I began to research on the Internet. Of course, after learning that I had cancer, I called and told members of my family. I had the good fortune of having a brother-in-law who is a doctor. He began to do some research in his medical library resources and sent me a lot of articles about base of tongue cancer. There was a lot in that literature about different treatment options.

I went to Seattle and saw some folks there to get a second opinion. They did not think I was a surgical candidate. They thought that I was a candidate for radiation or chemotherapy. So that gave me now a little more incentive to investigate a little further. I've gotten a different opinion now from another set of doctors.

I went immediately from there on to Houston. They determined that my cancer was treatable with radiation only. I was not to have any chemotherapy. They thought that there may be a possibility that I'd have to have some follow-up surgery but that it would not be surgery on the primary tumor site. It would be surgery in the neck dealing with the lymph nodes. My treatment consisted of six weeks of radiation initially and then several months later, a bilateral neck dissection. I decided not to continue my follow-up treatment. From Houston, the distance is so great and the cost is so exorbitant to make multiple trips every three months or so.

I do not have a normal swallowing mechanism. When you get radiation treatment, I'm told it basically changes the tissue. Your tongue doesn't work the same way. It's stiffer. It's not as elastic. It doesn't move as well, so you can't swallow the same. When I eat, I have to drink a lot of liquid. I do a lot of clearing of my throat where I get little food particles stuck in my throat that don't go down because swallowing hasn't worked. I have to cough and clear my throat and drink some more water. I've gotten to the point where that's fairly routine for me. I don't even think about it anymore while I'm doing it but it is something that's different for me.

Radiation kills the cells in your oral cavity that produce saliva. So you get what's called dry mouth. Some patients have an extreme condition of dry mouth, and they carry around a water bottle with them twenty-four hours a day because they're constantly taking sips of water. I seem to have some amount of saliva production intact. I do have times when my mouth gets dry. It seems to be in spells at certain spots in the day without really much of a pattern as I can tell. But I'll have times where I have to have something to drink close by to wet my throat down because I'm not producing the normal amount of saliva.

Always get a second opinion and maybe a third opinion. I think culturally, for people in Alaska, they are not inclined and never even think about getting a second opinion. Western medicine, in general for the Native culture, is something that they're not totally used to. The doctor speaks to them very authoritatively and has an opinion. They take that opinion as the final answer. I see the people in my region being culturally disadvantaged. They wouldn't ask for a second opinion. They wouldn't even go to a doctor when they have a pain, and that's a problem because then the diagnosis is delayed. I feel fortunate that from my background, education, and experience in life, I had the determination and the drive to go out and find as many answers as I could. To do the research, figure out where was going to be the best place for me to go, and go there. Clearly, I probably have some capability of doing that financially and such that many, many, many other people don't have. For me, location and price was not an option. This was my life. I wanted to go to the best place, and I was going to get there no matter what.

Body image is probably the biggest thing that I deal with on a daily basis. For years and years, I was about a 160-pound individual. In my late 40s, I put on an extra 15 or 20 pounds that I probably really didn't need. But after treatment, I had lost 40 pounds. I've lost a lot of lean muscle tissue on my body, and I haven't been able to put it back on. I haven't found a way to successfully gain any weight. Because it was radiation of the head and neck area, I got to a point in my treatment where I couldn't swallow any more. My throat was just so sore, I couldn't swallow. So they put a little tube into your stomach and you take your nourishment through a tube. That changes the whole dynamics of your eating habits and your metabolism. I don't have the same stature that I have always had. I've got an ugly little scar on my neck from the neck dissection that they did. That bothers me a little bit. But I always remind myself, in both of these instances, "Hey, I'm alive and I'm cancer-free at this point." These are minor problems that I just need to deal with.

One of the first things that happened after I was diagnosed was a friend of mine gave me Lance Armstrong's book, *It's not about the Bike*. The book was a great inspiration to me. Lance is a pretty tough guy. He was determined to get well. He was faced with some serious situations in his personal situation. It gave me a couple of clues about things that I was going to be up against. I remember reading in the book when Lance was talking about how his physical body type changed from pre-cancer to post-cancer. He was a little on the chunky side in the beginning but he turned into this wiry, strong guy after the fact. That was just a change in life that he was going to have to deal with. I really enjoyed and responded to the message that came out in the book. It was a help for me in terms of determining, "I need to get all the facts. I need to check out all the options." He talks in his book about weighing the options and ultimately making a choice to go to a specific institution that he thought was going to be the best for him and the best for his situation. That was a great help to have that as a starting point in my thinking about how I was going to approach the rest of my life.

LIVESTRONG is the approach that I felt like I tried to take in addressing my cancer. I'm a pretty stubborn, hardheaded, determined person. I was determined that I was going to do whatever it took. Go as hard as I could go at this and try to get a successful outcome. **LIVESTRONG** means having

that positive attitude and having the mental toughness to try to push your way through it. It surely has to involve living with those additional things now that you have to accept: lack of flexibility in the neck, inability to swallow properly, or any of the other side effects that one might have from the various types of cancer. You have to be a little tougher to deal with living with some of those side effects. I think that's the approach that people need to take.

My name is Tom, and I'm a two-year squamous cell carcinoma survivor.

TRINIKA CRAWFORD

TOPICS DISCUSSED:

BODY IMAGE; FINDING MEANING; PHYSICAL REHABILITATION

I was a basketball player, 8th grade. I did a split at practice one day. I felt a small pull in the innermost part of my left thigh. I ran on it for like two weeks. and then I began to have a loss of function in my leg. I couldn't bend it completely. I couldn't run without dragging my leg. And then I had a small mound my thigh bone. And we treated it like pulled muscle. I went through therapy with one of our trainers for basketball. That didn't work. It got worse.

In January 1993, I went to the Houston Clinic, and I had an x-ray done. And, of course, a big cloud showed up on mine, and I asked, "What in the world is that?" The doctor determined that it was a tumor. He forwarded me to an orthopedic oncologist. They did a biopsy, on January 17, 1993. That's when I found out I had cancer. I was coming out of the biopsy, and the doctor woke me up, and said, "The tumor is cancerous."

I started taking chemo in January. I didn't have bone transplant surgery until April of 1993. By that time the chemo had killed 90% of the cancer. In the bone transplant, they cut almost all of my left thigh bone out and replaced it with another bone. I had a plate put in, screws and everything, and got a new set of crutches and was well on my way. I continued taking the chemotherapy until March of 1994. The doctor said, "Okay. You'll probably be on the crutches from six months to a year." So at six months, I stopped using the crutches. I broke the plate by putting too much weight on it. I had to have another reconstructive surgery, in October of 1993.

I stayed on crutches until '97. I got off the crutches right before college. I went my first two years without crutches. Then in 1999, the bone itself broke in half. The bone broke in half again a year later in 2000. I just got off the cane in November 2002. And now, I am free of cancer and free of crutches.

With chemo, I actually gained weight. After three months without the steroids or anything, I just naturally gained weight. I gained 20 pounds probably over a span of three months. That's with the fluids and the food. I'd hardly ever got sick. I had the highest doses of Methotrexate and Adriamycin. You don't feel normal. You have the metallic taste in your mouth, very sore gums, sores in your mouth, those kinds of things. But as far as being nauseated, it really didn't do much. So I was very blessed.

My hair fell out, and that did not bother me at all, because I'm a tomboy. I didn't have to curl hair. It was fine with me. I wore bandanas. I'm one of those, if it's not my hair, I don't want it on my head. My mom was like, "Well, they can make you a wig with human hair." I told her, "No. That's not gonna work." So I had a bandana. And people used to buy me bandanas all the time. I had a bandana that matched every outfit I had. It started a trend at school, and a lot of people started wearing bandanas at school because of that.

I usually would go on a Friday to have the chemo. I would miss school on Friday. And I'd stay that weekend at Eggleston with the chemotherapy treatment. My mom, didn't have to work on weekends either, so that worked out well. We would come back on a Monday, and I'd usually go to school that Tuesday or Wednesday. I told my mom, "I cannot sit at home. I'm not sick. I can go to school. I mean, just talk to my teachers and allow them to give me time to get to class. You know, I'll be fine." It worked out really well.

Physically, you go from walking on your own, being very active to walking with aid for up to six months to a year, maybe more. I was on crutches for four years. Having to make that transition, that's the hardest part. I'm an independent person. Having people opening the doors for you or carrying stuff for you was hard. I had needles everywhere when I first came out of the surgery. I told my mom, "There is no way you're giving me a bath. I'm 13 years old. You can't do that." I wanted to do everything on my own.

Not being able to carry my books, not being able to go out in big, big crowds, because they could trip over my crutches or cause me to fall, which could cause me to break my bone again and have surgery again, that's one of the downfalls. Not being able to do the physical activity and seeing all my classmates run around, participating in the sports that I participated in, and not being able to do it myself again. I had to get over it, but it did hurt a couple of times.

I did learn how to walk on the crutches correctly. Not leaning on them, but actually pushing up and using your upper body to get around. I walked on my crutches everywhere, and I walked at a rate a normal person would walk. It got to the point where I was a pro. I went everywhere. I did everything myself. I still tried to avoid the big crowds. Even when I was in school, I'd carry my own books and that kind of thing. Muscular strength and muscular endurance, build up walking on the crutches. You can still swim. When you're in the water, you're weightless. You can still swim. It'll actually help. It's very therapeutic. It'll help build up the muscle.

Right now, I don't have any physical issues. The only thing is I can't do anything too strenuous. I can't run right now. I have not run since 1992, and that's all I used to do. I am looking forward to the day when I can run again. I told people, "I think I might be like Forrest Gump." Just keeping running. They'll have to tell me to stop.

One thing I can tell a survivor is the cancer does not define who you are. It's just a part of life. We all have our obstacles. We all have our trials. Unfortunately, cancer was one of mine. It does not define who you are. If you have goals, just go ahead and do what you can. Don't stop physical activity. Don't stop living. Set your goals, complete them in the best way you can. Keep going, just know what your limitations are.

Cancer helped me learn more about myself and more about life itself. I value life more and love it more. I appreciate friends and family more. I appreciate other people more. I met so many other people. It was a cultural experience. I'm a more eclectic person. I love some of everything. Having that attitude of "I got through cancer; I can get through anything else" is a good thing. I had the inner strength that helped me deal with other problems in different areas and to be able to work through them. It will help you find the inner strength.

As a survivor, you're gonna be a light to other people. Don't be saddened by the fact that you don't look like the other girls, and you can't have the hairstyles and can't do the running around. Be proud of the fact that you do have the strength to keep living and you will do what you can do. Know that you are a light to other girls. Being able to deal with something like cancer, something life threatening, but not actually allowing it to threaten your life is inspirational to other girls. Don't ever forget that you truly are an inspiration to other people.

Survivorship is just really living. It is dealing with cancer and living with it. Survivorship definitely is knowing that I have it. I don't stop living. I'm gonna deal with it. I'm gonna live with it. And I'm gonna get through it. It's having that determination to live.

My name is Trinika Crawford, I'm 24 years old, and I am a 10-year bone cancer survivor.

MARK AND JACK HOWARD

TOPIC DISCUSSED:
EMOTIONAL SUPPORT

My son, Jack, became a survivor on June 28, 2001, when he was diagnosed with a pelvic tumor.

They had found something in his stomach or in his pelvic region, and there was a tumor. The first thing you think of is, "Is he gonna die? What is this thing inside of him?" Instantly, in my mind, it switched over to how we're gonna get him better immediately, whatever it takes to get him better. Within a day, they had him in surgery to remove the tumor. He recovered from that. A couple of days after that, our son Dillon was born, so it was pretty hectic. Our lives turned upside down. We had a lot of discussions learning what cancer was about and tried to diagnose what it was. He is not officially diagnosed. It is not a tumor that they've ever seen before. The best thing that they could tell us was it was similar to what's called a PNET, which is similar to a brain tumor.

By October of that year, it had already grown from microscopic size to the size of a grape, so it was back again. They suggested chemotherapy. Through the chemo cycles, we had to have him on liquid diets. We did chemo for about six months, and they said that it contained the tumor, but did not kill it. They felt that the chemo was a failure. He was on Vincristine, Cytosan, and BP-16, which are very strong cancer drugs. After that, the next mode of operation was to take it out again. He had a follow-up surgery to take it out. He had to have a secondary surgery after that, because they gave him a colostomy, but his intestines started rolling back on themselves, so they had to go in and do it again. Instead of a three-day operation, we were in there for about 15 days. In July of 2002, we started radiation. They wanted to go in and make sure that the cells in the area were dead, so he had seven weeks of radiation. We had follow-ups every couple of weeks after that, then once every three months. He had to be cancer-free for two years until they'd even consider reversing his colostomy. At that time, he was cancer-free. He had his final surgery, hopefully, and they reversed his colostomy. He has had roughly 10 surgeries since he was two.

Now he's potty training as a five-year-old. Right now, he has to go through various stretching sessions. He has scar tissue from his recent connection of the rectum to the intestines. Because of the scar tissue and because of shrinkage of either the intestine or the rectum, he has to go every couple weeks to stretch him back out, so he's able to continue functioning, but that should end at some time. There's a potential he's not gonna be able to sustain his current condition, because of the inability to have muscle control. Right now, he has to wear Pull-Ups. He is very raw. We have to wipe him about every couple of hours, because he cannot control when he's going to the bathroom. There's a potential he may have to have some kind of an ostomy after this, unless he finds some ability to control it, which at this time we haven't seen yet. Our concern is as he'd get older, how's it going to affect him as a teen? Is he gonna get ridiculed because of it? So we figured we would try the reconstructive surgery, see how it works for him now, and see what his abilities are in the future.

The concerns for him, at this point, are going to be pelvic bone development. They're concerned that long-term, the pelvis may not grow to equal size of the rest of his body. We don't know if he's not gonna be able to walk, or if his body structure will be able to handle the weight for the rest of his body, or if he's gonna be limited on what he can do. We're gonna have to address sterility at some time, because of the radiation in the pelvic region. They were able to protect most of his organs, but for any of the sexual organs, there's a potential that they may be permanently damaged. We weren't able to save anything for him. We don't know if he's gonna be able to have a family in the future. That's something we'll have to address down the road.

We were each other's emotional support through this whole thing. It actually brought my wife and I closer together, because of the realization of how fragile life can be and the potential of losing our son. If something had happened, I don't know what our family would be like right now. I know we've talked about it, and Lori has said that if she ever lost him, she doesn't know if she'd ever be able to recover. I don't know how it would be at that point. He survived and because of the support of our friends and our family, we got through it pretty well. People ask me, "How do you do it?" You don't really know how you do it. You just do it because you have to. You have to go to work. You have to have insurance. You have to do the treatments. You have to drive there. You have to go through the traffic. I would be on almost a four-hour commute every day to work, to go for treatments, come back, drop them off, then go back to work. Then come home and get up the next morning and do that. But it's for seven weeks. Seven weeks for the rest of his life is certainly worth it. So you just do it.

Jack and Grant are very close and seem to play very well. Obviously, with his younger brother, he doesn't get along so well, but I think that's typical. I don't think this has changed their relationship in any way. I think Grant being older tries to understand what Jack has gone through. But our biggest concern, though, was a lot of attention was given to Jack. Dillon was very small. He was just born. He was with the babysitters or the family. I don't think that affected him. But Grant, probably at times, didn't understand why we weren't around, why Jack got so much attention, and why Jack gets presents. We've explained to him. He understands the term "cancer." He doesn't understand the concept or the potential finality of cancer. He doesn't understand death or anything like that, so that's good. Someday he may have to, but right now he doesn't. I don't think we really know what he was thinking. He's never told us. There are times where we see some emotional disconnect with him, and we wonder if it was because of the attention to Jack or if it's just his personality. I know when I was younger; I was a very solitary child. We see him like that sometimes, too.

While I was in the hospital, I was walking through the hall one day and Lance's first book was on the nurse's desk. As Jack was going through his treatments, I was in bed with him most of the time, so I was there for a couple of days. I finished the book in about a day and a half. I'd already known about Lance and had liked biking when I was growing up. But the way I read it, what he went through and the introspection the book gave me personally, was pretty inspiring. I had read in there that there's the Lance Armstrong Foundation. So I said, "Let me see what this is about." I started reading into it. It's easy to get involved with something that you enjoy. Number one, I like to bike. I don't get to do it as much as I'd like to, but I like it. I certainly love watching the Tour and rooting for Lance. There's a commonality there. We also work with a few other foundations as well as raise money. I thought it was a great idea. I read the inspirational portion of the Ride for the Roses and why it was originally done. I figured it was a great way to raise money and get involved with giving back to the cancer society. So I figured, why not get involved?

Survivorship means that you've been through a lot. It's a continuing journey. It's never-ending. You have gone through the worst battle that you've had to go through in your life. I don't think we'd ever have to go through anything that hard again, and hopefully we don't have to. It also is a more appreciative position in life. You appreciate things more or maybe you appreciate things that other people don't appreciate, because you've seen the potential loss or the potential disruption to what you currently have. It's also a very happy time, because it can be worse. You could not be a survivor. That's where that word becomes powerful. That person is still here with us and continuing on, whether it's Jack or anybody else that's had cancer. You can really appreciate the fact that they're still here and they're still battling every day.

My name is Mark Howard, and my son Jack is a three-year cancer survivor.

MARY SCHAEFFER

TOPICS DISCUSSED:

AFTEREFFECTS OF CANCER TREATMENT; EMOTIONAL EFFECTS OF CANCER

I gained a lot of weight. That was the most physical change that I realized. I used to weigh only 145 pounds. I'm up to 200 now. Even though I exercise, and do a lot of walking, I still keep gaining weight. I've finally leveled off now. I think it's a side effect from the Tamoxifen that I took for five years.

All I was told was there would be some side effects, but they didn't say it could be weight or anything. They figured it might affect my skin. It did to some degree, but it's not that bad. It's a lot more sensitive than it used to be. I can't handle Clorox and strong detergents. I've switched to non-chemical soaps. It was probably due to chemotherapy. I didn't go through radiation.

There was a lot of emotion. My mother-in-law had cancer. I had gone through that process of seeing what a cancer patient was going through. There were a lot of things that went through my mind. There was a lot of anger. There was a lot of anxiety. I kept saying, "Why her?" Usually I'm a very strong person, and I don't get emotional very easily. She and I were so close that it really had an impact on me. So when I ended up with cancer, I had a lot of anger. I said the same thing, too. "Why me?" I don't get sick. I don't go to the clinic. I'm very active. How come it's me? I think I eat the kinds of food that I should be eating. I don't eat junk food, like hamburgers and potato chips. Then I kept saying, "Why me? How did I end up getting it?" There was no history of cancer in my side of the family. But I had a lot of that kind of emotional stuff that I went through. I had some good support. I got over the emotional part of it pretty fast because I had other women that have had breast cancer and have survived. They gave me a lot of hope from just talking to them. That's where I started moving forward from.

I used to run the tribal doctor program. At that time, I wasn't working because we had just retired. My husband had been in the military 32 years, and we had moved back to Kotzebue from Anchorage. It wasn't until a year after I had cancer that I went back to work for Maniilaq, and that's when I ran the tribal doctor program. I had my X-rays here, and they did the mammogram and the sonogram. They said, "It's probably just fatty tissue." They told me to go ahead and go on to Anchorage and not disrupt my trip. So I went there, and I didn't even have the opportunity to see the tribal doctors.

The tribal doctors usually do a lot of massaging and blood-letting. If a tribal doctor finds an unusual lump in a person when they're working on them, usually they will refer them to the medical doctor, and they go from there. They don't try to diagnose it. Automatically, they'll refer them to the hospital to see the doctor.

The only time that they might get involved is after the patient comes home after treatment, depending on what type of cancer it is. If it has anything to do with muscles or blood, making sure there's no blood clots and stuff like that. Then they may go and see the tribal doctor. They don't usually go back to see the tribal doctors at all.

To me, **LIVESTRONG** means hope. As long as my body feels healthy, and I feel comfortable and don't have any aches and pains, I know that I don't have the recurrence. I look at it from that standpoint and go on, because there is hope. There's always hope at the end.

My name is Mary Schaeffer, and I'm an eight-year breast cancer survivor.

JEFF DUDA

TOPICS DISCUSSED:

AFTEREFFECTS OF CANCER TREATMENT; DATING AND NEW RELATIONSHIPS; HEALTH INSURANCE; LIVING WITH UNCERTAINTY; MALE INFERTILITY; TELLING OTHERS YOU ARE A SURVIVOR

I became a cancer survivor on August 1, 2000, when I was diagnosed with testicular cancer.

My only treatment was surgery. Since then, I've been undergoing observation. Other than a whole lot of doctor's appointments, blood work, x-rays, and CAT scans, it hasn't really interfered with my life at all in any way. You definitely worry every time. If the appointment weren't to go well, it'd really change what's going on in my life and how things would go. There is that stress associated with it every time. My choice early on was I could either have surgery to remove all of my lymph nodes and not have to worry about things, or I could have undergone observation and hoped that it hadn't spread. I definitely thought that not having the surgery was a better choice. I didn't want to have a surgery that I didn't need to have. From what they told me, that surgery had a pretty long recovery time, like six to eight weeks. That's right when I was supposed to start graduate school, so that would have put me behind a semester. Because of the way things were going for me at that point in my life, it made a lot more sense to do observation.

I discussed fertility with my doctors. They offered to do any tests that I wanted to examine that. I didn't have them done. If you did find out you were infertile, there's no way you would know that it was caused by the cancer. It could have been something else that happened before that, so even if you were to find out that was the case, you wouldn't even know specifically that that was the cause. One of the reasons I decided not to have the surgery is that to have a kid, you'd have to have surgery again. That wasn't something I especially wanted to do. I guess I had the option, but it was all pretty fast. From the time I was diagnosed to when I had surgery was only maybe a day or two, so it wasn't really a lot of time to think about it. The surgery itself didn't pose a whole lot of risk for that. It was more the possible treatments I would have had after the surgery where I would have really needed to consider that.

Initially after my diagnosis, I was definitely very scared, because I was supposed to be starting graduate school, supposed to be moving to a new city. I got all these things that I wanted to be doing, and now all of a sudden, there's this huge 'X' factor in my life. I didn't know how it was gonna change things. I don't know if I'm gonna be able to go to graduate school. I don't know if I move to this new city and it turns out I have to do chemo, will I have to move back home? Will I have people who can help me out? Will I be able to live independently or not? It really calls into question all the plans for the rest of your life. The best way that I found to deal with it is to say, "All I know is this is my situation right now. So I'm gonna do everything I can to live my life the way that I had planned on doing so and plow through it and assume you're going to be okay and do and act accordingly." Do the same things you would have done.

Emotionally, the most difficult thing early on is telling your family and friends what the current situation is. It's difficult only because I know what my situation is. This is how I'm going to deal with it. But to tell other people was in a lot of ways a lot worse than hearing it yourself. It's not near as bad now, because now I can say it was years ago and I'm fine; whereas, at that time, you can't say that. You can say, "I found out a week ago. I don't really know what's going to happen." I'd bring it up if I had to mention that I had a doctor's appointment today or a CAT scan. It's hard to bring up, because you never really know how people are going to react to it. Usually, they jump back a little

bit at first. But then, it's easy. It's not as bad, because I can tell them that it's been a while, everything's fine now. I'm still somewhat apprehensive, because you're never really sure if they're gonna treat you different afterwards. It's not been my experience that they do actually.

If I'm beginning to date someone or starting a new relationship, I'm still trying to figure out exactly what the best way is to bring up my history with cancer. Typically, I've tried to bring it up before it becomes an issue, so that they know ahead of time. Usually, I've never gotten a bad reaction. At the same time, it's a matter of how you bring it up and when you bring it up. It is a mood killer. You really don't know how they'll react. Should you let them find out on their own or should you tell them ahead of time? I've never gotten a bad reaction to anybody I've told ahead of time. I've tried the other method of not mentioning it. As it turns out, most people don't notice. I was surprised by that.

After I was diagnosed, I lived at home for the summer. It was in between college and graduate school. For a little while there, my mom was definitely overprotective. Luckily, I was moving to Philadelphia soon afterwards. Once I moved, I was on my own again. I have two brothers and a sister. They've been very supportive. One of the first things I did after I was diagnosed was talk to my brothers. I told them to give themselves a checkup. I'm not really sure how much of it is genetic, but it can't hurt to check. They were worried about me. I think anytime you hear that a family member has cancer, you're obviously gonna be concerned. Right after I was diagnosed, I did a lot of research on the web, so I could tell them about it. The odds were pretty good that I would be okay in the end. It helps when you go into it with a lot of knowledge about what you're talking about.

It's only been about half a year that I've been in the Life after Cancer Program. All my experiences with it so far have been really good, but I'm still pretty new to it. The doctor, who I had been seeing through all my visits, had referred me to it. He said, "You're at the three-year mark. Everything's been fine, so it's time to head over to the Life after Program." I was pretty excited about it. Some of my appointments are still the same, but it still feels good to go to the Cancer Survivor Center as opposed to the Oncology Unit. It's been fairly recent that I've been considered a cancer survivor. At some point before that, I may have been fine for a year or so, you're hesitant to refer to yourself as a cancer survivor. It almost seems like bad luck. You don't want to say that until you are really confident that it's true. For the first couple of years, "Yes, I'm doing fine." But you don't want to jinx yourself.

I think the biggest way that having had cancer might affect me is that it really might determine a big factor in where I would choose to live. Now, I would be very hesitant to live somewhere that wasn't near a really good hospital. I'll probably stick more towards big cities that have really good healthcare. Health insurance was a real issue when I was diagnosed. I was about two months out of a job that I'd been working, and I hadn't yet started graduate school, so that health insurance hadn't kicked in yet. Luckily, after you leave a job, you have 90 days to renew your health insurance. So I was 60 days out, and I could pay for the last two months. It covered the overlap between when I finished working and when I started graduate school. But otherwise, that would have been a real problem. I am worried about after graduate school, but I'm assuming I'll get a job after graduate school, and that that'll take care of that, hopefully. It is still an issue, because you never know how they'll treat things.

Survivorship means that I can live my life the way that I had planned on doing so. I'm no longer worried about what's gonna happen in the future, not near as much as I had been previously. I'm doing the same thing that I wanted to do. When I make plans for the future, I don't think about cancer as something that will occur again.

My name is Jeff Duda. I'm 27 years old, and I'm a three-and-a-half-year testicular cancer survivor.

LANCE ARMSTRONG

TOPICS DISCUSSED: COMMUNICATE WITH YOUR HEALTH CARE TEAM; EMOTIONAL SUPPORT; FEAR OF RECURRENCE; HEALTHY BEHAVIORS; HOPE; LIVING WITH UNCERTAINTY; SETTING PRIORITIES

Whenever I go in for checkups, obviously those are nervous days. In the first year, I was getting checked every month, so I think it was just a constant month of fear until I went to the next checkup. In year two and year three, that started to fade, and now I really don't get nervous about the checkups anymore. I don't know if that's a good or bad thing, but I think it's the truth.

We as cancer survivors depend on our doctors and nurses and the people in the hospital, then there's this huge extended network of friends and family and neighbors and teammates. These are the people that care about you and are involved in your life but, for me, I really depended on the doctors. When I finally decided to end up in Indianapolis, I just turned over everything to them. It's like turning over your life to somebody, so if they said things were going good, then I believed that. If they said things were not so good, I would have believed that, too.

You should certainly be involved. You should certainly ask hard questions. And some of those questions might make you uncomfortable. To look at somebody that you've trusted for, you know, just a week or two weeks and to say, "Look, I'm not sure this is the right thing. I want a second opinion. So I need to get all my records, I need to get all my X-rays, all my blood work, everything, collect it, and go somewhere else." It's not easy to do and you're worried that they're going to be offended, but you're talking about what's in the best interest for your life and you've got to do it. You've got to make the call to search for the best and the most advanced care.

The nurses are the ones who, in my opinion, do most of the work. The doctors obviously design the protocol, design the treatment and oversee it, but the nurses are the ones who are in the hospital wing or in the chemo room. They are the ones you see 90 percent of the time, and they're the ones that you get to talk to and the ones you have to ask questions to. They're the ones that make everything happen. My nurse Latrice, at the time, she was the boss. She was the one I really relied on, and if I had questions, if I just wanted to talk, I'd turn to Latrice.

I finished in December of '96 and I continued to call the doctors for months after that. If I was worried or if I just needed a little pep talk, I would call Dr. Nichols and bug him a little bit. I think they thought that I bugged them when I was being treated, but I really bugged them when I was done!

Hope can come from many ways. Certain people are very religious, so they find a lot of hope in religion or a belief that they have. Others can have hope in themselves, hope in the process, in the treatment, in the drugs, in the history that has come before them in proving that people can live and survive and thrive.

Hope can come in the form of just thinking that it could be a lot worse. I was in a position where it was bad for me, but I was sure that there was somebody out there that was worse off than I was. To me, that gave me hope that I wasn't in the group that they said, "You don't have that chance. You're not going to make it. We can treat you, we can prolong your life, but you're probably not going to live. We're 99.9 percent sure you're not going to live." I could not imagine being put in that place.

So if they tell me that I have a 40 or 50 percent chance to live, then I'd turn around and say, "Well, that's okay. At least they didn't tell me I had a 4 or 5 percent chance to live." So already I am a lot

further ahead than I could be. It sounds strange to think that that gave me hope, but I just felt optimistic that my life was not already predetermined to be short.

When you're fighting cancer there are no guarantees. I focused on getting better and I tried to say positive almost all the time that I was going to ultimately get better. But there are moments where you say, "Okay, this might not shake out and I might die from this." At the same time, now that I've made it through, I think that's a helpful thing to experience.

I'm sure that cancer will affect my life in some other way. For me to think, well, I got the disease when I was 25 so I'm going to cruise through life from now on and nobody I know or love is going to get this illness — that's silly. I'm not so sure that at some point in my life I won't get another form of cancer or have some other effects, either secondary cancer due to treatment or due to some process here. I'm quite confident that I won't get testicular cancer again or won't have a relapse, but when I'm 50 or 60 will I get prostate cancer? I don't know. I might. But I'll catch it early, I'm sure of that.

When you're diagnosed, I think everything changes. If you're a smoker, you stop smoking. If you've eaten poorly in the past, you try to improve your diet. If you drank a bunch of beer before, you try to stop. It's a serious wake-up call for most people, so in that sense it's a good thing.

I try to maintain a healthier lifestyle than I did before. I'm not of that camp that thinks I got sick because of a poor lifestyle or poor diet, so my situation is a little more random. I don't think it's because I ate a cheeseburger five times a year. But certainly it's good for people to wake up and understand that this is our shot and everything we do and everything we put in our body ultimately has some effect. Whether it's through diet or through fitness or through other lifestyle things, it's a good thing to change, a good thing to always look at.

I try not to take the risks that I feel are very risky, but at the same time I try to find the risks that are just below there. And I love to take those and I think those are great for pushing the envelope a little or just reminding yourself that you're alive. Fear is good and being scared is good. I need that at times. Whether or not that's going downhill on a bike at 70 miles an hour, or jumping off a cliff, or riding a motorcycle — those are just fears that I think are healthy. But would I go smoke a cigarette? Never, because that's a risk that I don't ever need to take.

My priorities have changed. My passion is becoming stronger for my job. I believe that I've learned we have to be happy, and in order to be happy you have to be honest and truthful. And I can't get up every day and not be happy or not be straightforward. I think if your heart tells you something, you need to listen to it. That's a serious priority for me. Many people can look at my situation and say, "Well, look at you. You're perfectly healthy and fit and better than you were before. This thing actually improved you." But other people lose a lot. They lose part of their mind. They lose parts of their body. They lose the ability to function or to work professionally.

This is an illness that isn't always pretty and most of the time it's messy. Along the way there are certain things we can do, I think, to affect that and make our lives more productive. If I lost a leg through the illness, then I would be a disabled athlete. I would focus on something like that. I would focus on the things that I still loved. I may not be a professional athlete, but I'd still have my passion and I'd still know that I woke up every day. For me that's a powerful message and one that, as bad as it is, it could be a hell of a lot worse.

We're thankful and glad that people have come to learn and to listen and to share their experience. I've heard thousands of times, especially in the last year being on the President's Cancer Panel, of people just looking for a place to go. They just need one source for information, for stories, for companionship, for anything, to know that somebody cares and is listening. We hope we can provide that for them. As I said, life is messy and this illness is messy. We hope that, through the information and knowledge here, we could help people not only to survive, but to thrive. So that's our mission, that's our goal, and hopefully this works.

LIVESTRONG is exactly I guess what it says. It's one thing to live, but it's another thing to **LIVESTRONG**, to attack the day and attack your life with a whole new attitude. This was a gift for me. I guess before the illness I just lived. Now, after the illness, I **LIVESTRONG**.

I'm Lance Armstrong, and I'm a seven-year cancer survivor.