

Rebecca Nellis:

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LuAnn Heinen:

That's Rebecca Nellis, Executive Director of Cancer and Careers, a non-profit that empowers and educates people with cancer to thrive in their workplace. Nearly half of cancer diagnoses are made in adults between the ages of 20 and 64, prime employment years. Those diagnosed while working have the same questions: How do I tell my boss? What will my coworkers think? How do I balance work and treatment? What can I expect from my employer? These are the questions that Cancer and Careers was founded to address. With more people being diagnosed and living longer with cancer, we'll speak with Rebecca about the life cycle of cancer intersecting with work from initial diagnosis through treatment, potential leave of absence, and return to work.

I'm LuAnn Heinen, and this is the Business Group on Health Podcast, conversations with experts on the most important health and well-being issues facing employers. My guest is Rebecca Nellis, Executive Director of Cancer and Careers, a non-profit created to support people working with cancer diagnoses.

Today's episode is sponsored by Accolade. Accolade provides personalized health care services to millions of people and their families through virtual primary care, mental health support, expert medical opinion services, and care navigation. Accolade is purpose-built to support health equity, creating personal and trusted connections with each member to identify and address barriers and guide them to the right care.

Hi, Rebecca, welcome to the podcast. Really glad you're here today.

Rebecca Nellis:

Thank you so much for having me. I'm excited to be here.

LuAnn Heinen:

I've been looking forward to this conversation and I'd like to start with having you tell us about the origin of Cancer and Careers.

Rebecca Nellis:

Sure. I think most people are a little bit surprised to discover that Cancer and Careers was started in 2001, after a number of board members of a membership association in the beauty industry had been diagnosed with cancer and couldn't find any information on how to think about their work lives as they were thinking about their health and their treatment and their recovery.

LuAnn Heinen:

Wow. So they got together and said, hey, we're all in this boat, let's do something about it.

Rebecca Nellis:

They did, spearheaded by the president of the trade association, Carlotta Jacobson, who is also the president of the CEW (Cosmetic Executive women) Foundation, which houses Cancer and Careers. These board members really confided in her. They talked to her about the challenges they were facing with work. These were women who had broken glass ceilings and had achieved huge things in their professional lives and didn't want to give up work and assumed that if they were finding this challenging, then everybody else must be too. That's really what drove the impetus to fill that white space.

LuAnn Heinen:

I love that. Well, talking about cancer as one disease is problematic. How do you navigate that?

Rebecca Nellis:

Oh, it's such a great point, and one that I think people often overlook when this conversation happens, really anywhere in the cancer space, and certainly to your point also in the workspace. We really focus on the work piece. We are not the experts on every nuance of every tumor type that's related to a cancer diagnosis for someone. We certainly understand a lot about it, and we try to continue to stay up to speed on how science and medicine are evolving and treatment is changing, and how those treatments might impact someone in the workplace.

LuAnn Heinen:

We know cancer is prevalent in the workplace. Nearly half of cancer patients diagnosed in the U.S. are 20 to 64 years old, if we use that cutoff, but at the same time, it's not very visible. Why is that?

Rebecca Nellis:

I would argue that part of that is driven by fear of disclosing or fear of disclosing too widely or fear of being treated differently once you've shared something like a diagnosis. Fear of not moving forward in the same way that you might have, fear of losing your job with the discovery of an illness like cancer. I think there is definitely an underlying concern, even though when we survey, people overwhelmingly have disclosed at least to a supervisor, that there is concern that it will change their experience at work or that they'll always be treated differently even if that different treatment isn't necessarily through a negative lens.

LuAnn Heinen:

Let's walk through what happens when an employee is initially diagnosed. What's the first move?

Rebecca Nellis:

Well, that person is going to be faced with a whole host of questions to ask themselves, things to think about in order to make decisions that will work best for them given their circumstances. This is where your point earlier about the umbrella terms is so important, because just like every person's diagnosis, treatment plan, prognosis, reaction to the treatment, all of those things are highly unique to the individual, even if many people have had a similar treatment and a similar diagnosis, it's also true that everyone's work circumstance is totally unique to them. What they do every day in their job is specific to them. How their side effects will impact them in that role is specific to them. The policies and procedures in place at their employer will be specific to them. Usually if all things are lining up in a way that's organized, which often is not the case, we encourage people to think through what their job requires, what they're hearing from their health care team, and then make decisions about disclosure based on that and the environment and culture that they work in and their personal preferences about privacy. There's a lot to look at.

LuAnn Heinen:

Yes, I can see that. Let's just say that the employee decides to talk to her supervisor. How should that ideally go? How can the manager be human without making promises that can't be sustained or how should that go?

Rebecca Nellis:

It's such a hard role managing people. The first way in which it's hard is that most managers, most supervisors aren't trained to be managers. They get elevated into a role where they supervise people because of how well they did their job or they manage deadlines or workflow or product development or whatever it is. It's not necessarily due to a facility with managing the humans that will work with them and support their team or their department. One of the big challenges for people who have been diagnosed and want to or need to disclose at work is facing someone who has no idea what to do after they share this information with them.

LuAnn Heinen:

To your point, managers are generally not prepared for this conversation despite how frequently it is happening, you know, every week and every month in the workplace. We hear a lot about training managers for mental health awareness. Do trainings exist for managers on cancer?

Rebecca Nellis:

They do and they're happening more and more. I certainly say that Cancer and Careers (CAC) is driving that goal. We're having those conversations with companies. But there are also tools and resources that managers can look to, even if their company isn't formally doing the work. It's just that usually a person doesn't do that until they're faced with the challenge in the moment. There's an etoolkit that Cancer and Careers is a partner on called *Workplace Transitions for People Touched by Cancer*. It can be found at <https://www.workplacetransitions.org/>. That's really taking a lot of the CAC content and thinking about it from a manager lens and bringing in some partnering organizations in order to create sort of a place where you might be able to go to even get the basics, and that's before you even start to bring in things like what are the company policies, but just sort of an essential understanding of what it might mean to you if you have an employee who sits down in front of you and discloses a cancer diagnosis.

LuAnn Heinen:

We do expect that the manager would have access to policies and benefits that would support the employee and encourage them to take full advantage of the flexibility, you know, for employees who are immunocompromised due to treatment, for example, may seek accommodation to work full-time remote. That kind of thing is what's going on in these early meetings.

Rebecca Nellis:

They are and part of the challenges, most of us, even me at the head of an organization, don't remember every nuance about our handbook or our policies and procedures in the moment, right? This is a very human exchange of hopefully being received in a welcoming and supportive way when this news is shared. Even a manager being able to say, I don't exactly know what happens next, but I am motivated to find out and figure it out with you, is really important. Certainly understanding things like how does the Americans with Disabilities Act impact this conversation, and is there already a process in place for requesting reasonable accommodations if you're eligible for them, are you large enough that the Family and Medical Leave Act applies to your organization, and then what does that mean for the employee? All of those things start to very rapidly become part of conversations.

LuAnn Heinen:

What are some of the don'ts for managers and also coworkers when someone is sharing a cancer diagnosis at work?

Rebecca Nellis:

I would say one of the biggest ones is almost all of your automatic reactions in terms of how you might want to sound supportive and be helpful can land flat. Like, don't say I know this is all going to be fine. Do say things like, I don't know what to do, but I'm ready to learn with you. I'm here for you right this second. I want to help figure this out. Making promises, whether it's like the most human reaction, which is just to want to say everything's going to be okay, that's so human. It's not like a malicious don't, it's just a not helpful for the person on the receiving end who is experiencing things that we can only begin to imagine, even if you've sat in their chair before, right? That's the key, is to try to find language that feels supportive without promising things or undermining the fear or the pain or the worry or whatever it is that the other person is also living with.

LuAnn Heinen:

The research is pretty clear that a cancer diagnosis puts people at risk for poor employment outcomes, including job loss. What determines whether people can work through their treatment?

Rebecca Nellis:

It's a wide range of things. One of them is obviously very specific to the treatment, the reaction to the treatment. When we survey people, we look and see are the respondents people who only had surgery. I don't mean only, like in if that's all that happened, I just mean only like specifically their treatment was surgery, what did that look like for them when it came to coming back to work versus someone who maybe had chemo and radiation and then surgery. Those differences can impact the experience that someone is having at work.

LuAnn Heinen:

Have you seen trends over the time that you've been at Cancer and Careers, which is a number of years. Some well-known people recently have worked as long as they could, nearly to the end, Steve Jobs, famously, Jeopardy host Alex Trebek. Is that a trend or is that sort of a celebrity privilege?

Rebecca Nellis:

That's a great question. I would say absolutely things have evolved and the way I look at someone like a Steve Jobs or an Alex Trebek or any number of the people who we would consider public figures, who it would be easy to say in some ways they had so much more support than someone else, or they could have designed their own experience in a way that your average employee can't. I would argue that what they show us is that work isn't solely about your paycheck and your health insurance and the benefits that come with all of that. It is absolutely partially, and maybe for some people the majority of why work is important, but there are all these other things that make work important to a person that speak to their identity, their contributions in the world, their sense of community. We spend a lot of time with the people that we work with. When I think about someone like Steve Jobs, it's pretty clear he didn't have to work. He wanted to work, he needed to work for other reasons.

LuAnn Heinen:

That's a wonderful point and it reminds me, you've said in the past that well-meaning employers trying to be supportive, used to try to get people on disability quickly. I think you've sort of explained why that's not necessarily the best initial step.

Rebecca Nellis:

In the early days of Cancer and Careers, that was sort of the thing we were hearing the most was really genuinely employers who had the ability to say to someone, let's get you out on disability, we're doing that thinking that that was what the employee wanted. In fact, health care providers were also very leaned into that, get the time off if you can and will focus on treatment and recovery, which is by no means a bad thing or a thing people shouldn't choose to do. The challenge was not every employee faced with both work and cancer and their life wanted to be out on disability, wanted to be separated from the work part of their lives, the normal part of their existence. So really understanding what an individual employee is looking for and then driving them towards the policies and procedures and opportunities that the company has based on those goals is the recommendation we have now.

LuAnn Heinen:

I'm speaking with Rebecca Nellis, who leads the non-profit Cancer and Careers, founded in 2001 by the Cosmetic Executive Women Professional Association and the associated CEW Foundation. The inspiration for what became Cancer and Careers came from a cosmetic executive women board meeting where the board discovered that five of its 40 members were facing breast cancer diagnoses. This group of action-oriented women decided to create a non-profit to support others coping with cancer in the workplace. This is the Business Group on Health podcast. I'll be back with Rebecca right after this.

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LuAnn Heinen:

The role that work plays in our identity, our purpose, our connection to others giving meaning, one reason many people are working longer, to your earlier point, and also valuing work for more than the access to health care and financial security it offers.

Rebecca Nellis:

If I could just give you a little nugget, we have some hot off the press data from this year. Every year we survey the community of people who have worked during and after a diagnosis and treatment. Consistently we hear that financial reasons are obviously a driver, health insurance is a driver, but sense of purpose, desire for things to feel as normal as possible, currently feeling well enough to keep working, are all drivers. This year 64% of the people who responded to the survey believed that people who've been diagnosed with cancer want to work, that that is something they want to do. These numbers are, as I said, remarkably consistent and I think important to recognizing we shouldn't use our own assumptions to stand in the way of letting our employee tell us what they would most like to be able to do. Then working together to see what's possible and realistic for both sides of that conversation.

LuAnn Heinen:

Well said. So two-thirds of people would like to come back to work, let's say after a leave, but something I want to ask you about, I've heard from survivors in my circle that the end of treatment, you know, getting ready to go back to work, can be paradoxically associated with acute anxiety because the fear of illness doesn't go away when treatment stops. At the same time, your friends, your colleagues, maybe your even your family, is expecting a return to self, and then that self may be experiencing a whole new normal.

Rebecca Nellis:

It's important to note that the experiences are different for people who choose to work during active treatment and people who choose to take some amount of time off and then go back to work either in an existing job or in the universe where you look for a new job after your cancer experience. Each of those points are different and then very much people are experiencing an expectation that they will somehow magically be the person they were before their cancer experience and that is almost never the case. It doesn't mean you can't be the same quality invested, productive employee. I am not defining what that difference is for any individual person. It's just the case that it's not one day you're finishing treatment and the next day everything is as it once was. Your body may still be reacting to things related to your treatment. Side effects go on for a long time for some people. Those accommodations can still be possible even after active treatment, right? There are so many layers to this and it's so important and so hard when a person is facing people at home or at work who think that suddenly things should be this whole other way now, because of this kind of arbitrary point in time.

LuAnn Heinen:

What can a workplace do, and maybe you have some survey data on this point, to support an employee returning after treatment?

Rebecca Nellis:

First of all, having some kind of return-to-work process. We have heard some stories anecdotally about people coming back from work. Let's say they took six weeks off and like the mountain of things waiting for them to jump right back into is so high because no one has really thought about how to onboard someone, reorient them, make sure that they can get their feet under them and jump back in. It doesn't mean they won't jump back in and be able to do their job, but think about when you come back from vacation for a week and how you feel overwhelmed by going through your inbox. It also depends on whether that person had disclosed, disclosed widely, does everyone know why they were away from work? Do only a couple of people know? There are so many layers to consider when you think about how to support and welcome someone back to their workplace.

LuAnn Heinen:

We've been talking almost implicitly assuming people have some level of flexibility, maybe can work remotely. Let's talk a little bit about frontline workers, health care workers, those who lack that kind of flexibility.

Rebecca Nellis:

It's very easy to fall into the idea that "everybody works in an office or at a desk" when, of course, we actually know everyone does not. Certainly the Covid 19 pandemic showed us the difference between the people who need to get up and go work in the grocery store so that the panic that there won't be enough food for everybody sheltering in place isn't a reality, right? It is a different equation to a degree, absolutely, but some of the things that need to be remembered about any kind of job is the ADA doesn't just support office workers and their need for a remote work opportunity. The ADA is about providing access to accommodations that make the essential functions of someone's job possible if they've got the support that they need to do it. It could be the ticket taker at the movie theater needs a stool, even though traditionally they stand. It sounds really small. I'm not saying it is small to that person or that it isn't an accumulation of a series of modifications to someone's job, but you really need to remember that that applies across any job type.

LuAnn Heinen:

Good example. The other thing in terms of risk for poor employment outcomes or non-employment, a couple years post-diagnosis, at the top of the list are people with lower education, at lower income levels, older workers and BIPOC. Anything to say about that?

Rebecca Nellis:

I think all of these things have an intersectional quality. One of the things that we did this year was really be able to look in our survey data at the difference between some of the races that we were able to survey and ethnicities we were able to survey. What I mean was we can now actually look in the 2022 data and see the distinct difference in experiences being articulated between the people who answered the survey and identified as white and the people who answered the survey and identified as black or Hispanic. There are differences. For instance, we were talking about return to work. About 25% of people across the survey would consider leaving their current job if they were required to go back to working in person. For one, that would allow them to work from home, but that number is actually much higher for the black and Hispanic respondents, for people currently in treatment, and for female adults. You can start to see where those differences show up when you start to drill down in the data and the experiences are different.

LuAnn Heinen:

We also know there are disparities in, for example, breast cancer outcomes for black women and white women. We have differences in disparities and then we have differences in sort of successful return to work. What are the trends looking like?

Rebecca Nellis:

It's really hard to say when you feel like you're sort of in the middle of a moment, if that makes sense. I hope the fact that we're talking about it more and that the conversation about diversity, equity and inclusion includes these intersectional experiences. Disability is part of that conversation. Race and ethnicity is part of that conversation. Gender identity is part of that conversation. The more we start to look at the drill down, Cancer and Careers is a great example, while we've always known that there were distinctions, we've never been able to take the same dataset and pick it apart with enough representation in it to look at differences before 2022. I'm happy to point to us as a slowly evolving space, because for a long time we thought given how niche our topic was, the biggest thing we could do is scream loudly that work is an important part of the survivorship dialogue. The truth is, it is, but we also need to talk about these other layers and the way in which experiencing more than one of these life experiences can affect your outcomes.

LuAnn Heinen:

Yes. I know that you're working with health care providers as well, so you're working with the cancer hospitals and delivery systems. What is their level of awareness? Is this something that can be worked on from that angle?

Rebecca Nellis:

They are a critical part of the angle. In all honesty, Cancer and Careers really focused on the health care prong of sort of this three-prong conversation, the individual, the employer, and the health care space, aggressively and early because social workers, navigators, nurses, and doctors are seeing so many more individuals every day facing the work challenges than we could possibly see on our own. They can see a lot of these conversations and also, of course, direct them to Cancer and Careers, which helps us have these conversations with employers too. They're a critical part of the dialogue for one, because there were misconceptions on the health care side, too. People don't want to work, people can't work, people shouldn't work, why would you work if you don't have to work? That was because they were only looking at it through their very important, sort of, lane.

But a person has more than one lane to consider. So evolving that conversation with health care providers has been a really important part of our work. To do that, we offer accredited training programs and we do something that I think is incredibly important, which is we have a lot of programs that are open to patient survivors, caregivers, health care professionals, and employers altogether. You start to hear from the groups you aren't a part of and you have a different understanding of your place in the conversation, whether you're the employee trying to figure out how to manage your diagnosis and your job, or you're the employer who hasn't really had enough contact with enough people to understand why work could be so important to someone.

LuAnn Heinen:

I'd like to ask you about any other macro trends that we haven't talked about that are impacting your work or that you're observing. For example, from the employer lens, there's been a big uptick in like attention on caregivers, caregiver leave, flexible work, and now a huge focus on the economic downturn, the affordability problem in health care that's being projected. We know that delivery systems are under a lot of pressure. How do any of these trends affect the work that you're doing and the individuals on behalf of whom you're working?

Rebecca Nellis:

They all do, absolutely. Paid caregiving is a great example because it just feels like, because it is, touching so many people. It's a need and a critical sort of component for so many people, and it of course affects cancer survivors and it affects caregivers of cancer survivors. So watching that conversation evolve, watching workplaces wanting to attract the best talent, shift how they think about some of the benefits and some of the flexibilities that they offer have huge benefit to the space that Cancer and Careers occupies. Millennials are a great example, even though I feel like we can often get a little too stuck in the generational cohorts, but they certainly were of a size and a different mindset around how work should fit into your life in a way that had a really big impact on the conversation. Covid 19 certainly changed the idea that people hadn't experienced illness in the workplace or a massive shift in how we work, and that has huge benefit to the population we serve who has been managing illness in the workplace all along.

LuAnn Heinen:

A little silver lining.

Rebecca Nellis:

Yes, well you have to find them somewhere. I think it's really important, even when you're sure if you could change something, you would've not had that happen at all. But the upside is remote work isn't something people think is being faked. There was a whole stretch of time in my life doing this work where people kind of looked at me like maybe I was gullible in thinking that remote work could be more widely accepted and utilized, and then look what happened.

LuAnn Heinen:

You're vindicated, yes.

Rebecca Nellis:

I do feel that way. I will also say to you just one other one that I think people sometimes maybe overlook not on the political end of it, but in terms of those kind of macro changes, people's relationship to their job because of their health insurance shifted some after the Affordable Care Act. It didn't change all of it. It didn't solve everything. That's not my point here. Prior to that, so many of the people we encountered were experiencing something called job lock, you know, not feeling like you could move from company to company or even have a period of time of unemployment because you would lose the ability to have health insurance. That was a trend, politics aside, that shifted how people could see work. It meant maybe you were going to have a couple part-time jobs and have more flexibility in your weekdays, but you could still have health insurance as an example.

LuAnn Heinen:

Yes, take advantage of the gig economy and not give up health care.

Rebecca Nellis:

Exactly.

LuAnn Heinen:

Are you aware of many cancer diagnosis or survivorship ERGs? We know there's some caregiver ERGs in large companies.

Rebecca Nellis:

Yes, there are some. I think it's delicate. I think people don't really know how to utilize the things their companies offer them pretty often. Some of it is a trust challenge. Like is this really private if I'm utilizing the EAP program? This obviously isn't private if I'm identifying myself to an employee resource group, right? How do I think about that? And then what is it my workplace can really offer me in those environments? Will it all be pro company? I just think there's a lot of messaging complexity that people face. We've been brought in by ERGs to talk about the employee experience with cancer, to train managers, to help co-workers think about what a person might be facing. There definitely are some. There have been support groups very specifically run for employees with cancer. I think there's varying success and I think it has a lot to do with how people feel in the company itself.

LuAnn Heinen:

Well, if you had a magic wand, Rebecca, what would you change?

Rebecca Nellis:

It's such a hard question, but I think that Cancer and Career's vision is to eliminate fear and uncertainty for people who've been diagnosed with cancer as they face their employment circumstances. I think that fear and uncertainty is somewhat on the individual, right? But it is also very much on the way in which we are comfortable and the systems with which we work in, so our workplaces, our companies, our company philosophies, culture, what's clear in the benefits, what's clear in the procedures. If I could wave a magic wand, I would create a much clearer pathway where companies who believe they're being supportive and welcoming actually find out if that's true for the employees themselves, because the employees feel safe enough to articulate it, that people didn't have to spend as much time trying to decide about whether to disclose or not out of the fear that it will negatively impact them at work, anything from never being promoted to being fired and everything in between. Those things are really heartbreaking for me. If I could change something that wasn't just solve it all, developing better pathways to make the employee who is facing something so challenging in their life and their health easier at work without so much rigamarole would be a goal of mine. Which is of course, what Cancer and Careers is trying to do every day with all of these prongs, but we're very small. If I had a wand, I could make expedient time of it.

LuAnn Heinen:

Well, that's a beautiful wrap. Thank you so much, Rebecca. It was wonderful speaking with you today.

Rebecca Nellis:

Thank you for giving this topic and this conversation the time. I'm so grateful to have been invited.

LuAnn Heinen:

I've been speaking with Rebecca Nellis of Cancer and Careers, an organization whose mission is to provide cancer patients and survivors with the information, tools and services they need to navigate work after a cancer diagnosis. Go to <https://www.cancerandcareers.org/> to learn more about how to share a cancer diagnosis with your supervisor and peers, how to break out of the cancer person box at work, and how to redirect the conversation when faced with well-meaning, but off-putting cancer related questions and comments.

I am LuAnn Heinen. This podcast is produced by Business Group on Health, with Connected Social Media. We hope you liked the conversation and will be inspired to rate us and leave a review.