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Proem (Preface)

Health Hats: My first clinical rotation in nursing school in 1973 traumatically seeded my approach to health service. Assigned to a couple committed to natural childbirth with the father in the delivery room, unusual at that time and place, the mother had a normal pregnancy. But she delivered a squalling baby with its chord wrapped tightly around its waist, normal from waist up and withered from the waist down. Dad and green student (me) pushed to the wall in a daze with Mom and babe stars of the show, the centers of attention. Filling a vacuum, I bonded with the distraught Dad. He was supporting cast in that setting, nonetheless a patient in need. Since I recorded these conversations with Olivia, Ryan, Bill, and Terri Tomoff, I've realized that I pay particular attention to the supporting cast when I watch a movie or TV show. Last night when I couldn't sleep, I watched, *Law and Order Criminal Intent*. Vincent D'Onofrio needs Kathryn Erbe. Steven Colbert needs Jon Baptiste. *Hansel and Gretel* need the witch. We all need supporting cast.

Introducing Family Tomoff 02:24

Health Hats: David Bourne, a fellow Podcasting Fellowship graduate, introduced me to the Tomoff's, Terri, Bill, Ryan, and Olivia. 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). The compelling story brings a fresh voice on strength, resilience, and coping strategies during an extraordinary medical journey. I read *The Focused Fight*, called Terri, feeling reluctant to use my podcast to hawk her book. Make no mistake, the book is gripping, well written, unusual, informative. I highly recommend you read it. But read the book. A conversation about the book would be a pale replica, unsatisfying. As we spoke, memories of my first childbirth experience flashed back. Major health issues are a family affair. The patient is the star, but the supporting characters are patients, too. I found that a story to reveal the supporting cast would add to the book. So, in these episodes, sister Olivia and the supportive families and communities, the supporting cast are stars. Let's start with the Tomoff's introducing themselves



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Olivia Tomoff: Hi, my name is Olivia Tomoff. It's nice to meet you. If I am giving additional information about myself, I would say I live in Washington, DC. I went to James Madison University.

Health Hats: So, your claim to fame, as far as famous to me, is that you're the sister of a brother who has had many go-rounds with cancer. I'm curious about your first memory of that.

Olivia Tomoff: My first memory of Ryan with cancer. I do not have too many memories from before cancer. Some of my first memories are a wooden train on C5-3 at Georgetown that we used to ride in before going to his hospital room or being in the clinic and doing art therapy. Being very young and that was, for many years, but I have memories of, I've seen in today's age handwashing is very important to everyone, but that was like knocked into my head from a very young age wash your hands.

Terri Tomoff: Hi, my name is Terri Tomoff, and I am a quilter and now brand-new author, and I love to travel, and I love photography, and I love the color fuchsia color

Bill Tomoff: I'm Bill Tomoff. Terri and I have been married coming up on 34 years next month. And we've had quite a journey together, lots of joy, lots of difficult times. But my career and my family are my greatest loves. I have many hobbies like technology, reading a lot, and writing, and I just enjoy social media. I enjoy bringing value to others.

Ryan Tomoff: Hello, my name is Ryan Tom off. It's great to be here. I appreciate you listening to myself and my story.

Health Hats: Okay. And you have quite a story. You're what I think you told me you're 26, 27?

Ryan Tomoff: 26 turning 27 in August.

We're different. That's normal. 06:46

Health Hats: How did it come into your consciousness hanging out with other people that this was different? Because when you're a kid, when you're that young, life is normal, whatever it is, you do, life is normal, and then comes the point where you start, there's more of other.

Olivia Tomoff: So, I would say that many of my friends who also had siblings, hung out with their siblings at home. And I also hung out with Ryan at home, but I also went to the hospital to hang out with him. So, I think that's where the differentiator was. They're going back home after school, and I'm going elsewhere so that I could be with my brother or with my family all together.

Health Hats: Was there ever a point where it was like, 'oh my God, enough already? I wish I were a queen for a day, and I could wave a magic wand, and he was just better. And life would be more like what I think my friends' lives are?'

Olivia Tomoff: I would say yes, but also because it was from the age of four on, I didn't know any different in my own life. So, it wasn't other than the reprieves that I guess from cancer treatment. He was diagnosed and then in remission and then relapse. So, the periods of remission, I was like, I hope this just sticks because I get to have everyone at home, and there's less back and forth and whatnot. But



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because I didn't know any different. I hope that you know this. Oh, I guess I hoped that it didn't happen so many times, but it just is what it was.

Health Hats: You've spent a God-awful amount of that time in the hospital, too much time. Yeah. And so now you're not, so that's great. One of the things that interested me about your story is that it's a family story that even though you're the star of the show, you're not the only actor in the play, right? There's a whole group of people, and you've been dealing with this stuff for a generation. Twenty years is a generation. What was going on when you first realized, 'Oh goodness, this is not, everybody's not dealing with what I'm dealing with.' Like when did that enter your consciousness?

Ryan Tomoff: Probably when I started school kindergarten, pre-K just not being at the school. Kids wonder, oh, why is he not here? He's skipping school. And at that time, you don't know what's going because you're in the hospital. You have cancer, but you don't understand the deep down and everything that comes with it. And that's when I realized, okay, this is different. And most of the kids in school don't deal with it. But yeah, it just hit me probably when I like four or five that it's okay to be different, but you're looked at like the weird kid.

Health Hats: Was there a point then where there were like you started discovering that there were kids who not necessarily, had experienced what you experience, but compared to other kids, they got it more than others. Some people appear to have more empathy or more understanding or are better listeners or more curious than others. So how did you first start experiencing that there were interested, curious people who had some background of experience that they could relate to you?

Ryan Tomoff: Yes. Most of it was hospital-related and people in the hospital that see us firsthand, especially in the C 500 or cancer ward. But outside of that, it's few and far between. To everyday people, you have a puffy face, and you're short. You have no hair, and you're looked at what is wrong with this kid? And you get weird looks, your parents get weird looks. And it's rough, but you have to get over it mentally. And I think that was my big thing. It was just like; people don't know what you're going through. So, it's hard to explain to them because they don't understand it.

Health Hats: When you were in the hospital, like I'm assuming, you can just correct me if I'm wrong, but a lot of the time you're in the hospital, you're really sick. And it's just about you. Like your brain is minute to minute the medical routine, whatever. But occasionally, you must have become aware that there were other kids in the unit that were experiencing whatever they were experiencing in the same unit. And they had families. Can you like, remember when you might have begun to compare your family to their family?

Ryan Tomoff: I don't think I ever compared families only because my family was the main priority, and their priority was obviously saving their child. I couldn't really think of other families. The only thing I was thinking of was, am I going to see you tomorrow? And keeping busy by playing video games, and that was about it.

Health Hats: Were you always in a room by yourself or in a room with other kids?



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Ryan Tomoff: I was always in an isolated room. Maybe if I was getting blood work and had to be on the floor, I was in a double room. Those were few and far between.

Spiritual, mental, physical 13:40

Health Hats: Disasters can make or break a family. I'm fascinated by the mystery of spiritual health. The Tomoff's spiritual strength stands out. How else could they survive together? You can learn more of the details in the book.

Terri Tomoff: I think I'll start with that. Our world was full of uncertainty and ambiguity, and it continues, I think, a little bit today. And we navigated our journey together mainly as a team. And that included the spirituality of the team, the mental capacity of the team, and the physical journey of our team. And I think my spirituality was not so much in the religious, what religion I practice, but the spirituality deep in my soul. So that made me even more spiritual as time went on. And I felt closer to God if you will. And navigating the uncharted waters that our son was going through time and time again. And the mental piece, too, of that would include Ryan showing his resilience at an early age, at the age of three. So, when he would have the same bacterial infection as a kid in the next room over, that child passed away during the night, but that kid hung on. I've never seen anything like it. So, his mental capacity was so strong, and I learned from him that I certainly could get through anything from him if he could be so strong as a three-year-old. So, he was my teacher. And then, of course, the physical part was if I could run or walk, and we were running on those days as much as I could. Because it was not for that running for me was yes, the by-product was the health of my body, but more it was for my mental capacity, really.

Bill Tomoff: Yeah. I will say that. And Terri and I both had a lot of conversations along the way. And when you talk about spiritual again our lives, where there was no organization, other than we had to get to the hospital do whatever had to happen. There was a part of us just said, we have to believe this is going to work out the way it's supposed to work out. We signed the protocol for Ryan, and you really put in yourself in the hands of other professionals. And at a different level, you desperately just want to believe whether that's God and yeah. If you're praying to something, I would not pray for an outcome. I would pray for the nurses, the doctors, our health, and the mental, as Terri said we were balancing with Olivia. She brought some normalcy to our life, but it was often separate. One of us was with her the other was with Ryan. Just day by day, we tell the together Dr. Shad's social workers at the hospital, we came to realize they were keeping an eye on Ryan and us to make sure that we were okay. I had conversations with Dr. Shad that I can't, like what do we do if people just say I can't do this anymore? So, it got intense, and we took it day by day.

Ryan Tomoff: I think I've been a lot closer to the man upstairs. I went to a Catholic high school. When I was 16, 17, I was in high school, and for me, it was just getting closer and expressing my thoughts and, I still pray every night and thank him for good health and everything that I have to live because it's not easy to get to where I am.



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Olivia Tomoff: So, I think to me, I would agree, I think to me spiritual health goes past the formalized religion, faith, like areas. From my perspective, and I think my parents would agree. Being cautiously optimistic and, focusing on giving back and volunteering and the idea of community or belonging to X, Y, and Z are all facets of your spiritual health, which is something that along with the power of prayer and good thoughts and healing thoughts from all over. Like my mom always says, it's not about who you pray to or what, or just that you consciously think positive thoughts and gratitude, whatever that means to you. Yeah. So, I believe that those pillars were instilled. I don't know if it would have been ingrained so strongly had this not been our journey. I have, I don't know how they plan to parent before this was graciously bestowed upon them or however you want, or you want to say it. But I do think that all of those things then enable you to be more mentally fit to then say to me being mentally fit, at least in our family, or it is, I'm sure you've heard this when you talked to them before, but the idea of taking it one day at a time is that is it.

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[Pillow, pills, poop, and piss 19:57](#)

Health Hats: A friend once described the experience of living with someone with chronic illness as a study in intimacy. Wearing your life, emotions, hopes, and fears on your sleeve. My mom described it as pillow, pills, poop, and piss. How did the Tomoff's deal with intimacy and boundaries? Olivia said it's like being a local celebrity, but not in a really good way. I think of it like winning a lottery you didn't buy a ticket for. A family is a unit, and it's not like there's a fence or a skin to protect you.

Terri Tomoff: I feel like it was almost like when you have a baby, you all bets are off. You have to just get through it. I think it was very similar to dealing with a child with cancer in a hospital for as long as we did. I think we came to love our staff. We came to trust our nurses and our attending physicians, which us to where we needed to be each day. And I think that was a huge component of how we could get through those boundaries or the fences or whatever you said to help us with those critical decisions that we had to make. Because we were relying on them and their medical expertise and the nurses for their love and nurturing daily. Most of the hospitals try to use continuity of care. So, if you had that nurse on a Monday and she was off Tuesday, Wednesday, we had Thursday, Fridays, whatever. And that was a really good rhythm to be into. That it helped us families, not only us, but I also noticed that on the rest of the floor. When you had those same nurses that you just know, they know you intimately, you get to know them, you get to know about their families, too, because we can't just be talking about what's going on right there. We bring that out. And I think that was such a light in that dark tunnel for us for so long. How about you, Bill?



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Bill Tomoff: Danny, that's a very interesting question. And Terri and I were, I'm I've changed a little bit, I think, but I'm not a very introverted person and privacy, and I can handle this, and this was my life. Okay, prior to Ryan's diagnosis. So, when the story first was, we were deciding whether to let it be told and the community, it was, my insides were turning out, and I'm worried about Ryan, and now we got this that's going to be happening. And it was brutal to deal with it. I will say that, and Terri and I've talked a lot about post-traumatic growth. I'll do anything I can now to help share a message, and I'm genuine, but I have no problem getting up and crying in front of a crowd. And people do care. And when you're vulnerable, that feels like you. It's not how you're supposed to be. But people like Terri said, especially at the hospitals. They care, they care. People just feel a different connection all the time. So, it helped to open up as difficult as it was. It was, but it helped tremendously. And we would advise anyone to go and share their story and help them.

[Freaking out. I've had enough. 23:32](#)

Health Hats: A few months after I was diagnosed with MS, I shared stories with my fellow pathologically optimistic friend Paulette who had her own health challenges. We realized that we had to take the time to freak out. Optimism 24/7 doesn't cut it. I looked over all the years, the Tomoffs had strengths, they persevered, they worked together. But they're human. In the normal ups and downs of everything, there must have been times when they freaked out. I'm just like, oh my God, how did they give each other space to do that and support each other in that?

Bill Tomoff: You look back and you wonder, honestly, you wonder how we did it. And I wonder I'm sure Terri wonders when we were going through it. I can tell you, there were days where I was at work and, you just go to the restroom and lose it for a second. Because there were times, you're asking yourself, how can this be. And okay, what's next? I can remember and, Terri and I talk and before going to transplant, we're trying to pick the institution and we had some insurance challenges and it was, I don't know what we don't know what to do. We have to make a choice and none of them are what we want to do, but we have to make a choice. So, we talked a lot, but we also dealt differently with things internally.

Terri Tomoff: And so, I'll follow up on that. I think there was a lot of times I faked it until I could make it because I really think that was a something that I needed to do, because again, both of our children in different capacities are watching both of us like a hawk. Ryan was watching me every move I made, anytime a doctor said something, a resident, a nurse he's looking at, he's looking to me for my reaction instead of the opposite. The fact about freaking out. Yes, it happened most of the time either. I was able to cry myself to sleep. So I was already down on my air mattress and he couldn't see cause he was up higher and that was it low or I went to the restroom and most of them at my crying, when I did due to crying, I didn't need it to release that pent up I was in the shower. The showers were just wonderful because I can let the tears flow and it was all part of the shower. And that was just huge release for me so I can get out of that shower. I can put on a set of clean clothes, and I can fight with him for that day. Yeah. And I think that was just a wonderful thing for me to do that. And I would also say our social workers were just unbelievable and they let me cry and carry on when I needed it most. Because



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sometimes my anxiety was off the charts because people didn't know what to say to us or me personally. And so I had to learn how to approach them and say, Hello, my name is, and if they didn't know me or if, even if they did know me, I know this is really hard for you to say anything to me. I gave them that out first. I had to learn that was through time. I learned how to deal with that. Because our case was so out there and so far away from even the kids that were in the hospital with us. So I was able to approach that a little bit differently. There was a big learning curve, but it was definitely well worth it.

Ryan Tomoff: Yeah, I do. I think for me, freaking out was not an option. Okay. Self, yes. freaking out intermittently. Yes. But showing the emotion to freaking out, I don't think it wasn't an option. It scares my parents to death if they happened and they'd be like, what's wrong. And my answers immediately were for me, it was like, let me freak out by myself and get over it. Let me scream and yell. I'm going through this internally and my body is, my body just must fight it.

[A generation! The experience over time. 27:37](#)

A couple of years ago, I did a series about young adults who had complex conditions transitioning from pediatric to adult medical care. I talked to a young adult or someone who had been a young adult and a parent of theirs and then the two together. Both the kid and the parent changed over the years. When a child sees adulthood and starts to assert themselves, they know more about what they want, and they begin to approach the world differently than their parents. The Tomoff's experienced their challenges over a generation as infants, toddlers, teenagers, and young adults. How did that experience change over time?

Bill Tomoff: So, I would say, and this is one of the blessings that Ryan has. Ryan's still lives with us and he's fine. Young man can't work full time, but he's got his interests and he's maturing. Two years ago, he would do things and we'd say that's about where Olivia was when she was 16. He's developmentally not there, but we've seen him take strides on his own to really develop. But as far as his care goes, he really, and he does it in a quiet way, but he really leans on us to help guide the process and he loves Terri or mostly Terri, but one of us to be with him to help the conversations, to help understand, to keep it all on track. So he's very much a partner allowing us to partner with him, even though he's 26. And I think Olivia she's matured into a fine young woman who's out working and, we're just blessed to see what she's done. But again, for both of them, we wonder what went through their heads at different times. It's we just can't imagine. Yeah,

Terri Tomoff: I wasn't going to add to that too. And I want to go back to the earlier comments that were made, and I didn't get a chance to say this, but I do want to say this, that vulnerability allow the deep connections for our family to move forward. If it wasn't for that vulnerability. And not even taking ourselves seriously, even though the disease and everything else was seriously, I think that helped and deepen those connections. And people want to help people that they have a deep connection to. I feel like we felt that, and we got that from the dog and the doctors to the dog walkers, as I say, because I think it took just this village for everything to come together and for us now, when the kids were growing up into different, of course it was almost a generation, as you say, Danny, I think we were



always honest with them. We never sugarcoated anything, no matter how difficult the conversations were. And we told them, and mostly age appropriately at their ages, how we can deal with things and how we're going to deal with as a family, and they trusted us. So not only that vulnerability helps us with the deep connections in our community and the world at large, but it also gave us that vulnerability with our own children, for them to trust us implicitly and deeply, because you can never, that's not there's no price tag on that. And so, I think that trust that just total bond, a trust above and beyond the normal family unit, I would think because we had to, we were forced into it day after day, minute after minute. And I think that's what catapulted us. And we're a very close family, I think, because of that. And that helps us all achieve what we're achieving today. I don't think we would have had that if we did something differently. I think what we did, even though we didn't know what we were doing back then 20 years ago, but that helped these kids. Do what they're doing today? So, I'm so thrilled. Like you see the buttons popping off my shirt here. Yeah. Thank you.

Health Hats: So, I'm trying to go with this. The I think this being straight with each other, even when it's difficult. I'm remembering when my, my son had a girlfriend and we partnered with her parents and a lot of what we did in terms of care. And sometimes they would get pretty upset especially with me because I was close with her mom. And so, we would talk and strategize and sometimes, they would get you're sharing stuff that it's ours to tell, not yours to tell. And what was good to me is we had that out. Not like we had a fist fight or anything, but it was like part of, when you say being vulnerable, the invulnerable a lot is we're doing the best we can. This isn't working. We're going to have to do something different as a family, and it might just be like, a one-degree shift to the right. It's not like being totally different, it's like being a little more sensitive about this and whatever, and I think you're right. That, because you can't avoid that. It's there's no playbook.

Terri Tomoff: We had those moments too, Danny.

Health Hats: I took a slightly different twist with Olivia. Certainly, her mom's attention was hugely on Ryan, her dad's a lot. Olivia could have gone the route of, 'oh my God, Ryan got so much attention, and I'm entitled to some of it.' How did that play out for her?

Olivia Tomoff: I think that's probably that has evolved tremendously through being 4, 8, 12, and then 24 or whatever 23, maybe, but regardless being in my youth and then being out of through college and working was very different. I imagine probably at four and six, I was, why do I not necessarily have the attention? But I do think that my parents did a very good job of Being forthcoming with information of what was happening with Ryan. And that was like, of course he was also forced to grow up long before he should have, but same because I think certain emotional or feelings that probably your average ten-year-old doesn't like to try to even understand was something that I had to just work on myself. My parents might disagree about, I do not think that I necessarily acted out to get attention, which is something that obviously the worry that, for me, it was more just, okay, I'm going to play soccer. I'm going to do my schoolwork. I'm going to be, just not a problem, hopefully.



Reflection 35:09

One day in fourth grade the teacher asked for a volunteer to carry this metal box, a speaker, from class to class. I raised my hand. I plugged the box into a phone socket. A kid at home was on the other end. I became the-carry-the-box-from-class-to-class guy, and Henrietta joined the class. I had no idea about her or her story. I just carried a box around and said hello and goodbye. After a couple of months, I received an invitation to her house. Wheelchair-bound, short, moon-faced, in hindsight, perhaps she had cerebral palsy. We became friends. She starred. I was supporting cast. We'll continue this conversation with the Tomoff's next week. Honor the Supporting Cast. Help the Helpers.



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