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Proem (Preface)

Welcome back to the Tomoff Family, Olivia, Bill, Terri, and Ryan. Terri Tomoff wrote a book, *The Focused Fight*, a story about hope and survival of one ordinary family and their community of support to bring a two-year-old through five cancers over twenty years (three times leukemia and twice adult tongue cancer). In episode 1, *Honor Supporting Cast, the Stars of Disabling Conditions*, we met the Tomoff's and talked about 'We're different, That's normal'; spiritual health; pillow, pills, poop, and piss; and freaking out. All inward-looking. Inward into the family.

Today we'll shift our gaze out to the community and into the future. As care partner to several family members' end-of-life-journeys, I felt the awkwardness of the loving, the concerned, and the generous. How can we help? What's acceptable language? Am I intruding? We'll hear thoughts from the Tomoffs about living through difficulties and bursting to share what worked and didn't work. How do these experiences change us? Do we see our same selves in the mirror year to year? We'll learn more about post-traumatic growth.

So, hang on while we chat some more with Bill, Olivia, Ryan, and Terri. If you didn't hear or read episode one, please stop and go back.

Help the helpers help. 02:05

Health Hats: When our boy Mike was dying at 26 and my mom at 87, we learned to manage people who wanted to help. They didn't know what to do. Just like, they didn't know what to say. A critical moment



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for us as a family was during our Friday family calls with Mike and his girlfriend. We planned everything we needed to do for the week - appointments, transportation, treatment, and support on these calls. Whatever they needed. Soon we added, what are four things we can say to people when they ask, what can we do? Because people don't know. We had a learning curve of getting to meet them where they were. They care. They don't have a clue; help them out. It was a big moment figuring that out.

Bill Tomoff: Danny, you're going in a direction that many families probably couldn't get to and including ours. People would say, let me know how we can help. And we were just flat out, and we advise people when you have somebody you care about and you want to help, just do something. Because to expect them to carry that burden for you. You don't realize it. So, kudos for what you guys did there.

Terri Tomoff: Yeah. Because I know it's difficult for when people say that when they said that to me and when I consult with people who are going through similar situations, and they asked me like, what can I do to help? I said I will never call you. But if you come and show up with your lawnmower and cut my grass, or you make brownies or cookies, which will never go to waste, that's how you can help. And that's tangible. I think people look for the tangible. Yes, are there people for you to call it in the middle of the night that you can cry too. Sure. There, there's a couple of them out there that will help you. But so tangible things that people want to do something for you. Yeah. And those things, but we'll never call you. If you can, call us or say there's something specific. Can I grocery shop for you? What's on your list? Let me get bread, milk, and lunch meat. Is that good for you? Yes. That's a tangible thing. People feel great about themselves when they can help on those tangible levels.

[Open heart, share wisdom, transform, bottle it 04:51](#)

Health Hats: As people find the energy to share, give back, and answer questions, they face new dilemmas – variable comfort with sharing, others' comfort with hearing, messaging. I asked Ryan about his experience.

Ryan Tomoff: My experience and how I overcame to use that; I had I think it's hard because some people don't understand, but you're going to tell, get your story across you've been through and just everything in between. I think it's hard talking about it, and people always say can I ask you about it? I'm like, yeah, ask me all you want. But some people may feel offended that you're asking about the experiences.

Health Hats: There's no playbook about how to manage family crises like these, whether they last a generation, a year, a few weeks. It kills me how unprepared we are. I don't know if there's any way to be prepared. But I wonder if we wanted to write a curriculum for a family or a school so that people are more prepared to have the kind of strength you need, the vulnerability you need. Perhaps we can bottle something and sell it.

Bill Tomoff: We've changed. I think Terri and I and Olivia and Ryan have changed dramatically from the people we were. Wonderfully, in a good way. I love what I've learned, how I feel now. I wouldn't trade it back, but we don't often get to choose things that sometimes happen. I talked to Terri last night about



this. We have a society where people are very much me-oriented, Me is fine if everyone's healthy, and I'm free to chase my pursuits. But the reality is many people don't have that. And so, we need, and this sounds cliché - but I'm passionate about it - this mindset of let's put others, think about others. Seriously, walk out the door and think about your community. Think about others. Just be kind to people. Don't think that only happens to them. Doesn't happen to me. Don't judge. You never know what someone's going through. If we could just build more on the buzzword now is emotional intelligence, but if we could get people there a little more genuinely. The world would be a much kinder and gentler place.

Terri Tomoff: I was just going to add to that list – empathy, and based on the past year and what we built dealt with too well for 24 years, going almost on 25, is the deep empathy needed. Not sympathy. Not the pity, but empathy. If we can teach that and we can bottle that up in schools, and we can bottle that and sell it around at Target, then let's do it. Let's bottle empathy because that's a massive piece of this whole pie that we're dealing with here. And it could be from again, the doctors, the dog walkers, it could be anyone in between a bit of neighborhood kid, the paperboy. It's that kind of thing.

Control, empathy, connection, movement 08:25

Olivia Tomoff: And I think whether what level you're at, whether this is someone learning in college or, dealing with an aging or a sick parent versus a child, certain things certainly go across all of that, but it might differ. But from my perspective, having empathy along with personal finance, how you have the empathy was not something that was taught in an institutionalized practice in any school really that I went to. But I think, the ability for me to understand what the priorities were and still feel like I was able to go forward and do my thing.

Health Hats: Have some control over your life.

Olivia Tomoff: Yeah. I'm not too much of a control freak, but I certainly like to have a plan or a loose plan. I think for so long, we tried to have structure, but that structure could just be operated at 2:00 a.m. or at any moment. Whatever. What I think should be formalized in a lesson or something? In that case, I believe empathy towards whoever is dealing with the illness and their immediate caretakers because it allows me to understand my purpose or rank and just focus on that. There was never, 'I should have both parents home with me because I'm also a Tomoff sibling.' The focus needed to be on Ryan because I'm healthy, he's not. So, I would say that's something that must be hard for a 10- or 12-year-old to understand, but it was helpful to me.

Health Hats: Olivia's self-awareness of her experience in a supporting role about what normality meant to her growing up facing adversity—informed her ability to share with and support others. She reflects on her development as an adult because of these powerful experiences.

Olivia Tomoff: It has been an interesting last year and a half with that question in general. But for me, and this has been the case since forever, going back to my childhood, movement is very important for me and my daily life. Some form of loose structure is helpful because then it's not complete chaos, even



though it changed, at least there was like an attempt at keeping everything normal and dealing with anything that might come my way. So yeah, playing soccer, running, playing tennis, walking, lifting whatever it may be, yoga, I love all of it. So, there's playing with the kayak tomorrow. There's any form for me being able to do something active daily. If I am so lucky to share an active activity with my friends or I walk the Parkway with my parents or Ryan and I go to the golfing range, whatever it may be, if I am so lucky to share that with someone, then that would be something that I would consider normal. Of course, there were many days that I can look back on that how we're spent; that was the furthest thing from anyone's mind. And when are they going to get a run? And it was more just okay, we're going to go strap it in for a 10-hour day at the hospital or whatever. So, I think for me, that's normal.

Health Hats: And that's comforting.

Olivia Tomoff: Yes, clear the mind, the body.

Health Hats: Movement activity. What a message for me, for you, for anyone in any circumstances? Normal equals movement. I love it.

Open doors, close doors with post-traumatic stress 12:54

Olivia Tomoff: Also, in a more tangible sense of things that I certainly know are from PTSD. Some siblings or families that I know their sibling has been like, I want to be a doctor, I want to be a nurse, I want to help other families. I was like, I want nothing to do with medicine, needles. You name it. I do not want to see them. I do not like needles. I give everyone a warning, at almost 30 years old, that I do not want to see it. I don't want to be told that's getting blood taken, getting shots, getting my flu shot, getting other vaccines. I've had lots of knee surgeries, so that's plenty of needles and hospitals, too. But all of that, like white coat syndrome, even though Ryan had the best doctors, most caring doctors, white coat syndrome for me is times a million. How I approach my personal and professional life is different. So, I am in tech consulting, doing system implementations, doing work at a big four accounting firm. And sometimes too, of course, deadlines are important. Job is important, but. And we should always strive to do our best and where you can extend yourself. I don't want to say over, but where you can overextend yourself or extend yourself, you should do that for your client, of course. But there are certain things to me where I will just say this is just not a priority. I don't need to work till 10 p.m. this Friday for you. It will either get done this weekend, or you can have it on Monday. And that's just; I think that the ability to say this is my perspective from everything that I have dealt with in my life is beneficial to my boundaries at work and in my personal life. I choose to deal with whatever storm, and if I don't want to, I just won't.

Health Hats: White coat syndrome. No needles. Reasonable PTSD to me.

Open and close doors with post-traumatic growth, too 15:23

Terri Tomoff: Post-traumatic growth was something that we've been doing a long time and taking meals to the hospital and delivering quilts to pediatric wards and so forth. We were on a plane to Nevada because we were going to be hiking out west. I was reading an article in the Oprah Winfrey Magazine. It



was about post-traumatic growth. Jenny Graves wrote this story. At 30,000 feet I was screaming in my chair saying, oh my gosh, Bill, you have to read this. There's a name for what we've been doing. It's called post-traumatic growth. And as soon as I'm done with this article, I'm going to pass it over to you. The [Leukemia Lymphoma Society](#) was built on this. The premise was this man who lost his child to leukemia back in the late seventies who started the Leukemia Lymphoma Foundation. He turned that ugly thing that happened to him, the child's death and started a foundation. Now it's worldwide. They mostly do research, but that's fine. And then everybody else followed suit. People who've gone to war have come back and helped their fellow veterans. That's post-traumatic growth. Not everybody can do it, though. We have to understand that it's not for everyone, but for those who want to learn from it, grow from it, and help others. Post traumatic growth can catapult you for the rest of your life. You put yourself in a different psyche, mindset. Bill, I want you to capitalize on what I just said.

Bill Tomoff: Danny. I would say that's what you are doing right here with this podcast. The good that you're trying to put out into the world in the awareness that you're trying is an example of post-traumatic growth that is built on these experiences that you've had, where you can go. You have this ability to take it to a much different level because of your experiences. I would say you're living proof of post-traumatic growth. Yep. The whole idea is, we hear a lot about PTSD, right? But if you go, when you check into YouTube for people who survived the Captain Sully landing on the Hudson, many of those people have put out Ted talks about post-traumatic growth. It's just changed them to where they are committed to doing good in the world because of this traumatic experience that they feel like I meant I'm destined for something different because I survived. We feel that to the core.

Health Hats: Yeah. My mother was a Holocaust survivor, and I think in her later years not, later years, meaning fifties and later. She really, I think that was her way of dealing with stuff, I liked that. I never heard that term. I don't know why, I just never had, so that was a new one for me in your book.

Ryan Tomoff: I think for me, with post-traumatic growth what happened was, you go through something that was so traumatic beating cancer five times. That's no mean feat itself. I think for me, it was just, how can I grow after this? So, when I got my transplant, I was cancer-free until I was 21 and had secondary cancer. So, after that, I was growing. You're still short; all your internal stuff stopped growing from chemo and radiation. You're on a bunch of drugs and medications to help you get hopefully get back on track. But for me, I think it was just, how can I grow from what I've experienced? Not grow this way.

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Succession planning 20:12

Health Hats: I asked what we should have talked about that we didn't. Bill and Terri spoke about succession planning. What's happening next for Ryan?

Bill Tomoff: One of the things that you can avoid us. How do you go through each day? We just talked about post-traumatic growth, especially with Ryan being a five times survivor. There's an overriding concern all the time. How do we plan for his future? It hangs on us if he survives, outlives us? It's hard to deal with those things, but we know at some point we got to deal with it. It's just inevitable. So those are things people have no idea. Insurance companies as well, and it's not just, you have the issues of the financial needs and care. They're not able to go out and support themselves, a normal adult and all that. Yeah. So, there's different wrinkles. What we treasure each day. It's hard to describe.

Health Hats: So, what okay. I got to go down this road. This business of succession planning it's Okay. Now you're faced with success. And if success continues, Ryan will survive you. And so how does it's like when it seems to me like with Olivia, you thought about succession planning differently. I remember my conversation with her, the decisions she made for herself as she got older and started taking control of her life and, but anyway, so how do you think about that? Now, how that figure into your gestalt thinking? I don't even know what to call it.

Bill Tomoff: Are you saying for Ryan? I tell Olivia, one of the greatest gifts any parent can appreciate this is when your child is out and gainfully working through their life, and they're supporting themselves. She'll buy things and bring it to the house for us. I know it's worried about her. And Ryan's new ball game. Ryan, he does in his way. I carried one of my responsibilities and Terri, now you want to talk about stress, Terri, and I talked about it a lot was carrying the insurance until he was 26. And then how do we go forward? We were able to figure out the logistics of Medicare or Medicaid and how he qualifies for that. And that's the greatest gift ever because yeah, he goes out and attacks the world, like a 26-year-old he's got appointments all the time.

Terri Tomoff: But the health healthcare right now for him is priceless. So even though he has to make under a certain amount per year to healthcare for us as priceless, he's like the janitor that leaves a million dollars to the school. They swept the floor, and he takes that money seriously and invests. And he does everything that you would think if you made five times more and he does it. But this kid's going to come out on top because he's got that mindset that he's just going to squirrel away his cash, whatever he little he has, and it's going to build for him. I think he believes that. And I think we do too. But that was the big piece like Bill said, and everybody else is that Medicaid piece and at 26 and he was okay with that because Bill talked about five, six hours a day, five hours a day of working is about enough for him. And because of the appointments that are constantly, thankfully, we've had the telehealth that's helped tremendously, but there are things that he still has to have blood draws and so forth and be checked by a physician in real life. So, we always have those



Bill Tomoff: Danny would be invisible to most people - Dr. Shad talks about the late effects. We talked about Ryan can only make a certain amount of money. So, there is opportunity that these kids lose for life, and it can be employment. It can be in chasing their dreams, relationships. And yet we're proud.

Honor the village 24:37

Health Hats: I love your book. Your book is riveting and well-written. At the end, what different people wrote in the end that you get gave people space for that was brilliant. I can add the book is good, but it's great because of that.

Terri Tomoff: Thank you. I there's a couple things with that. First, I didn't know how to end it initially because Ryan is still here and it's not a sad story. So, I started the book with the end and then I needed a real end. And then I started thinking about all the people who have seen us throughout this journey. And there's several hundred. Now I did put out there a few years ago, and these are the people that got back to me, and I thought, what better way, what testimony better way and how did their lives intersect with our lives? I just thought that was great. Yeah. There were some really heartfelt

Health Hats: There was, not just some what? A lot.

Terri Tomoff: A lot. Yeah. So, thank you. Yes. And I loved I loved how everyone had a little bit different angle and that's exactly what I wanted raw authentic from every individual. So, thank you.

Health Hats: So as a nurse, one of the things that was one of the more fascinating things to me about being a nurse, besides being nosy was an EKG, that there is like these 12 different views of this one organ. My vision of it is, that it's this room with all these windows and people are looking, or it's the blind men and the elephant, whatever that parable, but that, people experience, I think part of empathy is that realizing that people experience the same thing. Like it's not the same what you experienced and what they, it was like the core was what was going on with Ryan and these people all saw it from these different angles. And that is just so cool.

Terri Tomoff: I love that EKG analogy. Wow. That's powerful. I also think bottling empathy is probably another name for a good book. Yeah. Bottling empathy. Got it. I wrote it down.

Last words with Olivia 27:14

Health Hats: What should I be asking you that I'm not?

Olivia Tomoff: My mom said as she worked through the book, maybe you should tell people if you think that Ryan is untouchable. If Olivia leaves the microwave dirty all hell breaks loose, but if Ryan does... That's a bad example. If I do something, it is a different conversation than should Ryan do the same thing. Even at this age it's still true. It doesn't even necessarily bother me because I don't know that I would treat it any different if it were my kids. That being said, though, I just to call it out because it is to me, apparent.

Health Hats: Do you do desire to be a parent?



Olivia Tomoff: I think so, eventually.

Health Hats: Whenever it's the time. Yes. Cool.

The drama of family dynamics - intimate in a vulnerable state 28:34

Health Hats: Do you want to ask me anything?

Olivia Tomoff: Let's see. What is your favorite part about meeting different people and getting to hear their stories? That's a broad question, I know, but what's your favorite part?

Health Hats: Really, I think one of the things I really liked about being a nurse. I was intimately with people in their lives for a few minutes. I really enjoy it.

Olivia Tomoff: In a vulnerable state, too.

Health Hats: I always liked the most challenging family dynamics. And where people would be like, oh my God, they're such pains in the asses, or somebody, like to me, I like that because I could, let's like be in there, what, like what's going on? And I really enjoyed that. Just for some reason that did something for me,

Olivia Tomoff: there was minimal time for family drama just because there was other fish to fry.

Health Hats: I have very little tolerance for drama, but what I was good at was we're here to do something. the family needs to either be more prepared to deal with whatever they have to deal with that they're going home or they're at home. I could cut to the chase. How can I help you be more prepared, better able to deal things? With podcasting, oddly enough this is a real opportunity for me to have that intimacy with people and hear a story about their lives. I like the story of drama.

Olivia Tomoff: It's so fascinating. Certain dynamics are fascinating. That's fascinating to any human.

Health Hats: What people go through and what people deal with and their spirit. The solutions they find and the unexpected, the unexpected things that happen. I enjoy that.

Good news, the unexpected 30:51

Health Hats: What has been unexpected for you? No, it's too big of a question to ask about your whole life since you've been in this situation for your whole life. But in the last 10 years, what has been a positively unexpected something that's happened to you?

Olivia Tomoff: I never expected to stay at my current firm for almost six years. I have been very blessed with awesome mentors and coaches and people who really look out for me. Even when I think about, okay, what is my next career move? The people really make it, which has been the case for my whole life whether that's my soccer coaches, my friends, my teachers, my professors, whatever it might be. I think that it was unexpected to me because I never even thought I would make it past a year or two here and now, I'm getting into more senior levels. That has been unexpected for sure.



Health Hats: That's great. Good for you. Thank you. Thank you so much. Pleasure getting to know you and I wish you the best it's okay. I would love to have a cup of coffee someday. You never know. I go to DC once in a while.

Olivia Tomoff: Let me know.

Last words from Ryan 32:43

Health Hats: What should we be sharing with the listeners? What would you like to share with them that we haven't talked about?

Ryan Tomoff: Cancer is not rare. Some people may not want to share their stories, their experiences. But supply a meal, cut the grass, wash the house. That's something my parents never got to. So, the grass would grow a foot tall, and it looks like the house is abandoned because that's not their first thought.

Health Hats: They had to be at the hospital or get to the job or take care of Olivia or whatever. Okay. So, it's not rare, help out. What else?

Ryan Tomoff: Just do anything you can to help. I think that's the biggest one. Feel free to reach out to the family. They may not drop a note in the mailbox. They're not going to answer your text or your calls. There's a lot of people who say, what can I do to help? And they never helped. So, say that, man up and do it.

Health Hats: Yeah. Just do it. Yeah. This is great. Thank you so much for talking to me.

Ryan Tomoff: Thank you.

Reflection 34:01

Depending on the moment, the context, the setting, we star in the show or support the star; we help or need help. Whose story is it anyway? The person with symptoms usually stars, the family supports. But scratch the surface, shift your position, look in a different window, add a new EKG lead, and your view changes. Thanks to the Tomoff family for allowing us to open the curtains. I strongly urge you to read [*The Focused Fight: A Childhood Cancer from Mayhem to Miracles*](#) and hear more. If you have limited bandwidth (we understand limited bandwidth) I'd start by reading the last chapter, Chapter 34, *Illuminating Reflections from the Village* that takes almost thirty percent of the book. Each reflection from the village represents a different view on the Tomoff journey - unique, fascinating, raw, uplifting.

Ryan's mantra, the fire within that keeps burning: "Never give up. Never give in. Never, ever, ever give up." Everyone's mantra, want to help? Just do it.

