

# Ep. 63 A Tribute to Jay Caponigro: One Year Later (Mental Wellness & Cancer)

**M.J. Murray Vachon LCSW:** [00:00:00] Welcome to the podcast. It's spring time and we find ourselves in midst of the emergence of new life. Trees and flowers are blooming and where I live, there are hundreds of goslings. Today, I share an Encore episode as a tribute to the life of Jay Caponigro who passed away on May 11th, 2023. Just six weeks prior to his death, he and his wife, Lyn graciously sat down with me to discuss their journey with cancer. This episode is not about death. It's actually a Masterclass on life. As I navigate through South Bend Indiana, I am reminded of Jay's impact. His work at Notre Dame, including being the founding Director of the Robinson Community Center, where many programs have been created to this day that empower countless individuals and groups to flourish. Driving past the South Bend Schools office, I reflect on his tenure on the school board. And as I pass by the ice rink.

[00:01:00] I'm struck by the irony of a man who played hockey into his fifties, leaving us to soon. A few weeks ago, I taught a class at Notre Dame and his daughter was one of the students. In our conversation after the class, I could sense the spirit of her father's quiet activism. As his wife Lyn said to me, Jay never really wanted to write articles about his work. He wanted the work to speak for itself. A year later, the many works of his life, including his family, reflect his commitment to activism that was rooted in love and inclusion. His unquenchable thirst to make any community he was part of better by listening deeply to their needs and then working together to make change. And lastly, an openness to learning. Which for him meant dancing not fighting with cancer.

[00:02:00] So this year, I invite you to listen to Jay and Lyn's story as a way to honor Jay but also to connect to those parts in yourself that yearn to be a person who grows, who gives and who dances.

On the podcast today, I have invited Jay and Lyn Caponigro, who a year ago this month, learned that Jay, a very healthy 53-year-old, father of four fantastic humans, Senior Director of Community Engagement at Notre Dame, and husband to one phenomenal woman, was diagnosed with stage 4 pancreatic cancer.

As many of you know, a cancer diagnosis throws a person and their loved ones into a complex medical system full of experts and different opinions. Ups and downs that are not only physical, financial, but emotional, psychological, and spiritual. I have known and admired these two people for such a long time, and

I'm so grateful that they're willing to talk [00:03:00] with us about the role that mental wellness has played in their life as they have worked through, worked together, and moved with this journey of cancer.

Thank you both for coming today.

**Jay Caponigro:** Thanks for the invitation. We're humbled.

**MJ Murray Vachon LCSW:** Wonderful to be with you, MJ. You're just two of my favorite people. I always start the podcast asking people to define mental wellness for themselves. And how do you know when you feel mentally good?

**Jay Caponigro:** So pre cancer, maybe my definition would have been a little different, but I'm not sure yet.

**Jay Caponigro:** I'm still working through that. I would have said a healthy balance of physical health, definitely having a purpose, sense of direction. Work is tied into my mental health. Being able to have a perspective of others, be part of who I am and how I do what I do. Balance with community, balance with my own need for [00:04:00] taking care of myself.

**Jay Caponigro:** I think those things are all pieces of it. And then being able to know my feelings. I think this has become a little bit clearer to me with cancer is knowing my feelings when I'm having them and accepting them. Lyn and I often talk these days about having waves, waves of emotion. It's not something that we can name.

**Jay Caponigro:** Sometimes it's joy, sometimes it's sorrow, sometimes it's fear. It's just a wave of emotion. I think, more than ever, I'm clear that's just part of life. That's something that, I need to accept in myself and in Lyn, and in those around me, as part of our acknowledging our mental health, these things happen.

**Jay Caponigro:** While purpose is still really important, work is still really important, naming feelings, sometimes it just is overwhelming, but that's okay. We'll get through that together. That's where I think community has really grown tremendously in importance for my [00:05:00] mental well-being.

**Lyn Caponigro:** I think a big part of mental wellness for me is knowing who to go to, when to go to them.

**Lyn Caponigro:** And in recognizing those waves, sometimes those waves can be all of those emotions all at the same time, which is really an interesting phenomena. Laughing and crying at the same time, who knew that you could feel those both as strongly at the same time. But then having the people around us, and that's one thing that I really feel like has been solidified through this journey and through this whole experience is the community and how important that community is, and knowing where to go, and knowing that there are multiple people who, that we can go to. We can go to each other, but then beyond each other, we have resources that we can go to. When I'm mentally well, I'm identifying those people, and going to those people, and getting the support that I need.

**MJ Murray Vachon LCSW:** A part of what I hear you both articulating so beautifully is, it's really this one two dance of super [00:06:00] intense feelings, that you have to do something with. I wonder if you could talk about what that feels like, that super intense, overwhelming sense of two paradoxical feelings at the same time, that then the other part of the dance is what the heck do I do with it? How do you know how to do something with those overwhelming feelings?

**Jay Caponigro:** I think the Holy Spirit helps a lot with that. Some might call it serendipity. Sometimes it's just grinding it out. I love the word dance though. I'm really becoming a fan of that word in terms of my relationship with cancer. It's funny that you use that. A colleague and I were talking the other day, and I was sharing that I really hate this language about fighting cancer and this war. There's all sorts of verbs being used to talk about cancer that are negative, and it is a dance. We're playing a game. It's not a game. It is a dance. Cancer is moving ahead, and we're trying to stop. We stop it a little. [00:07:00] Cancer moves ahead. Then we nip it a little bit. And, and that physical feeling of being manifest in the mental. side of things is I like the language of dance because sometimes I do step on Lyn's toes still and the emotions are overwhelming either for me or for her but sometimes, wow, we get in the swing and it feels really reassuring, it feels comforting.

**Lyn Caponigro:** I feel like there's a lot of grounding that's involved. There's a lot of grounding, there's a lot of just breathing together, just being together, celebrating when there's something to really celebrate. Learn But yet then just being there with each other. And it's not only us. We've really brought our children into this.

**Lyn Caponigro:** Brought our children into this dance. And to the point where we accept them wherever they come from. And whatever they bring to this. And so, we're dancing with them too and through their emotions. And [00:08:00] we

check in with each one of them separately. And we check in as a group. And I think one of the parts that we definitely have held on to Its humor, and how humor has a role in all of this, has a role in this dance, and how we can be having our family FaceTime together right after we've gotten bad information, and someone's cracking some kind of joke to lighten the mood and to say, hey, we're still celebrating life.

**Lyn Caponigro:** We've got to find all sides of this.

**Jay Caponigro:** I think humor has been very important. The first night we found out what this was about, not the depth of it all, but that there was a real issue. It was cancer, and it was significant. I called a priest friend and I told him, and I said, I need to call this particular person because I need to say You need

**Lyn Caponigro:** to practice saying.

**Lyn Caponigro:** I

**Jay Caponigro:** need to practice saying what we have. Yeah, exactly. How do I talk about this, but how do I talk about it with some humor? It's been part of my life, it's going to have to be part of this journey, and I need to do it with somebody I trust and who I know has a [00:09:00] good sense of humor and can see the gravity of it, but also be able to see the levity, or at least bring some levity to it.

**Jay Caponigro:** And I think that's been helpful. Back to the original question about how do we manage the dance, I said serendipity and I said the Holy Spirit and sometimes they're the same. I was talking to a close family member and they said something that was off putting to me about cancer. And one thing we learned early on was that we don't have to solve everyone's grief for what we're going through.

**Jay Caponigro:** We don't have to solve how they're feeling. And I've had to remind a few people along the way about that. And this person being pretty close, I've had to remind a couple of times. I was feeling a little angsty about that, and then the next day I had a meeting with a colleague, and the colleague is the person who brought this dance language to it, to the table, and I just thought, gosh, that just changes my perspective and makes [00:10:00] me feel validated.

**Jay Caponigro:** But also gives me another way to talk about this, and be more positive about it, and have a perspective that I can engage people with, and that's how we've tried to live our lives together. Was that serendipity, or was

that the Holy Spirit bringing that person into my life that day? Yeah, so that helps.

**Jay Caponigro:** There are other days when, We are coming back from a trip to this or that doctor, and you go, how are we going to manage this next step? And Lyn and I talk about the in between stages. It's one thing to be on a treatment and say, okay, let's take this one for what it's worth. The harder stages of this dance are when we don't know what the next step is.

**Jay Caponigro:** And knowing that there'll be a time when there won't be a next step. That can be paralyzing if we don't hold each other's hand through that and then receive the love and the caring and the prayers from so many people around us. Being open [00:11:00] to that is really, I think, a gift that I cherish.

**MJ Murray Vachon LCSW:** A little known fact about mental wellness is it's really spiritual.

**MJ Murray Vachon LCSW:** Not necessarily religious, but part of what I hear you saying, Jay, beautifully, is from the very beginning. You listen to yourself, this little instinct, Holy Spirit, no synchronicity, whatever one wants to call it, that says, call this person. And from the beginning, you connected to the spirit of laughter, of humor, which is medicinal. There's actually studies that show that. You also have connected to the spirit of community first with each other. It was never a question to me if I would have one of you on because one of the things that my clients have taught me. And my dad taught me, who also had cancer, was it is a community experience. And the dance of the community that you are in is [00:12:00] always needing to be updated. Re choreographed might be a better way of saying it, because you are the only two who know what you need for yourselves. As you move through this, how much you can take away from it. Care of other people, how much you can give other people is so intensely personal and it's updated all the time.

**MJ Murray Vachon LCSW:** I too, I don't like the cancer verbiage of fighting. I know that we live in a super fighting kind of culture, but that's not been my experience of people who've been able to live with cancer. Where the dance metaphor, I think, is so much healthier and really just leans people into The spirit, whether it's their religious spirit, their spiritual spirit, or their mental wellness spirit.

**MJ Murray Vachon LCSW:** What were you going to say, Lyn?

**Lyn Caponigro:** I was just going to say a very poignant moment for me. A memory that I have from the very beginning. The very first time that we went to a scan and realized there was something going on because they sent Jay back in another time. [00:13:00] You could just tell from the medical personnel.

**Lyn Caponigro:** I'm a nurse. I know what the language is. I know what the body language is when something's going on. And Jay just reached over, held my hand, and said, Here we go. Wow. And it's been that. It's been, here we go. On to the next step. Here we go. Across the country. Here we go. Yeah.

**MJ Murray Vachon LCSW:** It's how you started out, right?

**MJ Murray Vachon LCSW:** This is in sickness and in health. When you said that, I imagined how we often felt on our wedding day. Oh, here we go. It's the for better. Yeah. This is the for worse. It seems to me that. Under the Here We Go is a tremendous amount of fear at that stage and at every stage when you're walking through this.

**MJ Murray Vachon LCSW:** And I'm just wondering if you can put into words, how do you tame the fear?

**Lyn Caponigro:** That's a really good question because I think we have realized that we have a different fear. We have different fears in this. And it took us a [00:14:00] while to come to that understanding that there are different, there are different approaches, different things that are going on for each one of us.

**Lyn Caponigro:** A big part of Taming the Fear, I think, was finding ways to prepare ourselves. Getting things physically set. Prepaying for a funeral plot, a funeral, and all those kind of things. Those kind of fears, financial fears, those kinds of things are being addressed and continue to be addressed. And then there are other fears that have come along the way.

**Lyn Caponigro:** As the fears come We try to address the physical parts that we can deal with. Are there still other fears that come up? Absolutely. There's a fear of watching him be in pain.

**Jay Caponigro:** What are you talking about? I'm never in pain.

**Lyn Caponigro:** But I know the fear for him is, what is the pain that's coming? And he can speak to that himself.

**Lyn Caponigro:** And that's where I come back to that community. There have been so many people that have been put in our path. People that are from our past, people that we have reconnected to from our past, but we haven't been as close to, that we are now developing deeper relationships with. So, there are people that are able to help me put that in [00:15:00] perspective.

**Lyn Caponigro:** Just being with them and letting them help me through that fear is very, very powerful for me. I think

**Jay Caponigro:** fear is, obviously you're absolutely right, it's part of what we encounter day to day. But I don't think I've ever put it in the same space as gratitude to, uh, kind of compare them. What I guess better said is I haven't really considered the relationship between fear and gratitude and how they work off each other or maybe, in my case, gratitude helps me deal with the fear.

**Jay Caponigro:** We are in a clinical trial with some of the best minds in the world at the National Institutes for Health. How the heck did I get there from the south side of Chicago? How did that happen? That's more than serendipity, but I'm incredibly grateful for it. And I'm grateful for a team of [00:16:00] clinicians that are thinking with, I get the feeling they're even thinking about it at home.

**Jay Caponigro:** How great is that to be working with somebody who sees that we want to make this happen. Yes, we're working humor with that relationship too. And we're honest about the fears with them. And I think we're all in it to figure out a way to make this better for somebody at some point. And if it starts now, we'll be even more grateful.

**Jay Caponigro:** But I do think it's not giving into the fear to be grateful. It's not fighting the fear to be grateful. It's just being overwhelmed. by that other really positive emotion and praying for that gratitude because sometimes you don't feel it but it helps to keep resentment at bay, it helps to keep anger at bay.

**Jay Caponigro:** I'm not afraid of being angry about this I just don't find much value in it. It doesn't make me feel better physically and it doesn't make me feel better mentally, but [00:17:00] gratitude does. That eases my discomfort. I hadn't really considered that that relationship maybe I'm overdoing it, but it's working for me.

**Jay Caponigro:** And prayer is there all the time. And the prayer is for gratitude. Prayer is for grace. And the prayer is for, yes, serenity. And that's an important prayer for us right now. There's no prayer of, why me, Lord? This happens to

people all over. It's what we've seen at Mayo. At our local oncology place and at the federal level, people are suffering everywhere.

**Jay Caponigro:** We're blessed to be in a community to be suffering with folks that connect with us in this suffering.

**Lyn Caponigro:** Speaking to that piece that you said about the why me, how is it that I, from the south side of Chicago, from this working-class family, am now at the National Institute of Health getting treatment, and I think so much of that is part of that serendipity or part of that, What has been placed along our way?

**Lyn Caponigro:** Why am I a nurse? How did I get to be to that point where I can read through and sift through a lot of the [00:18:00] information that I'm looking for? Why did my brother find this article that said here's a medication that might work for you? There's just so many different pieces along the way that I feel like are leading us towards this greater purpose.

**Lyn Caponigro:** We've often felt that sense of a greater purpose. I think that really helps with the fear, is that knowing that there's a reason, there is some greater reason why all of this is happening, and maybe we can be a part of that. Maybe we can use our gifts and the people that have been along our path in order to help us get to that, to see some meaning in all of this.

**Lyn Caponigro:** That

**Jay Caponigro:** is so true. I think you remind me of stories that we've heard from people who have experienced cancer and other serious illnesses, and they've said, you need an advocate. Make sure you have an advocate going in. One of the things I'm so grateful for is your medical training, but also your just dogged determination and persistence.

**Jay Caponigro:** And you ask questions that I wouldn't ask. Early on, I almost wanted to shush [00:19:00] you. Don't ask that question. And I was smart enough after 30 some years not to shush you, but also smart enough to watch in awe, to just sit back and let you lead. Really, the wisdom there, if I had any. It was Watch you lead and advocate and, and then to admire you because the doctors were saying things like, yeah, we should try that.

**Jay Caponigro:** Or let's call somebody about that. Or, oh, I know somebody who could help. When I said arriving at NIH is something I'm grateful for, to me, it wasn't serendipity. I agree. It was a path of relationships that connected to



relationships, like you were at the beginning of that and in the middle of that and continue to be A companion and a leader.

**Jay Caponigro:** And in that I'm very grateful in a selfish way. Um, I know it's, there's a reason you're doing it. That is for you too. I like having

**Lyn Caponigro:** you around .

**Jay Caponigro:** Thank you. Thank you for jumping in that and our kids like having you around, but I do worry it's hard [00:20:00] on you too and taking that responsibility, but I am

**MJ Murray Vachon LCSW:** very grateful.

**MJ Murray Vachon LCSW:** But part of what I hear you both saying. Lyn, you're a professor. This isn't about theory, but it is about theory, right? And Jay, in your earliest days, you were a community activist. And this is an activist project, that is for your own wellness, but hopefully for the wellness of others. But you said so many wise things that I want to do my best to mirror back because I don't want our listeners to miss all this wisdom.

**MJ Murray Vachon LCSW:** We started with fear and we moved to anger. Said you have learned in real life, Jay, activism often starts out of anger. This is not correct. This shouldn't be this way. What you have learned is anger isn't life giving. I can flip the fear into anger, or I could hold and dance with the fear. You find out that when I dance with it, I actually end up [00:21:00] Finding gratitude.

**MJ Murray Vachon LCSW:** Lyn, I think you're saying the same thing. You're dancing with the fear, but for you it makes you an advocate. That advocacy has really been a dance of knowledge and the knowledge leads you to places that keep having these connections and these aha moments, these epiphanies, that make All of this tolerable, even life giving and sustainable, because you're really doing all this inner work while you're very busy doing lots of outer work.

**MJ Murray Vachon LCSW:** You're using your whole selves, and you're using your whole relationship with each other. And Jay, I really am humbled by your ability to let go. And to let Lyn lead, and to not shush a woman who can't be shushed anyways, you know, that I know you can't Lyn. But I think that so much of a diagnosis like this is [00:22:00] can we accept our humble place in it.

**MJ Murray Vachon LCSW:** Humility isn't being false humility; humility is I have gifts and how do I lean into them for the benefit of all. And that's a beautiful dance. When we use our gifts for the benefit of all.

**Jay Caponigro:** There's so much in there that you just shared. In summary, thank you for reflecting that back with us. A couple of reactions.

**Jay Caponigro:** I spent 10 years as a community organizer, as you said. Organizing in the way that I learned it and practiced it and continue to use it in my work is understanding that anger is a very important motivator and driver. But hot anger leads to rage and flames out. Cold anger is a durable and longer-term source to help you reach your self-interest.

**Jay Caponigro:** In some ways, that's how I'm practicing being angry on this personal journey. My work in organizing [00:23:00] is in the public world of J Caponigro. It's not in my private world. The two, the principles don't match. They don't often translate over. Sometimes they do, but cold anger, a much healthier way to live, because you recognize that there are things that we should be angry about, but if you are stuck in the anger part of it, you flame out.

**Jay Caponigro:** I've had wiser people than me express it. Part of what we're dealing with in this much more private situation, the letting go piece is really tricky. Talking at the same two levels of life, on the public side, there's some things I have to let go of, too. And that's really hard, because I've built my life around my work, and my work is built around relationships in the community, and in the wider Notre Dame community.

**Jay Caponigro:** I find that I have to, part of what's great about my diagnosis in this past year has been, [00:24:00] my employer has been able to find a way for me to continue to work. That has been really meaningful to me, to be able to tie up loose ends, to be able to make transitions, to build relationships, Some redundancy in my role.

**Jay Caponigro:** I guess the question I have is whether I still have some room or energy to grow something or build something. I've built a lot. I'm a builder more than I am a maintainer. That's just what I've come to know about myself. My boss in particular has really given me some space to continue to be me in that role.

**Jay Caponigro:** Even though I have to take time out to travel or take time out for certain treatments. But letting go of some of the bigger things I've built when I know it's time, I've got to let those go to somebody else. It has been

another humbling part of this, but it's necessary, and I realize it, and the same in the private space, of knowing that there's certain things that I need to do differently with my family now, or I physically can't do the same way I did before, so I need to be in a different role.

**Jay Caponigro:** [00:25:00] Finding the new role, Finding the new way that I can be productive and contribute, that's been trickier. That sometimes gets me in a funk, but I think that I've been pulled along in some nice ways by my family, especially the kids, like you talked about, Lyn. Work wise there's just been some caring relationships that have helped me as well.

**Jay Caponigro:** Those are why it just comes back to that sense of gratitude around our community in so many different, at so many different levels.

**MJ Murray Vachon LCSW:** Can you talk a little bit about How you decided as a couple to really integrate your children into this?

**Lyn Caponigro:** MJ, part of it was the timing of it all. We were preparing for our oldest son's wedding two weeks after we got the diagnosis well, two weeks before the very first scan.

**Lyn Caponigro:** We didn't even have a diagnosis yet. Jay was just going to the doctor because he had a little extra gas. We knew we were getting ready for this big wedding out of town. We were all going to Texas to go celebrate a wedding. So, we knew we had [00:26:00] to do something. We knew we had to address it. We knew we were going to be at the wedding, if we could, in any possible way we could.

**Lyn Caponigro:** Very quickly, we decided that we needed to have the kids be a part of it. We very quickly decided we needed to invite them into, and invite the parents of our daughter in law into this conversation. We were about to have this huge party together. There was no way we were going to hold back. There was no way we were going to keep back from anybody this was going on.

**Lyn Caponigro:** They knew that he was going to the doctor, and very quickly, we got them involved. And started with our son's in laws, was the very first people that we told. They were very supportive. They said, yes, our daughter would want to know. And we just, we made it this big party.

**Jay Caponigro:** We were concerned that we would go to this big event, and there'd be the son and mom dance and there'd be dad on the sideline bawling his

eyes out and people would look and go, well that seems a little over sentimental.[00:27:00]

**Jay Caponigro:** Why is he crying so hard? Or that mom would have a similar experience at some other level of the ceremony. That would be the best-case scenario. The worst case would be that we'd be withdrawn or distant or not connecting with them in this most amazing experience.

**Lyn Caponigro:** Think you talked to that priest, the very first person you called, and you said, I need to figure out what I'm going to do. How do we address this with our children? And I think the response was, invite them.

**Jay Caponigro:** He had an experience that he felt badly he wasn't in the moment with. He had a particular, uh,

**Lyn Caponigro:** At a wedding. I believe he was at a wedding too.

**Jay Caponigro:** Yeah. We wanted to be in the moment, not for selfish reasons. We really wanted to have that honesty, which we've practiced with them. Fortunately, we had a couple of weeks so that they could digest it, at least be able to take a deep breath and know that we really wanted them to celebrate hard. Might have been a little hard, a little too hard for a couple of them.

**Jay Caponigro:** But we did, we just wanted them also to know if we had a few more tears, It wasn't because [00:28:00] we were unhappy they were getting married.

**Lyn Caponigro:** In a lot of ways, it was really a gift to have that right at that moment. It was such a celebration. We were surrounded by so many wonderfully supportive people. It was Jay's birthday and the rehearsal dinner night. Even that, we had this birthday celebration together that was just a beautiful. A beautiful celebration. It was us all coming together. Everyone there knew. There was no one who didn't know. We didn't want it to be the talk of the evening, but everyone knew so that everyone could be aware, could be sensitive, could not be offended if anyone had to walk away, those kind of things. So that just felt very supported.

**M.J. Murray Vachon LCSW:** It really goes to what you said earlier, Lyn, that capacity to carry multiple intense, difficult emotions all at the same time and be joyful. I think that's a beautiful example and something, when you use the word invite, that's so [00:29:00] soft. It's so different than tell, we're going to invite our children into this experience. You have four children. I know them. They're

awesome and they're really different from each other. So, when you invite them, they get to step in, in their own way, in their own time and figure out how they dance with this. And you're also saying to them, we can do really hard things. We can have the best moment of your life at a wedding, and we can hold this very scary uncertainty. I love the definition of courage where it isn't avoiding fear, it's holding fear and doing it anyways. And that was really courageous, really courageous to say, as a family, we can all step into this in our own way. It's beautiful

**Jay Caponigro:** that's a great definition, thanks.

**MJ Murray Vachon LCSW:** And the metaphor, that everyone needed a good party. Everyone needed to dance.

**Lyn Caponigro:** Yeah, we did. We did. We danced.

**MJ Murray Vachon LCSW:** How joyful. Yep. What do you know about life now that you didn't [00:30:00] know 18 months ago?

**Lyn Caponigro:** I think one of the big things that I've learned over these past 18 months is the trust in the dance and the trust in the community and how much I can count on that. And how resourceful and resilient. It's just amazing to me how there's these open offers of help from people. No one is ever offended if I say no. People are often very encouraging me to say yes. But I've really learned to trust in that more than I ever did before. And trust in the joy that comes out of all of it. And in the goodness that comes out of all of it.

**Jay Caponigro:** Boy, that's an interesting question. My mind goes straight to all of these little things that I've learned that are more about, oh, what I've learned about cancer. Oh, what I've learned about people's health. Oh, what I've learned about my own body. I like how you responded more broadly.

**Jay Caponigro:** A couple things come to mind. And one is that I don't know where this [00:31:00] cancer came from. It's true that I probably drank too much Mountain Dew growing up, but I don't think that's the cause of my cancer. As you said at the opening, healthy and exercising regularly and playing hockey and playing racquetball and playing baseball and I was doing things to take care of my body which also brought me joy and I had lots of little aches and pains that I chuckle about now.

**Jay Caponigro:** But in all, I was healthy. Those parts of my body that aren't affected by cancer are still pining for that. In broader terms, it's good to take

care of yourself, to pay attention, and to be healthy physically, because that's helping me do things now, to get through medications and treatments, to give doctors confidence that I can try new things, and that will last for a little while, anyway, but that's still something that I'm bringing from how I lived my life.[00:32:00]

**Jay Caponigro:** I would say the other thing is, and I don't mean this to be instrumental, we've invested a lot in relationships over time, and I didn't even realize how much that was happening. All of our time here in this community, my work was relationships. I don't want to say take it for granted, but there's a lot of blending of personal and work.

**Jay Caponigro:** There was friends on the kid's soccer field on the sidelines, and there was somebody you worked with on the sidelines, too, so it's a mixing that way where it is personal and public and a lot more personal than I realized until this came to be. I think that's probably the most important thing I've learned about life is investing in relationships and being kind.

**Jay Caponigro:** There's real value in that. It's not just that you're going to get repaid in some way if you get cancer. It's more, wow, this feels really good when you hear from [00:33:00] somebody. It's motivating and it's sustaining. And it's affirming. I hope that in some way my children also feel that and learn that. And I hope that with the time that I have, I'm more intentional about authentic relationships.

**Jay Caponigro:** Even though I feel like that's been something important to me forever. I just feel like, wow, there's another knot I can aim for. Maybe a little higher or something.

**MJ Murray Vachon LCSW:** I would say the Caponigros are relationally affluent humans.

**Lyn Caponigro:** There's another piece of this that becomes a burden that we have realized. That all of those people that love and care for us so much are hurting through this too.

**Lyn Caponigro:** That's really, it's hard to, it's hard to share that information when we know that it's hurting someone.

**Jay Caponigro:** Yeah, it was great to post a note saying, Hey, Mekinist is really doing this great number on Jay's tumors, and stuff is shrinking, and I feel great. A month and a [00:34:00] half later, it's all going the opposite direction,

which we knew it would. The doctor said it's going to last maybe two months, maybe it's going to last six months, we have no idea. We jumped at it anyway. The first post was great, and everyone's sending us messages, and they're very happy. And then the second post we're about to send, we're going, oh, we can't do this to people. We really raised the question for me of hope.

**Jay Caponigro:** What is hope about? Do we dare? This is where you can get all philosophical, theological, and all of my academic stuff could come out, which I don't want to do, but it's, yeah, do I dare to hope in the midst of all of this? Because I could be hurt. We just raised a level of hope for so many other people.

**Jay Caponigro:** That's the responsibility or burden. We knew we were doing it, but we felt, nope, they've asked to be on this journey. We're going to dive in, because without hope, why would we do any of it? We have a greater hope that is beyond the cancer, that moves us as a family and as a couple, which has always [00:35:00] been at the center of our lives.

**Jay Caponigro:** So, we're going to be hopeful, and yep, we're going to write that second post when we have to, and we did. It was hard.

**Lyn Caponigro:** It was hard, but yet there's still so much support around it. Like you said, we've invited people into the journey. We have invited people to know and to have the information. We're not requiring it. We're not demanding it from anyone. They are going themselves, and they are seeking out this information. Yeah, would they love to see more happy posts? Of course, they would, because we know we would too. But yet, they are still there.

**Jay Caponigro:** It's a great post of someone who said we're an Easter people with living in a Good Friday world and that just nailed it. That was great because yes we're living with the Easter hope. I can't say it better and they would like to see it. Better news because they love us and we so appreciate that they would be disappointed.

**MJ Murray Vachon LCSW:** This is a hard question to ask but how has the last year changed how you think about death? How you think about Good Friday?

**Jay Caponigro:** It's never been lost on me [00:36:00] that we're all going to die. The fear is how we're going to die. And how much of it is on our own terms to the degree that we can play any role in it. I'm, at some level, very fortunate to be

able to have some time to think about my death and prepare for it the way that Lyn talked about thinking about where do we want to be buried.

**Jay Caponigro:** We're building an urn or things that are meaningful to me about death. It certainly punctuates the preciousness of life. And has me thinking more about how do I want to spend this next weekend? What's the balance between personal and work? What's the balance between financial and other pressures? Or other desires.

**Jay Caponigro:** Yeah, I lost my train of thought on that one.

**Lyn Caponigro:** I think there's really been a sense of the preciousness of life that has really been renewed. We had the experience of my father [00:37:00] passing away recently. That has been a death experienced amidst this other experience that we're having. He was already not himself. He was suffering through dementia and, you know, there was a long goodbye, right?

**Lyn Caponigro:** He's, we've been saying goodbye for years. There's a peace in his passing. He wasn't happy any longer. So, I'm wondering what part of that will we go through as cancer progresses. So, there's a little bit of fear there, but yet there's still many people around us that I know that will help us through that, so I have that trust that there will be people to help us through that.

**Lyn Caponigro:** There are moments where it does feel like it's just not time yet.

**Jay Caponigro:** Yeah, I think we felt that a lot at the beginning, not knowing what this diagnosis meant, specifically knowing it was very dire. Yeah. Yeah. Yeah. Yeah. Looking at each other and saying, Oh, we just bought the camper. Oh, wait, no, that's not right.

**Jay Caponigro:** We've just got two kids married off, and what about grandkids? That sense that we were getting ready for a new [00:38:00] phase in our relationship, or we were evolving into that new phase already. We were practicing it. We were putting it on and trying it out, and there was a lot of excitement about that. And so, Death feels too soon in that way, but from the perspective of the world around us, I am hit with the gratitude again of, wow, how did we get this far and have so much in our lives already that we can be looking back on and reflective of and grateful for.

**Jay Caponigro:** And I don't want it to end, but I don't want to be suffering in a way that it's affecting all the quality of life of those around me if I can't really be



with them. I think it's contrasted in an interesting way with the fact that our daughter and son in law are pregnant and waiting. week now, to have our first grandchild.

**Jay Caponigro:** So, all of what they're experiencing as new parents to be is just [00:39:00] so fun. I think about the excitement of a new child coming into our family, God willing, it hits hard on the point of the preciousness of life and how we have to live it fully and until I can't. We found ourselves at one point, maybe three or four months into this diagnosis, and Lyn was driving more carefully.

**Jay Caponigro:** She admitted to saying it. I was thinking it. And she said, yeah, because we can't have both of us going at the same time for the kid's sake. Or And then I'm thinking, no, you can't go first 'cause I need you for so many different things. So yes, please drive more carefully. Not that she wasn't a careful driver, but the full stop at the stop sign.

**Jay Caponigro:** You were doing a lot more driving at that point. It was a little bit of a reminder. Yes, maybe we don't take things so for granted, let's be just a little more cautious. I appreciate the moments. I think there've been a lot more pictures taken of me that bothers the heck out of me from an old Jay perspective, but I also know it's really important to people, [00:40:00] and it's important to me now.

**Jay Caponigro:** Actually, it's become more important to me that I be in those photos when I think about the grandchild, especially. I don't know that I focus so much on death. The real question that you asked is just more about the real appreciation and understanding of how much of a gift our life has been and how much of a gift life can be, and we really need to hold that, enhance it.

**Jay Caponigro:** And not just respect it, but enhance it in all its forms, because that's the way we've tried to live our lives, and that's how I want to go out.

**Lyn Caponigro:** One of the precious gifts that we've been given of this time is the opportunity for people to share stories of interaction with our family, interaction just with Jay, or to share their own personal stories.

**Lyn Caponigro:** And there's one in particular that's standing out to me right now that is a friend who shared a story that, Her favorite grandparent was the grandparent that was never there because she heard the stories of this grandparent. What a gift I feel to even have that little piece of that they could know their [00:41:00] grandparent just from the stories that have been shared.

**Lyn Caponigro:** And boy, we've been really collecting the stories now. So, another gift that we've had of this past year is just having those stories.

**M.J. Murray Vachon LCSW:** This has been so powerful. I knew it would be powerful, but this is 10 times more than what I knew, which was a really high expectation. Is there anything, just in closing, you feel I'd like to say that?

**Jay Caponigro:** No, I think we've covered a lot of ground. Thank you for the opportunity to share.

**Lyn Caponigro:** I think I just want to reiterate that I just feel like this has all been coming to us as part of this journey. I'm so grateful that we have been able to take advantage of and to really engage in all of these different pieces that have been so life giving to us and yet supportive of this whole community that is surrounding us.

**M.J. Murray Vachon LCSW:** I really want to thank you for the role models you've always been. This is not a new role for the two of you. I think we as a culture really struggle when things don't go our way. [00:42:00] Whether it's illness, whether it's an election, whether it's not getting into grad school or Notre Dame. And we need role models for people who opt to dance. And find that, oh my God, I didn't know I could hold such terror and such joy all at one wedding reception. To move through a year where you really are practicing what you always preached. It's just a different type of dance floor. I really want to thank you and I know that I'm not alone in that. I read the Caring Bridge posts. Thank you so much.

**M.J. Murray Vachon LCSW:** Thank you for being part of that team.

**Jay Caponigro:** Of course, this could all fall apart tomorrow.

**M.J. Murray Vachon LCSW:** What a beautiful conversation. I doubt any of us listening to Jay and Lyn missed the paradox that they really didn't talk to us much about dying or cancer, but really about living. So, here are my inner challenge insights, thanks to their wisdom.[00:43:00]

**MJ Murray Vachon LCSW:** Insight number one. I loved Jay's line when he first heard about his diagnosis. I need to call my friend and practice saying I have cancer. From the beginning, he took a humble stance. I don't know how to do this, so I will learn. How do I learn? I practice.

**MJ Murray Vachon LCSW:** Insight number two.

**MJ Murray Vachon LCSW:** In the Caponiers words, Here we go. We don't have to solve this. We have different fears. We are always learning to be in relationship with each other. These, my listeners, are dancing words. We can fight cancer or we can dance with cancer. For those who choose to dance, I imagine that their heart is much more open to their partner. After all, who wants to dance alone?

**MJ Murray Vachon LCSW:** Insight number three. My favorite line from Jay was this, I'm not afraid of being angry, I just don't [00:44:00] find much value in it.

**MJ Murray Vachon LCSW:** Insight number four. A terminal illness confronts us once again with the question, Who Am I? It's not easy to let go of work, especially when it's meaningful and connects to so many in the community. My hats off to the University of Notre Dame, who once again has been so supportive to one of its employees. And to Jay's boss for being flexible, adaptive, and coherent as Jay moves through this process of answering the question, who am I now that I'm sick? This gives him energy and stability as he and his family navigate these challenging months.

**MJ Murray Vachon LCSW:** For one to stay mentally well during an illness, the role the employer takes on is huge. In my clinical practice, I have seen the difference. It has nothing to do with the luck of the Irish, but a real commitment to its employees.

**MJ Murray Vachon LCSW:** Insight number five. [00:45:00] In my career, I've had many conversations with clients that begin with this question, how should I tell my kids? From now on, I will encourage inviting, not telling.

**MJ Murray Vachon LCSW:** Insight number six. This is my last insight, and it's a bit long, but please bear with me. Because I think what we learned from Jay and Lyn has a profound message for mental wellness. So, Insight number six. What if our culture's number one value was relational affluence? Where our main ambition was not money, Importance or winning, but rather a high RAS score. You know, Relational Affluence score. We would look at people like Jay and Lyn like we do star athletes. People to admire for their relational affluence. People we are glad to have on our team. You know, Team Earth. If relational affluence was [00:46:00] the number one goal of an Earthling, we would coo at babies and hope they grow up to be kind and honest and real contributors to the well-being of others. Even at times putting their own wants and needs second. As parents, we'd lose sleep if our child was being selfish or was prone to fits of anger because we would wisely know such behavior might bring down their

RAS score if they carry it into adulthood. We'd cheer for the neighbor kid who got the last spot on the team or maybe the lead in the play even though we knew our child was disappointed because we understood that a victory for our neighbor was really a victory for our own child. The Caponigros, the whole family, are relationally affluent. This did not start because of a cancer diagnosis, but cancer made it clear to them that all the love and effort they had poured into their family, their work, their community, their school, [00:47:00] their church, has come back in spades this past year. Endless meals, pumpkins painted purple, palms left on the picnic table, Walks with friends and doctors who really, really care. While not expecting this, they could look back and see how it happened. This type of support does not always happen because it must be nurtured. But it is what we, as humans, need. We are not wired for large bank accounts or championship trophies. These are nice. But what we're wired for is human connection and support. Jay and Lyn are wise in the middle of all this, to hope that their children, all in their twenties, are taking notice of this inheritance. I hope the same for my children. I hope the same for yours. In a world where we have unintentionally over focused on competition, starting as early as age 3, [00:48:00] and given our children phones that have replaced much of the face-to-face time previous generations have spent with friends, I worry that all of our children are being robbed of their rightful inheritance: relational affluence.

**MJ Murray Vachon LCSW:** Many say we have a mental health crisis in this country. I, of all people, am not disagreeing. But often, I think it's a friendship crisis. So, let's put the phones away and play a board game after dinner. Invite our kids to come out of their rooms and have their friends over and bring back the potluck. We need each other and it has nothing to do with cancer.

**MJ Murray Vachon LCSW:** Thanks for listening to this most special episode. As you move through your week, do me a favor. Send a prayer, a blessing, or well wishes to Jay and Lyn. This is your Inner [00:49:00] Challenge.