How to be a Powerful and Healthy Cancer Survivor
Webcast
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Introduction

Andrew Schorr:
Hello and thank you for being with us once again. We're on a summertime warm and sunny webcast from Seattle. I'm Andrew Schorr. I'm delighted you could be with us. Every two weeks we do another one of these webcasts sponsored by the Seattle Cancer Care Alliance, their commitment to you and your family to connect you with leading experts in cancer and always inspiring patients. Hopefully I give you a little inspiration as well.

Well, no matter what cancer has touched you or your family happily in many cases medical progress and your own strength has led to you being a cancer survivor. Well, that brings up a lot of issues. There are millions of American cancer survivors and others around the world now. Well, did you know that the Seattle Cancer Care Alliance has one of the very special cancer survivorship programs? We're going to talk about what's available to you in that program through the SCCA but also about many of the issues that come up for those of us who are cancer survivors.

I want you to meet someone else who has gone down this road and that's Jayne Collins. Jayne is 47, and back in 2005 she was diagnosed with breast cancer, and it turned out to be the type of breast cancer that not infrequently affects women who are younger, premenopausal, and that is the HER-2/neu type, which used to be one of the more aggressive forms. Happily now there's new targeted therapy that's helped a lot and she's benefitted from that, a drug actually called Herceptin. But she had a lot of medicine and a lumpectomy and radiation and then ongoing medicine, and then some medicine she continues to take today. And along the way she was trying to complete her college degree in business administration, which she has now completed. And she was trying to maintain her marriage, which unfortunately now she's separated.

Jayne, so you have walked the walk of being a cancer patient and a cancer survivor. It's not an easy road and these issues of survivorship are significant, aren't they?
Jayne’s story

Jayne:
They are, and it's something you live with every single day. When you talk to people around you think they think that as a cancer patient your treatment finishes when your hair grows back, and unfortunately while some of the medication stops around that point the mental anguish goes on for years, and that's something I struggle with every day right now. It's affected my life in a negative way, but it's also had a really positive impact on me the way I look at life moving forward.

Andrew Schorr:
Right. Well, that's a recurring theme. I felt that way and it sounds like you do too. We know we've been given a gift to be out in the sunshine today, you know, in Seattle, walk around Green Lake or whatever your favorite spot is and say, Here I am and I feel pretty good. Maybe I feel great. But hopefully you have that time back, and that's a new lease on life, and millions of us have that now as cancer survivors here in America. But when you're in the thick of treatment you're just so focused on beating the cancer or knocking it back, and then some day somebody says, Well, you're a cancer survivor and it's like, Well, now what? Where is the manual?

Jayne:
Who do I do now?

Andrew Schorr:
Yeah, what do I do now? Let's talk about some of these issues for you. So first of all, if you want, can we delve into marriage for a little bit. It does put strains on marriage. Not everybody comes out the other side. I'm fortunate that so far as a 12-year survivor, I have. It's been more difficult for you. Often serious illness can put tremendous strains on a marriage. What would you say about that to people?

Jayne:
I think it just makes you examine what's really important to you, and it sounds like a very selfish thing to go through but I've had a number of experiences in the time that I've gone through cancer treatment, losses of people in our family, my dad died. And seeing how my husband reacted to me during those events as well as during my treatment, it was very hurtful to know that we didn't connect on the same level, and it really made me feel can I stay in this marriage for the rest of my life? Can I feel unhappy towards my husband for the rest of my life? It's not fair towards him.

And that's just part the Survivorship Program at the Fred Hutchinson Cancer Research Center. I actually went through six months of counseling with a very wonderful doctor who really helped me sort my head out and make sure that any decisions I made were carefully thought through and were the best for me, not necessarily for my husband and I but for what was going to make me happy in the
long run. And I don't know what's going to make me happy in the long run, but I know we didn't share the same interests enough to stay together and get through this period of my life.

Andrew Schorr:
You got clarity on that through you counseling.

Jayne:
I did.

Andrew Schorr:
Which is wonderful. We'll hear more about the resources. So there's your domestic life and then work life. After all, you've gotten this degree now in business administration. How do you approach the workplace knowing that you went through a lot of treatments, you still take some medicine, there's always the fear, can the cancer come back. How do you approach that?

Jayne:
Last year at the very first survivorship seminar I went to, which was in June of 2007, there were a number of break-out sessions and I signed up for one in particular to do with workplace discrimination toward cancer survivors. I sat there madly taking notes, listening to everything that was going on and took all the hand-outs with me because I wanted to make sure that when I was looking for work I was behaving in the appropriate way while I was interviewing with people and also that there was no discrimination coming back towards me.

And it was only when I started looking for work in October last year, took a long vacation in November and December, and when I got back I really started in the job hunt good and proper. So when I started interviewing I was really nervous wondering what people would think. I didn't wear any jewelry. I have a nice white gold pink ribbon with rubies in it my mum gave me for graduation last year. I took that off. I didn't want any evidence of breast cancer haunting me in my job application. So it wasn't until I'd officially accepted a job offer that I told the HR manager that I was a cancer survivor.

I felt I couldn't keep it from her any longer. I just needed to fess up because there were questions I had about what my insurance, my health plan coverage would cover and wouldn't cover, and it was something I couldn't keep it bottled up because I needed to know ahead of me moving forward knowing that my husband and I would likely separate what do I do when I go to the doctor. You know, is this defining going to cover all the follow-up visits I have? Is it going to cover a breast MRI if I'm worried about something, which I have been recently. So I needed to talk about all the important things related to ongoing care after I'd accepted an offer in writing. I couldn't discuss them beforehand. I thought there might be some workplace discrimination, and they would pick somebody else over me because they weren't a cancer survivor.
Andrew Schorr:
How did it conversation go?

Jayne:
It went very well because unbeknownst to me at that time one of my co-workers went through breast cancer treatment last year so the company as a whole was aware of it. But coming in as an outsider you don't feel comfortable talking about it with colleague to start with, but I knew with the HR people I had to have the discussion to make sure that the insurance they were going to offer me would meet my needs. So it was pretty stressful for me, kept me awake a number of nights.

Andrew Schorr:
I'm sure. I'm sure. We're going to talk more about that as we get into it. And I invite our listeners to participate in the discussion of cancer survivorship. And also we'll understand what resources are available in the very special cancer survivorship program at the Seattle Cancer Care Alliance. What's available to you. Here's a phone number to call if you want to join the conversation. Or you can send us an e-mail. The e-mail address is patientpower@seattlecca.org.

Now, as you know, Jayne, the director the Survivorship Program is doctor Karen Syrjala, a clinical psychologist. She's been at Fred Hutchinson there for 24 years. So she's well known there and has devoted herself to helping cancer patients and survivors.

Dr. Syrjala, thank you so much for joining us. The issues we've been talking about with Jayne I know are just the tip of the iceberg, but they're not atypical at all, are they?

Issues for the Cancer Survivor

Dr. Syrjala:
Not in any way at all, and in fact Jane's description of her experiences is both common and she really did the right thing I would say. When she was talking about both examining her relationships and when she was talking about how she approached work, these are challenging issues for a lot of cancer survivors. When do I discuss my cancer experience with new people I'm meeting or new employers. So these are a lot of issues that people are commonly looking at, as well as her positive experience. And I was really pleased to hear the two of you talking about the positive growth things that have happened from your experience because we know that cancer survivors, two-thirds of them, report that their experience through cancer has actually led to some positive opportunities for them.

Andrew Schorr:
Right. Well, here I am doing Patient Power. This is my passion, and it's very clear to me. So that's what fuels me is life after a cancer diagnosis is to do this, and I'm delighted I can. There's something that Jayne touched on, and I'm sure it's hit all of us as cancer survivors. You mentioned, Jayne, you said you were worried about something medically, and one of the things I think for all of us as cancer survivors
is when to worry. And I like to tell this story. I went to my oncologist for a checkup and he said, well, you should start taking a baby aspirin for your heart. And of course the whole idea of taking care of my heart was like a revelation because he's the oncologist and I was always worried about my blood test results as a leukemia survivor. But he started to help me begin to think of my whole body and my whole self beyond just cancer or cancer coming back. But, that said, we always worry, every little ache and pain or bump, whatever, could it be the cancer again.

Dr. Syrjala, what about that? How do we put that in perspective and say, you know what, you've come through this and hopefully forever, and you have to get past it.

**Dr. Syrjala:**
Well, Andrew, I'm really glad you brought that up because I like the way you said that, how do you put it in perspective. A lot of people really approach the worry that comes after cancer and that virtually everyone experiences as something to get rid of. And what we've learned about worry and about feelings in general is that our goal isn't really accomplishable to get rid of it, but rather what we have to do is accept that that's part of what you live with now. And then you say, Okay, what can I do about it? What are the parts I control and what don't I control? You can't control having feelings, but you can take the actions that are available to you to say, Okay, am I getting my regular screenings? Am I seeing my oncologist like you were describing on a regular bases so that I can check on these things, get a clean bill of health once a year. And then when you kind of see yourself worrying you can say, you know what, I've had that checked out. Everything is good to go. Let me see what else I can do in my life so I'm not just staying focused on the what-ifs.

**Andrew Schorr:**
Right. Right. Before we take a break I just want to understand your program. So tell us about Lance Armstrong, who we all know, dollars they've raised from yellow bracelets and all that and your survivorship program.

**Dr. Syrjala:**
Oh, thank you. I'm delighted to talk about that. We were very fortunate that among the eight centers of excellence that the Lance Armstrong Foundation has supported around the country we were actually the third center to receive funds, and what that's allowed us to do with our survivorship program is to really make survivorship opportunities available to everyone who has gone through cancer treatment. The SCCA and the Fred Hutchinson have actually had one of the longest survivorship programs, 30 years old it is, for transplant survivors. We've also had long-term programs for breast cancer survivors, like Jayne, people with prostate cancer. So we've had a number of programs that are committed to survivorship, but now we have the opportunity to extend those to everybody.

And what we can really focused on is what you were talking about earlier, Andrew, which is when you're done with cancer your issues now are not just preventing cancer from returning but also thinking about what are the other issues that I have
to live with now. So we know, for instance, that people after cancer may have decreased bone density, they may have more cardiovascular risks, they may have other issues in their health or their well-being that are different from someone who hasn't had cancer. So with the Survivorship Program we really have the opportunity to bring expertise from around our entire Western Washington community to bring that expertise in to meet the needs of people who have gone through cancer treatment. And it's been a really terrific experience, I think.

**Andrew Schorr:**
Well, we want to help people understand how they can be involved. We're going to take a quick break. I want to remind people if you would like to join the discussion, ask a question of Dr. Karen Syrjala, clinical psychologist who runs the Survivorship Program at the SCCA, and we're going to talk more with Jayne Collins and find out about how she's participated in the program and what benefits it's brought her. All that's coming up as we continue our Patient Power program on empowering the cancer survivor, sponsored by the Seattle Cancer Care Alliance.

**Andrew Schorr:**
Welcome back on our very beautiful summer evening here in Seattle. I'm Andrew Schorr. This is one of our live webcasts that we do with the Seattle Cancer Care Alliance, and they have an exemplary program in cancer survivorship. And as you were just hearing from the director, Dr. Karen Syrjala, how it's been expanding with some helpful funding and recognition from the Lance Armstrong Foundation, and you can believe that that's really special here.

Now, Jayne Collins is a breast cancer survivor who has really taken advantage of that. Jayne, tell us how you got involved in the Survivorship Program and the way you've kind of drawn strength from it. You've already mentioned a couple of specific examples, but I'm sure there are others as well.

**Resources for Cancer Survivors**

**Jayne:**
I got involved with it when, I'm a life-long Lance Armstrong fan, by the way, so I followed his career when I lived in Europe, and I was a big cycling fan, based in Europe obviously, so I watched the Tour de France for many years, and I followed his progress. And then I stopped at one point and picked up his book and read his book. So when I read what he had gone through when he received his testicular cancer diagnosis I went straight to his website, lancearmstrongfoundation.org, and just really took notice of what was going on there, and that's where I found out the information about the SCCA program here.

So after I'd finished my clinical treatment, which would have been around September, 2006, I hadn't quite finished everything, I made an appointment to go down for an intake exam with one of the nurses at the Fred Hutch SCCA program, and I was so relieved that I'd found somewhere, a local resource that I could go to, a top-notch facility that I could go to as a survivor and have another set of eyes watching out for me. Because as my distance from my diagnosis progressed I felt
that the apron strings were getting looser and looser, and my oncologists were setting me free, and I didn't like that feeling. So it was really comforting and reassuring to know that there was a program out there that I could go to and have a yearly checkup and somewhere that I could turn to for advice in between if it wasn't time for my follow-up with my oncologist.

It was an amazing experience to go and have my intake exam, have lots of blood work done and have lots of different questionnaires and things filled out and get a baseline measurement of where I was at that point, and then I went back again in September last year. And, you know, as part of the program you're handed a binder with all of your statistics from all of the tests that you had, and you can actually track where you move on in your health history, which is really valuable. I'm all about the numbers, and I like to see things on paper. So it's really helped me have a tool I can go back to. You know, if I'm dwelling on something, go look at a particular number and say, Okay, I'm not doing so bad there. I'm feeling okay. There's nothing to worry about.

But last September when I went in to visit with my nurse, Colley, I had a major breakdown. I sat in her office and cried, and she asked me what was going on and I said, I'm not happy in my marriage. And this has been a struggle for me after going through cancer treatment. So she referred me to a therapist who works only with cancer survivors and patients and their families. And it was, it was a mind-blowing experience to know that there was dedicated to helping us. And that's really helped me in the last year to really get a handle on my emotions coming out of this turmoil from cancer, you know, the clinical cancer treatment. So there are so many valuable aspects of this program.

One is having another resource to go to to make sure I'm okay. You know, my oncologist is always there, but she's busy with cancer patients. I'm a cancer survivor now so to have a program I can go to is really comforting. And then to have somewhere where I know I'm going to get a regular heart checkup, I'm going to get a regular bone density test, I'm going to get a thorough blood draw done, I'm going to have every type of examination done that's good for me as a survivor, not as a patient. And you know as well as every other cancer survivor that when you go through chemotherapy you can suffer heart muscle damage, and that's not something that's talked about when you're going through active treatment.

Andrew Schorr:
Or chemo brain, right?

Jayne:
Right. I suffer from that all the time.

Andrew Schorr:
I wondered is it age or is it chemobrain. I want to ask Dr. Syrjala a question. So you're a clinical psychologist. We're getting all the, we get cleared for take-off and how are we doing with this and that and our blood, etc., and then Jayne was just talking about, our head. No, do you also help us connect with other people
who've walked in these shoes before? Because the big thing now, you know, on the internet is like social networking. But even social working among patients, but is that that kind of networking and support in the SCCA family, if you will, where we know we're not alone and that people have actually gone on to long, happy, healthy lives?

**Social Networking**

**Dr. Syrjala:**
There are lots of supports in the community. And the SCCA itself doesn't provide a lot of support groups, and a lot of times it's because cancer survivors when they're done kind of want to get back to their lives, and some of them really want to stop coming to the cancer center. And that's very legitimate to say I want to move on. So the Survivorship Program is not necessarily designed to be a place that keeps you coming in once a week for ongoing care. But there are lots of support groups like Team Survivor Northwest.

Exercise, we haven't talked yet about exercise. But that's one of the biggest changes that I see many people making after they've gone through treatment. People who have kind of always wanted to be more active, and all of a sudden they say, Here's my opportunity. I can use this to motivate me to get moving. And so we have a number of activity programs like that. And there are other programs in the community that I want to point out too. Cancer Lifeline has terrific yoga and other physical activities, Pilates, other kinds of program. Gilda's Club has a number of support activities, not only for people going through cancer but as survivors. So we do have lots of ways that people can connect.

The websites that are available through the National Coalition of Cancer Survivors, The Wellness Community, the Lance Armstrong, if you go to livestrong.org you'll also see some links there. So there are a lot of ways to get connected to other people that I hope people will seek out and use because I know from what people tell me that it's really valuable to talk to someone who has gone through a similar kind of treatment as you, to really be able to put your heads together and say, Did you have this experience? Well no, mine was really different. I had this happen or this is how I dealt with it. This has really worked with me. So I think it's tremendously valuable to have that chance to talk with each other, not just going through treatment but later as well.

**Andrew Schorr:**
I want to go back to something that Jayne mentioned that I know is part of your program. So Jayne went through and a lot of the breast cancer drugs I think that matter enough, the bad guys, adriamycin or one of them, but you know it can affect your heart or certainly I know my bone marrow was nicked by some heavy-duty treatment that I had. So we're not, I mean, we have to be alert to these things and then hopefully regain our health and go on, so apparently clinically when you come for checkups as part of the Survivorship Program, you say, Look, you're doing well, but we want to keep our eyes out for X or Y or Z. Some of it may be, for instance, a side effect, right, of medicine you have?
Creating a Personalized Action Plan

Dr. Syrjala:
Absolutely. In fact what we're seeing in the long-term effects for cancer survivors it's really much more the result of the treatments that they've received than it is the cancer itself causing these long-term effects. And in the big picture goal that we all share we want to prevent these kinds of long-term effects, so part of our attempt's to not only cure cancer but also to find treatments that are less toxic, don't cause these heart problems. But if someone, for instance, took an anthracycline, like adriamycin as you mentioned, or had chest radiation for, say, Hodgkin's disease, they could be at increased risk for cardiac problems later on and probably should at, say, two to five years after treatment should get their heart checked out just to see how it's doing and to put their minds at rest in terms of any potential long term effects.

So one of the things the Survivorship Program offers is that it really lists out for you all the treatments that you've had and what are then the kinds of problems you want to be aware of. So, for instance, if you had adriamycin or chest radiation you might want to get your heart checked more regularly. If you had steroids for a long time or you're not able to take hormone replacement and you're postmenopausal and you're a woman, you may want to be monitoring your bone density more often. So if you've had certain kinds of treatment, you may have an increased risk of breast cancer.

So really what we do is try to try to itemize for you what are your personal risks based on your specific treatment, and that way you really can make a plan with the person to say, Okay, this piece you want to monitor every year. Maybe a mammogram you want to have every year. Cardiac check, gee, if that looks good, put your mind at rest, go on. Five years from now we'll do that again. But really give you your own personalized action plan, or healthcare action plan as I like to call it, so that you know I'm taken care of.

Andrew Schorr:
Well, that sounds great. We're going to find out more how people get involved. We'll get suggestions from Jayne Collins about that.

We're going to take another one of our little SCCA breaks. There's great information during our breaks as well. And then we'll be back with much more of our live webcast discussion. Now you can call in if you want. Or send us an e-mail, and I have received a few. Patientpower@seattlecca.org. We'll be right back with our summertime discussion on the wonderful cancer survivorship program at the SCCA right after this. Stay with us.
Andrew Schorr:
Welcome back to our live webcast. Jayne Collins, you've participated in this survivorship program, so for someone listening who just hasn't made that step, what would you say would be the help to them both clinically and maybe for their head as well?

Jayne:
Well, there's a lot of benefit to be had here. There is the comfort and reassurance that if for whatever reason your oncologist happens to miss something, there's like a catch-all. You've got a safety net around you with a team of people, an army of people at the SCCA who are there to help you overcome that anxiety. And that's something that I'm still dealing with. You'd think after three years it would have diminished a little bit, but I've just celebrated my three-year anniversary June 14th, and the week, the lead-up for that anniversary I was in a state of panic. So it's nice to know there's a team of people that can help you over that hurdle.

Andrew Schorr:
I get twitchy on every blood test. I go for checkups every six months and I get really twitchy.

Jayne:
Right.

Andrew Schorr:
And I don't tell my wife. I just, like I'm stoic, right?

Jayne:
She probably knows.

Andrew Schorr:
But inside I've got a lot of flutters. I understand. But continue, please.

Jayne:
That's the reassuring part for me. And the other part is that there are resources through this program. For example I've just completed, two weeks ago I just completed a ten-week exercise and thrive program, which was the first run through the Survivorship Program. It was for a group of 15 survivors of all kinds of different types of cancers and stuff, so now I have 14 new friends who know exactly how I feel. And I've made a very good connection with a couple of women in that group and I sense that we'll be friends for a long, long time to come. So it was a first of its kind program at the Survivorship Program at the SCCA.

We were invited to exercise at a gym in downtown Seattle on Monday and Wednesday night, actually seven days a week if we wanted to, but particularly we would meet Monday, Wednesday under the supervision of three personal trainers that were trained in how to handle cancer survivor physical issues and surgeries and treatments and all of that. So we had supervision for ten weeks, twice a week, going through an exercise program that was customized for us. And it was free.
Andrew Schorr:
Wow.

Jayne:
It still floors me that this kind of program was made available to us free of charge. And the trainers that we worked with at this gym I think really enjoyed the experience too because they got to see the kind of things that we worry about as a group, you know, chemobrain, and aches and brain and soreness from certain exercises and stuff. So they really customized each of our programs individually to work with the ailment or the frustrations that we would have to put up with. And it was a really unique experience. I don't like to dwell on the bad news from cancer because there's too much positive that comes out of it to me, so this was one of the highlights, I think, of the Survivorship Program to date, so it was really great to know that that kind of resource was made available and that it hadn't been available before, and I was lucky enough to take advantage of it first time around.

Andrew Schorr:
That's so neat. Now I have a question for you. Dr. Syrjala mentioned a minute ago about how some people, they want to leave cancer totally in the rearview mirror and don't want to get near it, and that might be not mentioning it, not thinking about it, maybe hesitant even on checkups, and not getting together with other people that they know to be survivors for fear that it's just going to be sort of a crying session about, Oh, well, we were unfortunate enough to have a cancer diagnosis, even though it's affected millions and millions of people.

But I don't think that's what I'm hearing from you. I'm hearing about people who may have had some experience, they were touched by this word cancer, but they're really working to go on with their life in a beautiful, healthy, full way.

Jayne:
We are. I know as a group, I know that one of the patients in particular has just relapsed. He relapsed at the beginning of this exercise program, but, man, he showed up every week. He was still there. He was doing what he had control over to better the chances that his health outcome would be as good as possible. So he was in there exercising twice a week, and I thought that was pretty amazing considering he'd relapsed. So myself, I've taken out my anger and frustration at this disease by volunteering for all kinds of breast cancer-related events in the Seattle area.

And when I went through treatment, when I was in the middle of clinical therapy I didn't want to go to any programs and associate my situation to anybody else's, knowing it would be very different. And I think the turning point for me was when my hair fell out. I decided to really fight. So as stressful as it was I decided, Okay, my hair is gone. I don't have much of an appetite. I don't feel like exercising, but there's a few things I can do here, so I really buckled down, reread Lance Armstrong's first book over and over again to make me realize how lucky I was to
only be going through breast cancer treatment when he went through hell and then get involved in the community and different breast cancer-related activities like the Race For the Cure and the Breast Cancer 3-Day.

So I went from one end of the stick not wanting to really socialize with people who were going through active treatment to the other end of the spectrum and get out there with the thousands of people that do these events every year. It's been an important part of me trying to move on from my experience. Obviously, it's not working because I'm talking to you tonight. I haven't decided to crawl up into a corner and be quiet about it. I've toned it down a little bit.

Andrew Schorr:
No. Thank you. You're passionate. Now, Dr. Syrjala, so we're talking about millions of people now in America who are cancer survivors, and as the population ages, not always but often cancer happens as we get older, and there are newer and better treatments all the time. This is a big deal, right? I mean the idea of millions of people being survivors, it's not just a small thing. It affects a lot of people and their families.

Dr. Syrjala:
I'm glad you made that point. It affects 12 million people in the US right now. 12 million people are cancer survivors, and we expect that to become in the next two years to be 2 million new people a year so it's definitely an experience that all of us either will have ourselves or that someone we love will become a cancer survivor. And the good news is really that two-thirds of people diagnosed with cancer will be alive five years from now. So we have made huge progress, but there are these then leftover affects, and it's not just the person who's gone through treatment but it is also affecting their family. And each of you who has gone through it knows as well as I do that this is a family disease. And the worry and sometimes the difficult times, the concerns about eating, about exercise, how much can you do, how much do you pay attention to symptoms, all those kinds of worries and fears are really shared by family members as well.

Andrew Schorr:
Yes, so many important points. Now, if somebody wants to take advantage of your program, how do they start?

Dr. Syrjala:
All they have to go is go to fhcrc.org and click on the Survivorship Program. Just look on the links there for the Survivorship Program. Or they can call us at 206-667-2814 and just say they'd like to make an appointment to come in. It's available to anybody who has had cancer. And we have a Children's Hospital. We have also a program for people who have had cancer as kids. And if they're not yet 21 then they can go to Children's to what we call the access program. So we really have something available to everybody, and if you call that 667–2814 you will be able to get to whomever you need to for your own needs. We'll make sure of that.
Andrew Schorr:
I understand the point about children as they grow older, and I know kids like that who treated for leukemia and being followed knowledgeable as part of the Survivorship Program. What about kids of cancer survivors? Is there anything there to help them? Because obviously, you know, Jayne didn't have kids as she was going through all this. I did. My kids didn't seem to need it, but sometimes it can be very traumatic for them. And then worries long term about, well, dad seems well but is he really. Is he really here for a long time?

Dr. Syrjala:
There was some wonderful research by a colleague of ours, Dr. Fran Lewis at the University in the School of Nursing, and she's doing a study right now called When Mommy and Daddy Have Cancer. And she's finding out that those kids, like you describe, who look fine and act fine still are holding in a lot of their own concerns. They're very tuned in, very aware of what's going on, and it really can be helpful for them to have a place to talk about what they are concerned about as well. So I think that's a great opportunity, and if you want more resources on that just give us a call to that same phone number and we'll get you linked up to that.

Andrew Schorr:
Right. That's the point. So it sounds like the Survivorship Program is a touch point for both what you have right there and resources in the community that we know from experience touch families in different situations. Could be if you have kids, concerns that the kids have or you worry about the kid having. Could be about your spouse. Could be about your parents. Could be about yourself, and then all the clinical stuff and what's going on in your body, either the cancer or worries about that or all the other things we have to worry about, as I mentioned, whether effects of treatment or just as you get older and you happen to be a cancer survivor. So wonderful resource. That's the number again, 206–667–2814.

We're going to talk about some of these other issues, and Jayne is just so eloquent about some of the stuff that she's being working through, and I'll share some of my two cents as we continue our live Seattle Cancer Care Alliance webcast. And we're discussing their survivorship program, which is really one of the best, and also how to just be empowered as a cancer survivor because you came through the treatment, well, now what? And hopefully that's a long, healthy, vibrant life. Maybe a different life than you thought but maybe one where you can make a tremendous contribution, have tremendous enjoyment of life and people around you. We'll be back with much more of our live webcast right after this.

Andrew Schorr:
I wanted to tell you about the incredible depth of our library of programs we've been producing with the Seattle Cancer Care Alliance and the experts there. Here's just an example. Remember, not very long ago there was the diagnosis of brain cancer of Senator Ted Kennedy and then in the paper every day, what's brain cancer and glioblastoma and all this. Well, guess what? We had done a very in-depth program on the latest understanding of that with Dr. Mar Chamberlain, and we trotted that out, and that was on the SCCA website. So please take a look
at our library of programs because surely not just the things that happen in the news but the thing that may touch your family or a neighbor or a friend or a relative, it's all there. We've discussed so many topics like we're discussing survivorship issues today.

Now, Jayne Collins, so you've been working through your matrimonial situation and decided to separate. Divorce and separation is not at all uncommon among cancer survivors, is it?

Jayne:
I don't think it is, and I can see why it isn't uncommon because I'm a very strong-willed person anyway which helped getting through the cancer treatment, but when you come out of something like this it really puts a microscope on everything you do in life. So it maybe made me examine things that I may not have been happy with before that I would have otherwise turned a blind eye to, but to feel that I didn't feel emotionally looked-after during my treatment, I couldn't neglect that, coming out this side of it. I just couldn't let that go. If this had never come along I may have let it go by the by and just pushed it aside, but it really made me feel, especially with everything else that was going on. My sister was diagnosed with thyroid cancer. My dad was dying of emphysema and lung cancer, and at the same time I thought where is all this emotional support a husband's supposed to give you? It really put everything under a microscope, so it was my decision to do something and look for counseling help through the Survivorship Program and deal with these issues because I just couldn't deal with them on my own.

Andrew Schorr:
Right. We have gotten an e-mail from Jonathan in Modesto, California, wondered whether divorce rates among patients were elevated. Dr. Syrjala, what about that, about the pressure on marriages and whether that does lead to higher divorce rates or the resources that can be brought to bear to try to get everybody communicating and maybe help tamp that down?

Impact of Cancer on Marriage

Dr. Syrjala:
There is no question that using the resources available and getting counseling for partners going through cancer is also valuable in improving a marital relationship. Our own research says that divorce is actually not more common after cancer than it is in people who have not begun through cancer, but I think that Jayne is pointing out exactly why. Because there are marriages that are very vulnerable and cancer may be the straw on the camel that breaks the camel's back. But these are already fragile marriages. Other marriages become more solid as a result of going through this dramatic and traumatic experience.

Andrew Schorr:
I think mine is stronger. I think mine is one like that.
Dr. Syrjala:
I'm glad to hear that.

Andrew Schorr:
Yeah. We had to work through a lot and we did have to go through counseling. Now, we touched on the employment issue with Jayne. So there's this worry about financial issues, insurance, maybe health insurance issues, economic issues. That's a very real overlay on top of the all the clinical stuff, isn't it, Dr. Syrjala?

Dr. Syrjala:
It really is, and that's the important thing. When you get past treatment you start looking at the rest of your world, and all of a sudden you realize that cancer can start to invade a little bit all the other aspects, your relationships with friends where you may feel a little more detached from some people than others. Your finances certainly are affected by all these extra costs coming in. And work is another area where you really have to for many people to reevaluate. Can I continue doing what I've been doing? Do I need to let my employer know? Do I keep it a secret. So there are a lot of issues that do come up around employment like there are with the other aspects of your life, and it's really both an opportunity and a challenge to kind of reassess the whole picture of your life and what direction you're going.

Andrew Schorr:
Well, we'll cover in other programs, but I know a big issue, let's say, for a woman who has been treated for breast cancer is body image, intimacy, sexuality. You were talking about the later effects of medicines if, let's say, for a younger woman like Jayne you're thrown into menopause by the treatments, how does that affect your enjoyment of sex or how comfortable you are with it. So there are a lot of issues we can discuss, and it's all tied up with survivorship. If you're a man who has been treated for prostate cancer do you have erectile dysfunction? Do you have urinary incontinence? Do you just worry about all that? So those are issues too and it goes on and on depending upon what you may have been treated for.

But, that said, you're not alone, right, Dr. Syrjala? I mean, we're talking about millions of people now, and there are many examples of how people say, okay, I've been given this gift of hopefully a long life and maybe there's some effects, and as you say there are a lot of efforts to try to limit those effects of treatment. But the treatment was successful so now what and how do you go on with your life and feel good about it?

Dr. Syrjala:
And people do go on with their lives and feel good about it, and when they get together with other people who have gone through that experience, like Jayne describes, like you, Andrew, have described, I think that what they find is that they're actually inspired to do more than they might have thought of doing on their own because they feel now like they're part of this larger community that's really pulling together, that's working together to change policy, to change medical practice, to simply educate the rest of us about those experiences.
Like for instance you were talking about sexual function. Sexual function, now that we're talking about it, we've come to understand is one of the most common difficulties, along with fatigue, that affect the lives of more cancer survivors than virtually any other long-term effect. So these are areas that 10 years ago, 20 years ago people never discussed, and survivors themselves are the ones that are changing our world and our understanding by saying, Wait, I need to know more about this.

**Andrew Schorr:**
I've got one I'm going to go to work on. I got a call, I think it was yesterday from my insurance agent, who is a great guy, and he's been trying for years, I'm a 12-year leukemia survivor to be able to make changes and help me get more insurance and change the terms of my insurance, and the insurance company keeps saying no. And we keep saying, you know, here's this guy, 12-year survivor, and he's helping a lot of us now, and Herceptin is an example with Jayne, we're rewriting the medical textbooks about illnesses where maybe we wouldn't have been a survivor before or our health would have been much less and now we hopefully can look forward to a good life. Well, why shouldn't we be able to have insurance like everybody else or make changes in the insurance?

So you're right. There are public policy issues. So we've got this wave of survivors coming, and we're talking to one another. And thank goodness we have a program like yours at the SCCA where we can connect with clinicians, and it's a touch point for all these support services. Jayne, when we talk about this program I know it's made a big difference to you. It sounds like people who are at least around the Seattle area or come for treatment to the SCCA should check it out. What would you say?

**Jayne:**
Oh, definitely. And you know we are so fortunate in this country to have this center right in our back yard. And if I had known more about the center I feel very strongly I would have gone there for my chemotherapy and radiation and all the treatment I needed. But second best is to have it there as a safety net for me now because chose to go to an institution on the east side of Seattle where I was living at the time. But to know that the program is there, I tell everybody I know who is a survivor about it because it's a resource that hasn't been there before so how would people know about it if we don't tell them about it. So I'm a very strong advocate for it. It's a wonderful program. The people I'm involved with there are very caring, they're genuinely concerned for your health and your well-being in the future, and it's just a resource that we need to get the word out about. It's phenomenal.

**Andrew Schorr:**
Right. And you made a great point, and Dr. Syrjala said it earlier. You don't have to have been a Fred Hutchinson, UW, SCCA, Children's patient.

**Jayne:**
No, absolutely not.
Andrew Schorr:
Anybody can take advantage of it and please do. Here's the phone number once again. Certainly there's information on the SCCA website, on the Fred Hutchinson Cancer Research Center website, Children's etc. You can connect with it. And tell others about it, but I urge people to check it out. And as this survivorship movement continues I'm willing to bet, Dr. Syrjala, that your program, like your sister programs around the country will be the touch point for checking in on what's happening. Whether it's the clinical issues for long-term survival or the emotional issues or checking in on what the resources are or the advocacy issues as well.

Dr. Syrjala:
Or the latest research. Because we stay up to date. We provide lots of education programs. So if you check website you'll see that we're doing lots of lectures and things that people are welcome to attend. And I'm glad you made the point that it's accessible to anyone no matter where they've been treated. We want to see you if you're interested in learning more.

Andrew Schorr:
Well, Dr. Syrjala, you've been around all this for 24 years now, so I want to thank you for your commitment to us and all of work you've done over, really, a quarter of a century, now, right?

Dr. Syrjala:
Frightening thought.

Andrew Schorr:
There you go. And being director the Survivorship Program. And you're right, Jayne Collins, what you said is we're so lucky to have that right here.

Jayne:
And you know I've only recently met Dr. Syrjala and I feel a very strong connection with her, and I'm just so impressed that she's heading up the Survivorship Program now. It's something we should all participate in and enjoy, and I thank her for her support too.

Dr. Syrjala:
Well, it's a mutual admiration here, so.

Andrew Schorr:
Well, thank you, ladies, for your eloquence tonight and talking about this. And I know we'll talk about survivorship again and again, but I think all of us who have been touched by cancer, whether it's ourselves, a loved one, family member, friend, neighbor, then what does this mean? You know, maybe getting a message. I'd like to think, you know, I was already in health communication when I was diagnosed with leukemia. I fortunately was treated well, was in a clinical trial that worked. It's the treatment most people get, and I said, well, what's it all about?
And so here I am passionate about Patient Power, and I'm so delighted that we can work with the SCCA and really spread this message of survivorship. So thanks to both of you, and I wish you well. Jayne, all the best. You got your degree, you're retooling your life, and you're very committed to other people touched by cancer and after all that exercise program you must be just gorgeous now.

**Jayne:**
I've lost some weight since January by going to Weight Watchers and combining it with exercise, and I'm doing this for my future health.

**Andrew Schorr:**
Okay. Well, there you go. Well, all the best to you.

**Jayne:**
Thank you.

**Andrew Schorr:**
Well, this is what we do on Patient Power with the Seattle Cancer Care Alliance. Every two weeks you can tune in for one of our programs. We have that vast library that keeps growing. Tell your friends. Look at the transcripts, download it as a podcast, take it for a walk, whether it's around Green Lake or up in the Cascades for a hike or wherever you go. And if you are a cancer survivor just enjoy every day. String those days together, and I hope it's many, many years of a long, rich life. Thank you so much for joining us.

I like to say that knowledge can be the best medicine of all. There was a lot of knowledge today, and if you can take advantage the Survivorship Program at the Seattle Cancer Care Alliance. I'm Andrew Schorr. We'll see you in two weeks. Have a great evening.

*Please remember the opinions expressed on Patient Power are not necessarily the views of Seattle Cancer Care Alliance, its medical staff or Patient Power. Our discussions are not a substitute for seeking medical advice or care from your own doctor. That's how you'll get care that's most appropriate for you.*