Welcome back to Living Transplant. Happy December everyone. I think we're all surprised we made it to the end of what has been, you know, the longest year ever. I don't know about you, Britt, but -

It's time.

Yeah, I'm ready to move on.

I'm ready to close this chapter of 2020.

It's been a really intense year and I can't really imagine what it would be like for someone living with, organ failure or someone with a loved one in the hospital, losing a loved one this year. That would be so, so challenging on top of everything that's going on the world.

Yeah. And, I think this year for this episode, at least we want to try and give a picture of what it looks like to be in the hospital around the holidays and try and shed some light on how it may not be all that terrible. I mean, the nurses try.
Courtney: Yeah, for sure. I think, you know, for families of deceased organ donors, the holidays can be kind of a tricky time as well, especially if this is maybe your first holiday without your loved one. So we've we talked to someone who, you know, it's been, I think 11 years for them, and so we've talked to them a little bit too, about what, do their holidays look like now? What was their first one like? All just with kind of the intention of bringing everyone out there, some, comfort and some solace to let you know that -

Brittany: - you're not alone -

Courtney: - you're not alone. Yeah, exactly.

We should read out some of the reviews that we've received and also just to thank everyone so much for all the support that we've received so far, it's really, really heartwarming after a lot of hard work to get such good feedback. So please keep continuing to leave us reviews, rate us, follow us or subscribe. We really, really appreciate it.

Brittany: Yeah, it's very exciting that we keep getting all these reviews. I'm like, wow. So legit.

Courtney: I know. Do - should we read them?

Brittany: Yeah. Okay. So we got one from Len. His review says "Excellent. So informative, interesting and entertaining interviews, relevant and useful content for recipients, donors, family, caregivers, or anyone just interested in learning more about the transplant experience. I'm looking forward to hearing what comes next." Thank you, Len. Thank you. Five stars.

Courtney: Of course, nothing but! So this one is from the Research Nerd, "Amazing podcast. I don't listen to podcasts much, but after listening to Living Transplant, I'm hooked. The content is so interesting. It's both heartwarming and informative to hear so many different perspectives on transplant. From patients to donors, to the staff that work behind the scenes and the hosts are amazing. Thank you. They're funny as great questions and make it all really personable." Thank you so much. Really appreciate that.

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Brittany: Thank you, Research Nerd. So don't forget to rate and review us on Apple podcasts. Unfortunately, you can't review on Spotify. I don't think.

Courtney: No, you can only review on Apple podcasts. So even if you don't listen there, go there and leave us a review. And just so everyone knows, we are planning a little special kind of giveaway contest for everyone who leaves us a review. So yeah, make sure, make sure you submit your review and keep listening to hear who the winners are.

Brittany: Yeah. It's really exciting. It really helps our podcast do well for the future and -

Courtney: It's free. It's a free way to support us.
Brittany: Yes. Great support. So we really appreciate anything that, any reviews and rates. So sit back,

Courtney: Put on your mask and Santa hat

Brittany: and enjoy the show

Courtney: So today our guest is Stefan Pankiw. He works in spiritual care and is an excellent support system for all of our patients and staff in some difficult times and good times, just an excellent all-around support. So,

Courtney: thanks for joining us Stefan. So what is spiritual care just for people listening?

Stephan: So spiritual care is, as Brittany said, it's a support, a service here at the hospital. We've kind of evolved as a profession over the, last little while. You know, I think our origins come from a chaplaincy. I think a lot more people are familiar with that [00:05:00] that is and chaplains, traditionally were, folks with a religious background. So they would be priests or imams or rabbis but that's changed and shifted and morphed into spiritual care and spiritual care it's a wholesome support for the person, incorporating their spirituality and their emotional needs and struggles through their hospital stay. So if religion or you know, very specifically religion is important to them,, talking about God or their understanding of God or, crisis of faith. That's something that we would definitely, engage with them, that conversation that we would engage with them. And, but we also, don't have to, don't have to. I have a lot of encounters with people who identify very strongly as atheists. So it's not necessarily about that religious support. It's more about,, how are you able to cope with what you're dealing with right now?

Brittany: Yeah.

Stephan: I find my work here in the hospital to be part of my vocation of the journey of what am I supposed to be doing in my life. And it fits, right now. This is what I love to do.

Courtney: That's awesome.

Brittany: Yeah.

Courtney: Very cool.

Brittany: So, what does it look like during the holidays, Stefan?

Stephan: So the holiday season is - it can be tough for patients. It can be tough for patients because it, it elicits all kinds of different emotions. You know, usually we think of, times of, holiday season as a time to be together with family. And there's always
a lot of nostalgia that goes with it. So it can be very isolating for patients to be here at the hospital.

[00:06:42] It's something that spiritual care does year round. You know, we support people as they journey through their hardships, their struggles, but we find that especially, meaningful, around the holiday season that, we have the privilege to be that person, to journey with the patient when nobody can come and see them, looking at the transplant program, we're a pretty cool team. It's a transplant family. I've heard that term used so many times, you know, the, the trust that is very obvious and evident between all the staff is amazing to watch, how cohesively everybody works. There's always bumps in the road, but by and large, there's, there's this level of trust. That's very obvious. The decorations that went up last week. They're lovely.

[00:07:34] **Brittany:** [00:07:34] Our nurses are really, really creative. Every unit in the hospital has a Christmas decorating competition. Right. And you don't win anything. It's just bragging rights. And one year we, like, I think our unit had kind of newly opened and one of our nurses is very competitive. She decorated the unit and another unit had taken all of her ideas and decorated their unit based off of ours. And, they won. The next year we came back with a vengeance. Okay. I will try and find some pictures so we can post them on the page because this Christmas decorating contest was amazing. And they got down to business. One of our nurses made two gingerbread men that were like life-sized gingerbread men and or women. And, they had organs, you know, placed all over them. And then one was a nephro, one with like a hemo line and a PD cath. It's amazing. And then, they had one of the other nurses had decorated, like, you know, jujubes and candy canes and little candies, like hanging from the sky. They were gorgeous, like wrapped in cellophane and they were big and absolutely amazing.

[00:08:53] And then another nurse had made these little gingerbread men and different little Christmas characters and placed them very carefully around the unit. So one of them had been sitting on the computer as the little gingerbread, but it was like, pre liver, like, you know, pooping or one had diarrhea and like one was vomiting, and they were all super, super creative and then they may, she made a wreath, this was so cute. I wish - I hope, I think we still have it. It's a Christmas wreath with all these different organs, the team was blown away. I was there and I was showing off, like I was selling them. Like I sold them on the team. I was like, "Oh, did you notice like this? Or did you notice that?" They're like, "Oh, nice." Like, so we won.

[00:09:40] **Courtney:** [00:09:40] Congratulations.

[00:09:42] **Brittany:** [00:09:42] It was incredible. I talk about it all the time. Because it was amazing the - I, I didn't, I'm not going to lie. I had no part of this. All I was - I was just awestruck. Yeah. I was just like, "Oh my God. But did you see that?" And I'm like, that's like, so I didn't make anything but -

[00:09:58] **Courtney:** [00:09:58] So, Stefan, if you like, obviously there's this like epic contest that goes on every year at the hospital and you're moving around all around TGH. What are in your opinion, which units are some of the best at decorating?
Stephan: I'd have to go back into the archives and take a look at some pictures to judge that I don't know. Okay.

Courtney: Yeah. I guess you also don't want to be recorded saying yeah, I hear you.

Stephan: You read between the lines.

Leslie: When you're in a hospital for an extended period of time, you learn to adapt and make the best of the situation.

And that includes things like birthdays and holidays, both of which I experienced in the hospital. Hanukkah occurred during the second week of December that year, about three weeks after my transplant. Hanukkah is the Jewish festival of lights and it commemorates the rededication of the Holy temple in Jerusalem. It also celebrates a miracle when a single day supply of oil managed to provide light for eight days. As you can imagine, recovering from a liver transplant is slow and painful. So I really hadn't been up for too many visitors, but my mother-in-law and my sister, and brother-in-law all live in Toronto and they really wanted to come see me and to celebrate not just the miracle of the oil, but also the miracle of my transplant. So they brought Hanukkah to the hospital that year.

They set up a space in the family lounge and brought a big package of potato latkes. Those are potato pancakes fried up in a bit of oil because we like to eat things cooked in oil at Hanukkah, the symbolism, you know, and served with applesauce or sour cream. So they brought all the fixings too. Let me tell you, after a steady diet of hospital food, lactulose, and medication, I was so ready to taste something delicious and while I didn't really have much of an appetite, I remember that the food tasted so good. And in case anybody's wondering, for my latkes, I'm totally team sour cream.

While I'd rather have spent the holiday at home or a little hospital party really made my day, I was so grateful to be alive and to celebrate the gift of life that I was given to have another holiday season with my loved ones. The hospital staff was so great and supportive in allowing us to have this little celebration. I'll never forget that little Hanukkah celebration that we had in the family lounge at TGH.

Len: In Christmas, 2018, my wife, and I were sitting watching TV and we watched one of those corny Hallmark Christmas movies, 'Once Upon a Christmas Miracle.' And, in the movie, you know, it's the typical guy meets girl. They get married, live happily ever after, kind of thing. But in this case, it's got a little bit of a twist to it. So, the lady gets sick, it turns out she needs a liver transplant and this stranger steps up and donates a piece of his liver. And, of course in the end, they fall in love and get married and all that sort of thing.

That's when I discovered you could actually donate a piece of your liver. I started digging into that just to kind of see what was involved and I went to the Toronto General Hospital website and so on, and I thought, you know, I could do that. And, one thing led to the next, filled out the questionnaire, send it in on January 1st and the gears
started turning. A few months later, I got a phone call from Zubaida, transplant coordinator at the time, and we went through a whole bunch of questions and, and got a thumbs up on that first step. And then of course the testing begins. MRI, CT scans, x-rays, liver biopsy. But, anyway, that all went really well. And, in the end I got a thumbs up and a little later, I went through the surgery and, it went really, really well.

[00:13:38] So up to that point, everything seems really kind of sequential. You know, you fill out the paperwork, you get a bunch of tests, you talked to a bunch of people, you have some surgery, blah, blah, blah. Not that it wasn't interesting and even exciting. But it was just kind of matter of fact, you know, step A, step B, step C, but everything changed the day after the surgery, [00:14:00] the recipient surgeon, I call the recipient, my liver buddy. So my liver buddy's surgeon came in and told me that he was doing really well. And that just changed everything. It just suddenly became so real. And so emotional.

[00:14:17] I got to exchange a letter with the recipient’s family. I sent them a letter first, in that I just said how glad I was to be able to do this. And of course wish them well and all the best. And a little while later, I got a call from Chantal saying she had a letter for me. When I opened that letter, it was, well, let’s just say it was really hard not to cry standing in the hallway. My liver buddy was doing amazingly well and how much better can it be than that, right so I keep both of those letters on my desk and a double-sided frame and every now and then I’ll read them just as a little pick me up. And I can say to you that if I could do this again, which unfortunately I can’t, [00:15:00] I would be in line for round two.

[00:15:03] Courtney: [00:15:09] how many times have you dressed up as Santa. Oh man, a lot if you have to think about it.

[00:15:13] Stephan: [00:15:13] Got to be three or four times, three or four times. I came in, in this fall last year I started. So last Christmas was my first Christmas. I've definitely felt the warmth here. Every unit, there was - the kind of, the holiday cheer was very obvious, very present. I was even motivated this year. I have little spiritual care boards that I have one each unit. And I did some decorating too. I have little nutcrackers, reindeer. And then there's a polar bear too, sticking out somewhere. So I tried to be part of it too, you know? You want to participate, it's -

[00:15:53] Brittany: [00:15:53] - yeah, it's it's it creates an environment that's a little bit more wholesome and [00:16:00] homey, even though there's only so much that you can do to make a nursing unit or a ward look like someone's home, but we try, we really do try to make patients feel a. That they're comfortable in that it's there's a little bit more light heartedness around the holidays and for the staff that if they have to work Christmas or if they have to work new year's or they have to work their holiday, that they're, that they celebrate that they don't necessarily feel like they're missing out too much. Like maybe they're not with their family, but they're with their work family. And in previous years, we've, you know, sometimes ordered food or had potlucks, might be a little different this year.

[00:16:43] Stephan: [00:16:43] We can still maybe order food, technically.
Technically you probably can.

I think when you decorate your environment for whatever you're celebrating and the people who work there feel it, the people who are, you know, living there for the time, kind of feel it. And then I feel like it puts everyone like in that festive spirit. Cause it must be hard to spend the holidays in the hospital.

You know, I, I definitely agree with what you're saying, when staff feel that when, when you're able to decorate that, the kind of work home environment, you spend 12 hours a day here, the nurses do, right? It's a long time, but when you feel comfortable and you feel that cheer it's. It rubs off, right? It rubs off. When you go into a patient's room, you're smiling. You're, I don't know. There's, there's this cheer that, that you pass on to everybody you encounter and it's contagious. So I love seeing that I really do.

A couple of years ago, we. One of our ward clerks, I think dressed up as Santa and we had a bunch of blankets I think, donated to us and we gave them out to each patient. I think that was like one of our first years open. And everyone got a new blanket and like a chocolate on their, on their dinner tray, which was pretty cute. Yeah.

Yeah. I think that's kind of going back to what you were saying too, like I think there's something really nice about any holiday is just, there's something humans, I think, gravitate towards kind of collective experiences. It's a nice reminder that we're all connected, that we all have the capacity to bring each other joy and like all these kind of lovely reminders that there's something really genuine about, about celebrating with people. If that makes sense.

It definitely does.

Absolutely. You're right. We are relational beings. We love to be in, you know, the company of one another. I like to always, go down memory lane with people in terms of what have their experiences been of the holidays outside of the hospital. And that will oftentimes bring joy to them. To help them feel that, well, first of all, that somebody cares, somebody is listening. Not always. Sometimes it does make them sad and, and kind of remember the loss that they're going through right now because the are in the hospital. But we try to bridge it as much as we can. We're very fortunate to have iPads and, and get patients together with their families, even if it's virtually. It goes a long way. Yeah. It definitely goes a long way for sure.

Also I find that people - you know it has happened a number of times where, holidays are a time where we remember, we started remembering the good and the bad that's happened throughout the year and oftentimes the bad can be associated with losses, right? So if a family member dies or somebody close to them is no longer part of their life. So on one level it's sad and it's, it's a hard thing to go through, but on another level it does to help to, to let them feel like there's some type of closure happening because they are embarking on another, you know, on another year, on another part of their life.
[00:19:53] So they’re, heavy duty conversations at times. They can be very emotional, but, I feel very privileged to be part of [00:20:00] that, to be invited into their story like that.

[00:20:02] Courtney: [00:20:02] Yeah. I was, I was just about to ask you, what’s the most rewarding part of your job, but it sounds like the job itself has kind of, it's own reward for you.

[00:20:12] Stephan: [00:20:12] A hundred percent. I get to do - I get to listen professionally. If that makes sense, I get to honor people's dignity. I get to really help a person feel like they're not alone. That's amazing. It's easily forgotten because we live in a very, you know, medical world ... being in a hospital, obviously, you know, everything is cheques and balances and it's measured this way and that way, and, we want to fix, fix and address address, but sometimes, looking at the person holistically doesn't happen, and, giving somebody that ability to talk it out, to connect with another person, to have some of their experience affirmed. It is very rewarding. I'm very, very blessed.

[00:20:59] Brittany: [00:20:59] That's [00:21:00] beautiful. Yeah. Will we be seeing ... Santa this year?

[00:21:05] Is Santa coming to TGH?

[00:21:10] Stephan: [00:21:10] I'm gonna have to look at his, schedule, schedule. Yeah, he hasn't shared it with me yet. I haven't gotten -

[00:21:16] Brittany: [00:21:16] He's going to be busy this year,

[00:21:18] Heather: [00:21:25] Organ transplantation was not on my radar at all until almost 12 years ago when my son, Jonathan, who was a 22 year old kinesioncology student at York University, was in a fatal car crash. He was the passenger. And his friend was driving at at least triple the speed limit when he crashed into a hydro pool. And my son, Jonathan sustained a traumatic head injury. The next morning, the police [00:22:00] arrived at my door. It was every parent's worst nightmare. They asked, "do you have a son named Jonathan Talbot, is he a York University student? We found a backpack with his books in the vehicle. you know, it's a horrible car crash. You better come to Sunnybrook Hospital fast, or you might not see your son alive."

[00:22:22] And so my husband and daughter and I went to the hospital and the doctors would not let us see Jonathan at first. He was on life support, there were monitors, there were tubes. And the doctors showed us the computer monitor, showing Jonathan's skull fracture with his brain swollen, and the doctor said "we cannot fix this." He brought us into Jonathan's room. Jonathan's head was covered halfway with the hood. And other than that, his body was perfect. There wasn't a scratch on him. Anyway, they asked us if Jonathan had signed his donor card, because back then there [00:23:00] was no. organ donor registry. It was just, you signed your driver's license. And I said, "I don't know if he signed his card" and our daughter, Emily, who was just a year younger, she was 21 at the time, she said, "Oh yes, he did sign his card. Yeah. We discussed it." And he actually called her a loser for not signing her card when she got her driver's license.
Anyway. I was reluctant still to consent to organ donation because I thought it was against my religion. I'm Jewish. I raised my kids Jewish and, I called a rabbi who said, "no, it's a mitzvah, it's the biggest mitzvah, a good deed, you're saving lives and the Jewish religion now recognizes that." So. We did consent. And this was Sunday. We had all day Sunday with him, all day Monday with him. We saw more views of his brain on the computer screen. It was just getting more swollen. Our, we could tell that he wasn't improving. He was just getting worse and they told us that they would remove life support, 6 a.m. on the Tuesday morning.

And they did that. They removed the ventilator. And I saw that he never took another breath, which in a way, - it relieved me that he was only being kept alive by the machine. And then, his heart kept beating for a few more minutes and then it stopped and they had to wait five more minutes to make sure that his heart definitely stopped and they wheeled him away. And then we went home without Jonathan.

Um, the Trillium Gift of Life Network contacted me and asked if I wanted to write letters to his organ recipients. And so I did. Each kidney was given to a different man, his lungs were given to a man, his liver was given to a man, and his heart valves were sent to Sick Kids Hospital. I received letters back and we wrote back and forth a bit. And I really treasure these letters about how these people's lives were so improved, you know, the people on - with the kidney transplants didn't have to be on dialysis anymore. The person was lungs could breathe again,, they could go on with pretty normal lives after that and they appreciated so much this gift of life that Jonathan gave. And it really brought home, what an amazing gift transplant is, that it really does save lives. And the families of those people, their lives are also changed, and they're ecstatic. And they didn't have to go through the grief that I went through losing Jonathan.

So many people now have told me that because of Jonathan, they have now registered to be organ donors. So it really gave me solace in my grief, that Jonathan thought to donate his organs. You know, Jonathan’s death is the worst thing that ever happened. But I gained this gift of having a purpose in my life, to be able to honor his memory and hopefully do good by encouraging more people to be organ donors and saving more lives.

The first holiday after Jonathan’s death, the first, well Hanukkah, he wasn’t there to sing the blessing. Usually Emily and Jonathan, and I sing the blessing over the Hanukkah candles in the menorah for the eight nights of Hanukkah. He wasn't there, wasn't there to share in the latkes. So that was very sad for me. And also we celebrate Christmas because my husband is Christian. And so we've always had a tree. And my husband and I did not want to put up the tree that Christmas and Emily, our daughter insisted. And as she has done now, every Christmas. And so Terry has to bring the tree up and the ornaments. And really it is a lovely thing to have this tree because there are so many ornaments that bring back memories of Jonathan. There are all kinds of ornaments that, or he and Emily both made these little crafty decorations when they were in daycare, when they were in primary school. And also we have ornaments with Jonathan's name on them. Some of them were gifts, you know, from friends and I had found a box of ornaments, the first
Christmas, and they were hanging diamonds like each, you know, a diamond hanging from a strand. And so I gave them out to all of the members of my family and everybody in my family has a tree and they have the diamond. On Jonathon's grave the epitaph is "shine on forever Johnny T" and also on his memorial bench, it says "shine on forever Johnny T," from the pink Floyd, "Shine On You Crazy Diamond." And so when I go to people's houses that I've given these diamonds to, of course not this year because of COVID, they always say, "Oh, look, there's Jonathan's ornament." And it's the diamond hanging there.

[00:27:54] So you know, that really, it really does help. And, you know, it, it [00:28:00] hurts at the same time. It's very bittersweet, but, we do celebrate, and I know that the family, you know, we get together usually with Terry's whole family and they really, they're grieving too. And they loved him too, and they really want it to help us and help us to heal and to include Jonathan in our celebration and remember him. So, yeah, it's like I say, bittersweet, but, you know, every year I guess it gets a little bit easier, a little bit easier. And, and you know, every time I tell my story, tell Jonathan's story, I think it heals me a little bit more to, like they say, "Oh, you have to tell your story a thousand times." Well, I think I'm probably there.

[00:28:44] Maariyah: [00:28:45] so my case is a little bit special. I was actually in the hospital, because I went in, for chest pain and then was immediately diagnosed with, heart failure. So I didn't even know that I was sick.

[00:28:57] but I waited about a week for a [00:29:00] transplant. and they told me two days before I got it. on December 22nd, I was in the CVICU and they told me that a heart was available. and then two days later I got my transplant.

[00:29:10] I remember there being like decorations, so that, that made me feel a little bit better because I would definitely want it to be home by Christmas and, like spend time with my family and, you know, Christmas activities and whatever.

[00:29:24] but I was in the hospital obviously. And the nurses were just so awesome and they decorated the unit and they made me feel really supported and really cared for. so that was really cool. and then, I was in there for new year's as well. And, we had like a little new year's party.

[00:29:40] I have a huge family, so there was like six of us and then six of my, aunts and uncles and their children, and then another six. So we probably had about 20, 20 people and we put like a slide show and we use like one of the rooms in the hospital. I think it was like a waiting room or something.

[00:29:57] and like we brought food and everything and we had like a little [00:30:00] party for new year's. So it was, it was pretty cool.

[00:30:02] Christmas is definitely a lot different now. we celebrate every year. well that my heart aversary we, we celebrate because my transplant was on December 24th. So Christmas Eve, normally we don't celebrate Christmas,, because we’re Muslim, but like it's a lot different this year and like going forward after transplant, we put up a tree and we put up lights and, we call it the tree of hope and all our ornaments are hard ornaments.
So it's pretty cool. Christmas definitely looks a lot different, but it's definitely time like for the family to get together and everyone to just kind of look back on everything that happened and everything that we've all overcome together and what we're all grateful for. So it's super awesome that we all have that bond, that family bond.

Courtney: [00:30:55] just one last question. What is something you would, or I guess you [00:31:00] will tell some people in the hospital, but, or people at home as well, who maybe are just having their first Christmas without their loved ones. What's something, any, comfort or advice that you would offer to people who are having a tough holiday season?

Stephan: [00:31:12] I would encourage them to, to remember that they're not alone. That there is, from the transplant perspective, that transplant family, we are all here. Not just myself. I see the compassion that the nurses have, that all the staff have. Everybody's a friendly face here., While it is hard, it's not necessarily something that any one of us can control when we are in the hospital, how long we have to be in the hospital. I think reminding ourselves of that is helpful. When we try to reason something out, it makes it that much easier to process, but when we can't, it makes it hard. I would encourage those people to touch into their roots, to actually take a minute to reflect on what is important in their life and why. [00:32:00] Where is it that they draw their strength from? That's a very common question that I ask patients when I first meet them. Sometimes again, having those intentional reflective moments can get us through very tough situations. Because we are human beings that are - we're frail. At the same time, we are very strong and resilient.

And again, good to remind yourself that every once in a while.

Courtney: [00:32:28] For sure. Thank you so much Stefan

Brittany: [00:32:30] Thank you.

Stephan: [00:32:30] It's been a pleasure. Thank you.

Courtney: [00:32:35] Thanks for listening to this episode of Living Transplant. If you have questions or suggestions for future episodes, email us at livingorgandonation@uhn.ca.

Brit: [00:32:44] Don't forget to subscribe, rate, and review living transplant on iTunes, Spotify, or wherever you listen to podcasts

Courtney: [00:32:51] and follow us @givelifeUHN on Facebook, Twitter, and Instagram.

Brit: [00:32:55] See you next time.