

Your Stories: Conquering Cancer – Making Advocacy Count – Scout & Dr. Don Dizon

Don

Welcome to Your Stories podcast, where we hear candid stories from people conquering cancer. I'm your host, Dr. Don Dizon. I'm exceptionally proud to welcome my friend Scout during Pride Month. Scout is the executive director of the National LGBT Cancer Network and the principal investigator of both the CDC funded LGBTQ tobacco related disparity in network and out the National Cancer Survey. Scout and I work together on LGBTQ related issues surrounding people with cancer during treatment and during survivorship.

Scout

Thank you so much. I am delighted to be here, Don. You know, you're one of my favorite people and certainly one of the best dressed people I know, which makes it even more entertaining to do anything with you.

Don and Scout

DD: I'll take that as the compliment. I know it was meant to be. So for listeners who may not know, what is the National LGBT Cancer Network?

S: We basically do work with both the people who are impacted by cancer than the people who treat cancer. We do a lot of work to try and educate our own population about the fact that we have a disproportionate cancer burden, both because we have increased risks and then some care problems as well.

Scout

And then we make sure we do a lot of training with providers. And then we also advocate to make sure that the mainstream cancer organizations are doing a better job of including our population in their outreach and in their engagement.

Don

I remember when we first met. And I shared with you an experience that I had very recently when I when I found my daughter, a new pediatrician and was asked to produce adoption records and how that was just personally just humiliating to me as a gay father to be put into position to legitimize my parenthood, to prove that I was actually a parent of this child.

Don

I remember thinking this happened to me as an oncologist, as a professional. And I can just imagine the types of oppression that our community goes through. I was wondering if you wanted to shed light on those kinds of experiences for this for this audience.

Scout

I had a very similar experience myself. I've had a few of them. But like one of them, just as an example, as I was trying to get mental health services for my son, it took me till about the third meeting with the psychiatrist, a rare psychiatrist that I could find. It took our insurance to realize all he wanted to talk about was the fact that I was trans, which had nothing to do with my son's mental health problems whatsoever.

Scout

And again, like you, I thought the same kind of thing. Like here I'm a Ph.D., I'm highly educated. You know, I have a job. I have so many resources. I'm a health expert. But what happens when all the other families that are trying to deal with all the different types of burdens that come through your life have to navigate this kind of thing, too? And I think that as we listen to more and more cancer survivors, one of the things that really strikes me just about the whole population is that it's a group of people that sees health care providers in such quick succession.

Scout

And you may have already moved to the more welcoming part of town, or you may have already developed a network of friends who are more welcoming, or you may not talk to your, you know, anti-gay aunt anymore kind of thing so that you are leaning more on those parts of your life that are more welcoming and accepting. But when you get the cancer diagnosis, you're just kind of pushed into a different world very quickly. And it's not like you can take the time to shop around because in many cases there's a lot of urgency.

Scout

One of the things that's really standing out is we do this data analysis of this big survivor survey we just conducted. Twenty-seven hundred survivors participated in the survey is how many of them are talking about the fact that their provider told them they had cancer in a really rude and unprofessional way.

Scout

And it really makes me wonder if what might not be underneath that is this is people's homophobia leaking out.

Scout

But I feel like we've still progressed a little bit more in that people don't say you're a freak or I just won't serve you anymore. But it leaks out in all sorts of ways. And it makes me wonder if that isn't part of why all these LGBTQ survivors are saying, "hey told me I had cancer in a really horrific way."

Don

From my perspective, you know, having to refer folks who are LGBTQ, oftentimes the worry I have is that I believe most, if not all of the colleagues that I know personally are decent human beings and are not at all biased individuals. But sometimes the biases we don't recognize are the ones that are the most harmful to people who are trying to serve. And certainly this whole idea of implicit bias is something that that I think we need to be more cognizant about, because, again, it's not anything it's not something you consciously choose to project, but it's projected regardless.

Scout

Yeah, it's loud and clear, like we really recognize when it's a frosty environment one way or another. And too often we're kind of subjected to that frosty environment. I think it was maybe about five years ago there was a study of first year medical students that showed an overwhelming percent of them had that implicit bias against LGBT alone and they didn't even ask about 'T' or maybe nonbinary too, which might even usually incur even more of that.

Don

Right. Right. And I applaud the work that LGBTQ Cancer Network is doing, especially the oncology space, not in terms of, you know, canceling people, but in terms of educating people around this whole concept of what you don't know you project is something that you can still change once you recognize it.

Don

The worry that you and I share is that when transgender people, you know, this also applies to lesbians and gay men, when they experience these types of oppression, our concern is that they will run away from care and essentially face an increased risk of either the morbidity from cancer or a higher death rate due to or related to cancer. I'm wondering what you see as the oppressive structures that we as a community face, either as an LGBTQ plus community, which I am on record as saying. I don't think even among our community we have the same concerns or coming from the perspective of who I feel is probably at the most risk of oppression, which is the transgender community.

Scout

Yeah, you know, I was just reminded actually earlier today that maybe about 10 years ago, New York hospital system commissioned a full employee top tip to tail set of trainings on cultural competency. And it was really interesting that our organization actually created some videos for that. And they really loved

the video, went through all of it and said, that's great, that's great, that's great. Except for one little scene when there was a masculine person breastfeeding.

Scout

And they really argued to have that one scene out of the video because it was too much for our providers to even consider. And that was even before we've had such a huge wave of increase in identification as non binary and even increase in identification as trans. So you really kind of are reminded that this is the well-meaning people. But they're like, wait a second, not that far. Let's just accept these gender roles. You're really going to mess with our brains. It's going to melt everything down and we can't do it. And so I'm like, what is it about our population that threatens people so much when the gender binary boxes of male and female are in some way expanded, swapped or thrown away altogether. But whatever it is, really does threaten people. And I don't know why that is, but it certainly makes it hard to walk in that space.

Don

Now, when it comes to cancers, cancer itself doesn't have a gender. So you can, in fact, be born with ovaries and get ovarian cancer. It has nothing to do with being female. And for some reason, I agree. Even among my colleagues in gynecologic oncology, finding a word that can replace it and gynecologic in that term is difficult.

Scout

Right. But we do woman's cancer, right? Or even men's cancer. Men's health screenings, things like that. I think it's we're getting I mean, I think it's a positive sign that we're getting a lot of outreach from cancer centers now with their community engagement arms being like, wait, how do we do this? You know, the concept of women's well, woman's visit with someone literally just said to me is like gynecologists just said to me, is such a well packaged and well understood and not questioned concept.

Scout

But then you're like, wait a second. For some people, it's a fail. You have to start kind of again, the changes aren't necessarily huge. You know, just refer to the body parts, people with ovaries, people with a cervix, people with prostate.

Don

In fact, I've come to realize that oncologists are the best place to advocate for this, the break between gender and cancer, because as a breast cancer specialist, I've seen enough men undergo the experience of mammography and undergo the experience of trying to find support in a community of survivors that is

so overwhelmingly linked with femininity and womanhood. And, you know, there is now this national call to stop using clinical trial eligibility criteria in breast cancer trials as requiring one to be female.

Scout

Yeah, and there's actually rising incidence in men, if I'm correct. Right. So, I mean, I don't want to see rising incidence of cancer in any single population. But if that helps us reflect back on another piece of our care that is falling short, then that piece of it is an advancement.

Don

And I think one of the things that I love about the work you advocate is this whole notion that. People when this within this community are not solely identified based on orientation or gender. There is this whole concept that extends well beyond LGBTQ people of social determinants of health and how that's so important. And I love the concept that we talked about of intersectionality. And I'm wondering if you can just expand really quickly about intersectionality in the context of LGBTQ cancer care and how that all comes together. This whole notion of gender minorities, some people hate the term and also marginalized identities and how they all just come together to influence how people who identify as LGBTQ experience and live with cancer.

Scout

Where is it in all of this? So but we really we really see I mean, I think in one of the ways that there's honestly been a small but productive outcome from the covid pandemic is that people finally understand health disparities. They finally understand that this isn't about the genetics. This is about the treatment and the care you get in life and how that really charts a different course for your health outcomes. So we absolutely see this in every aspect of cancer.

Scout

Like we we're just right now doing our analysis of that big survey that I mentioned. And every time we ask a question, if we split it out by are you trans or nonbinary, are you a person of color in practically every single one of the measures, the problem is going to get bigger if you're any one of those underserved populations.

Scout

So if your social status is as a queer person, that's openly queer, you're going to have fewer supports in the first place. If your social status as a person of color, you're going to have fewer supports in the first place. You know, we've heard so much more information now about how if you're a black person, you're much less likely to have family income, family wealth, family, landowning, all this sort of stuff.

Scout

That's just this addition of hundreds of years of systemic racism in a cumulative effect, not just in you, but in the people, in your family around you who you know, who you rely on as part of your support system. And so whenever you add any of those. Discriminatory factors together, you have someone who's that much less stable.

Scout

So there's just so many ways starting from early on that these different factors impact your life that sure enough, they absolutely show up in cancer, they show up and how soon you get screened, they show up and what level of access you have for doctors, whether you have referrals to doctors who are more welcoming, whether you know, people who've been able to navigate out of a mandatory insurance system and could go over to more of a private insurance doctor.

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There's just the equation just doesn't stop. It keeps adding and adding. And what covid really helped us see was it creates very different outcomes.

Don

And I think you're right around the pandemic. It did. It shed very bright lights, I think, on on the inequities in the system sometimes, although I have a sense that where that light shines when it comes to the difficulties of the LGBTQ community hasn't we haven't seen much data, at least I haven't in terms of how the pandemic has impacted us, because we already in a large part and I'm looking at this as a very intersectional way, we are already very much in the dark.

Don

We started in that dark, we're not counted. But unless you count people within cancer organizations, within cancer centers, within a huge data collection systems and in the government, we don't exist. And so we can understand the experience. And so one of the questions that we continue to struggle with within the community is sort of. The standard and collection of data.

Scout

I keep asking for data collection in every different forum and every different circumstance. It's all about how can you advocate for data collection today? And in the health arena particularly, we've had great improvement in the last decade in getting the questions on some of these surveys.

Scout

It went from like one to thirty nine states shows to add sexual orientation and gender identity measures to their largest health survey. That's a great change where we're not seeing it match. And just to be clear, even on surveys, it still is horrible because that's not all the states in the country. So we still don't have full population data. And you're absolutely right. There was zero data related to covid.

Scout

And so you're right, when you are in a room without any lights on, you don't see what furniture you're going to bump into. You can't see the elephant in the room. And that's what we're constantly, constantly struggling with in the health records world. That's where it's not even keeping up with the surveys.

Scout

It's really that many more steps behind. And it's interesting because we show we have some research showing that even in something as unsettling as an E.R. situation, 90 percent of LGBTQ people are willing to disclose if you ask them on a health record. But on the other hand, it's like 80 percent, I think it was of providers think you shouldn't ask. So there is this interesting. Like we're like, sure, please ask us. But the providers are like, no, no, no, too private doesn't have anything to do with health or things like that.

Don

What is your answer, though, when you when you do hear that? Because it is it is a question that has been asked quite a bit. Why does it matter to collect such private data? Why is it important to collect it?

Scout

Well, nothing in our health world gets fixed without data as a starting point. You cannot write a proposal and get it approved, even research a topic unless you have enough data to show that there's a potential problem in this topic. So let's say I want to fix something having to do with cancer outcomes for LGBTQ folks. We know that we have lower satisfaction with care, lower optimism about life after care.

Scout

So if I want to address something like that, OK, well, I know that because of health risk information, for example, the fact that we smoke at rates that are 40 percent higher than the general population, there's going to be higher cancer risk among my communities, but then my data chain disappears. Why? Because you only get the data about how many of us get cancer from the health records. So suddenly my story stops and I can't say anything more about what percent of people get cancer.

Scout

Is it greater or less than the general population? I've been part of some efforts to try and piece together parts of this information, but we can only ask the survivors. And as we're talking about, if we're less stable to start with and work, the cancer is caught later because many of us are worried about going to get to see a provider and what kind of welcoming care we're going to get, then fewer of us are going to survive. So if you only ask the survivors, it doesn't show the full picture.

Scout

I cannot tell you what our cancer disproportionate burden is. I can tell you that it's almost impossible that it's nothing because we have one like one, the health lottery. That just doesn't happen in the real world. We do have a disparity related to cancer. But until they're asking things like this that are reported through the system based on health records.

Scout

So what seems like a little innocuous are you LGBT as a question on that health record is actually one of the most powerful questions we have. We're changing our health.

Don

Thank you. I think that is the most succinct explanation I have. It's all about a needs assessment. If you can't if you can't numerically understand the need, you can't even begin to address the issue.

Scout

You know, I think back to the HIV epidemic and remember, like long ago, at the beginning of the HIV epidemic, there was a bunch of, you know, impacted gay, bi men, trans women saying you have to collect HIV data and you have to put down if someone is gay, bi, trans. And then there's a bunch of other people saying, no, you can't. Those data will be get released, will be stigmatized, everything like that.

Scout

But now look at the huge engine of HIV resources that has been turned towards our community. It's all been built on the fact that there was data collection. So we can still to this day, say a huge percentage of people with HIV are from our communities because there's data collection. If we had instead say don't collect, whether you're part of our community, but just collect HIV data, we would probably have a huge amount of HIV resources now pointed at other communities because we couldn't say how many of us were impacted. So until you count, you don't count.

Don

So what is your advice to clinicians who walk into a room where it's not entirely obvious either because someone told them or because it's written down somewhere, but it's not obvious what relationships are among people in the room?

Scout

So that's a great question. I think whenever we are encouraging someone to disclose something where there is a stigma around it, we want to make it as easy and value neutral to disclose.

Scout

And so, you know, the first step would be, is your organization or are you putting out some kind of a welcoming step? And then second of all. How can you do something to make it a very easy way for them to disclose and then when you see that on the intake form, it can be as simple as I saw that you put down the LGBTQ on the intake form. That's great. I just wanted to check in on who your partner was and who your support team is or something like that that might really reinforce not only do I see you, but I also see that there's some disparities with this population that I want to show you.

Don

Yeah, I have to say, one of the things that I find I don't even know what the right word is. I'm still disturbed by it. Even among the people that I've treated in the past, it's been very clear. And I've known and they've known, I've known. And we were just very open about them being in a same sex relationship. There is always a look. Of trepidation for the partner, like, I am physically ready for you to kick me out of this room, I'm physically ready to be insulted, and it's something that it's something that's almost palpable as much as even I and I have this close to many of my patients.

Don

But just putting that out there, just saying, ah, do you have any questions after I'm done speaking with the patient? Do you have any questions? Is there anything I can clarify, including them in the conversation, that sort of welcoming aspect? Maybe it's me, but it's all in this attempt to ensure they know that they are a part of this relationship. And I think probably the one place I have found is when I didn't offer up that opportunity to clarify it just and recently I was I saw somebody and I finally decided I never once asked to and I should have.

Don

I apologize right now. But can you just clarify for me your relationship? Yeah, we're together, we're together, and I was like, you know what, that's beautiful, congratulations, I am so sorry I never asked you.

Scout

And I think one of the things the barrier is that I think we we're used to I've been indoctrinated, got a lifetime of experiences. Yeah. I think one of the saddest things we hear is when we hear from a survivor who says that they didn't bring their partner because they're afraid of that. And cancer is such an experience where you need all the support you can get. The idea that especially when you're already in a situation, your birth family may not be as welcoming to you, you know, as they are to your cis, straight sister or brother kind of thing.

Scout

The idea that in addition to that you would not bring your partner is just it's so sad.

Don

Yeah, yeah, absolutely.

Scout

But, you know, I know you're going to bring this up, but, you know, one of the neat tips we have related to that is the pronoun stuff, right?

Don

Yes. I was actually going to bring up. So why don't you explain about let's go even take the step back. Where did this idea of pronouns begin? You know, actually, why is it important now?

Scout

I remember I once was asking someone, I'm like, why is it he, him, his? Why do we need to teach people how to use English? Why wouldn't we just put him in there, for crimony sakes? And it was funny because the answer was because when it was he they were thinking that it was actually some kind of a name instead of a pronoun. So you had to just put a few so people could understand you're putting pronouns back there.

Don

OK, I did not know that. So. That's right.

Scout

I know. Right. I know it makes some sense because I'm like, why do we need to teach them English? But the pronoun stuff started because particularly the trans community, because. All of us were assigned a pronoun at birth and then at some point made a very active decision to change it, and probably many of

us might have gone through a period in the middle where it might have flexed between different pronouns.

Scout

And many of us might have looked for a time when we might have been in a time when we were looking for something that seemed more like a middle pronoun, like they them as an example. And so at least in my community, it's been common for quite a long time that we ask people the pronouns or we introduce ourselves with pronouns because they may not be what you expect. They may not be what you're reading from us whatsoever. Right. And I think the expansion of this, so that now allies are doing it, too, or other people in the LGBT community as well, is probably one of the greatest new things that I can think has happened in quite a while.

Scout

Because it's such a low bandwidth way to basically hold out a rainbow flag and say you don't say you're part of the community, because if you introduce yourself with pronouns, you're not saying that you're a queer person by any means. You're simply saying, I'm trying to be welcoming.

Scout

It's a really simple way when you walk into a room and say, "hi, my name is Don, my pronouns are he/him and, good to meet you." I mean, it's just a beautiful way of having a tiny rainbow flag there and saying, you know, I'm open to the idea of you telling me your pronouns or not telling me your pronouns, but you can tell that I'm educated enough to understand that this is a challenge for some people, and I want it not to be a challenge for some people.

Don

Do you think that could lead to better cancer-related outcomes?

Scout

Absolutely, yeah, I mean, we just you know, I've got, as you say, most providers are well-meaning. They just don't know what they don't know.

Scout

And it helps just remind people that there is a historical disparity that you don't want to that you no longer want to be a part of perpetuating.

Don

I that's a great way to put it. And certainly using it as an eye towards addressing disparities. It's a very easy way to understand what one is trying to accomplish with the use of their pronouns. So Scout, 10 years from now, what is your hope for the LGBTQ cancer community?

Scout

I've been working in this arena for so long that I will have to say I've been convinced that change is incredibly, incredibly slow, but we're now seeing a shift in the population that I have not seen in my adult life. And that's the number of people who are increasingly identifying as non binary or gender nonconforming is really starting to move the total population. We have over 15 percent of the under 18 year olds identifying as non binary or gender nonconforming.

Scout

So I suspect in 10 years we are going to continue to see that denominator of people really increase. And I think that group is really going to push a lot of people to reexamine how they're doing health now. You know, that next generation coming up is going to challenge all of us. But we're going to expand our care. And that's you know, even I learn new identity labels every day. What's a demigirlflux? That was my new one for this week. So but we love those things because it means people who before felt isolated now feel like they're part of a pack and that's healthier for them.

Don

Do you want to explain what demigirlflux is?

Scout

That will just confuse everybody. I think the takeaway is you don't need to know the details. You don't just need to know that it's good to ask people what identity they prefer and introduce yourself with your pronouns. There we go.

Don

All right. I think I like the answer. We'll leave it right there. All right. So, Scott, the most important question of the day. How do you answer?

Scout

One of the things that's been a real profound lesson about cancer is how isolated so many queer people are. So I think we conquer cancer as an organization by trying to connect people to each other and connect information to the people who want it.

Don

I think for every single person who's had to admit they were different and the other, we've all done that alone. Now, no one no one can really hold your hand as you discover your own identity. But once you once you make that decision, no matter how long or drawn out or how quick and painless it is to understand that there is a community behind you, I think is one of the most brilliant things that one can discover. This whole notion that one can actually choose their family.

Don

If there's anything that the cancer community can learn from the LGBTQ cancer, LGBTQ community, is this whole concept that family isn't one that you're born into right now, that the bond that you make in a community, the people that you decide to be your family, is as real as any blood.

Scout

Yeah, and we see that overlapping. And again, with intersectionality, you know, Black communities have had this concept of fictive kin for many, many years. And so there's just a lot of roots and a lot of places where people choose their family. And that is an incredible source of power and strength for us. Now, if the health care world can, you know, keep up, it will be part of that, too.

Don

Yeah, and if the health care world broadens their definitions of family as well to welcome ours. Yes, exactly, to be better. All right. Thank you for joining us on the podcast today and sharing your story. Hearing the experiences of others can help people cope with the challenges cancer brings. Help others find these inspiring stories by leaving a review of the podcast and subscribe today on iTunes or Google Play to hear every new episode. Thanks for listening to Your Stories: Conquering Cancer.