

## SICKKIDS VS CANCER'S SHADOW

**Hannah Bank:** You're about to hear from a mom named Adrienne, who lives in London, Ontario. She describes her daughter Rae as a formidable character. She has a beautiful personality...

**Adrienne:** She has a beautiful personality. She is sparkly. She loves people. She loves engaging with others. She loves school and friends. She particularly loves reading. Her mom's a librarian—what would you expect? She's sort of your typical 14-year-old girl. And then in some ways, she's spectacular.

**Hannah:** Can you take me back and tell me a little bit about her story?

**Adrienne:** Just before she turned four years old, it was in the summer, and the whole family got sick with a summer cold. We all got better over a few weeks. But she stayed sick. She got very tired. She stopped eating. She wasn't feeling well. She started coughing at night. She was keeping me up at night. So one morning I took her to a paediatric walk-in clinic. And while I was talking to that doctor, and he was looking her over, he said, "I'm going to give you a note, and I want you to take her to paediatric emergency right now. You do not stop. You go in and you give the nurses this note. And if you can, tell me later how you're doing." I was stunned, I didn't know what that meant, but I did what he said. I took her straight to emergency. I handed them the note and we went straight into the back. The whole hospital descended on us. I had no idea what was happening. I thought she had pneumonia. But what was happening and why we were immediately put into isolation in E.R. was that she was experiencing heart failure. So the coughing wasn't coughing. It was heart failure. And that's because she had leukemia. So that's when we got her diagnosis, and her journey began.

**Hannah:** Rae underwent therapy, but the cancer returned in her spinal fluid. So she started a new treatment plan and clinical trial based in London. Yet the cancer came back—again.

**Adrienne:** But this time it was in her eye. And that triggered our next round of treatment, which was to go to SickKids in Toronto for a stem cell transplant.

**Hannah:** A stem cell transplant is a life-saving procedure that replaces stem cells that have been destroyed by cancer or the high-dose therapies used to treat it. A stem cell transplant is gruelling and comes with its own side effects.

**Hannah:** At that point, there had been so much emotional and physical trauma, I imagine. What were you all like when she went in for that stem cell transplant?

**Adrienne:** I described to someone recently that the initial diagnosis is a sideswipe in your life. You know, it comes out of nowhere. You can't plan for that. Relapses are a different form of trauma because you know what's coming next now. I once told someone, if I had to write a three- or four-word, horror story, it would be: "The cancer is back." That's the whole story.

**Hannah:** Every year in Canada, around 1,000 children are diagnosed with cancer. Like Rae, over 85% of kids will be cured. Yet their journey doesn't end at remission.

Treatments to kill cancer cells are typically toxic. And toxic therapy affects normal tissues and developing organs. So some survivors develop something known as "late effects" from their cancer or its treatment. These late effects can include heart problems, infertility, mental health concerns like depression or anxiety, and the possibility of new cancers forming.

**Adrienne:** For Rae, the initial two years of treatment had its own version of late effects around chemotherapy. And those include heart and growth issues, lung issues, and breathing. A lot of kids experience hearing loss with that, and growth issues later on. There's fertility challenges that are part of just that form of treatment in and of itself if you move into radiation. So Rae had cranial radiation, ocular radiation for the relapse in her eye and her spinal fluid. So that has its own unique late effects around growth and development. And then around brain injury. There's something called chemo fog that a lot of these kids experience and executive functioning issues that that they end up with. So she faces some learning challenges.

**Hannah:** Too many kids face these kinds of outcomes — sometimes well into adulthood. But you're about to hear from one SickKids doctor who's discovering new ways to improve support for more survivors. He's even leaning on a unique collaborator to get an insider's perspective.

You're listening to SickKids VS, where we take you to the frontlines in the fight for child health. I'm Hannah Bank, and this is SickKids VS Cancer's Shadow.

**Dr. Paul Nathan:** I'm Paul Nathan. I am a paediatric oncologist.

**Hannah:** Paul heads up the Solid Tumour Section here, supporting children newly diagnosed with cancer. Around 25 years ago, when Paul first entered the field, he says...

**Paul:** There was a lot of progress going on in terms of treating cancer. And, as a consequence, there was a considerable improvement in how many kids survived. And so it was really this shift in focus where colleges were saying, "This is not just about can we cure kids — it's about what are their lives like after we cure them?" Because now we literally have thousands and thousands of long-term survivors of childhood cancer. Some are still kids. Many are now adults. And so there was this real opportunity in this field called aftercare, which is really focused on once the chemotherapy ends, what happens next.

**Hannah:** At SickKids, Paul leads the AfterCare Program. The program helps childhood cancer survivors manage — and minimize — the physical, emotional, and psychological toll of what they've been through. It's one of the most robust — and well-regarded — programs of its kind in the country.

As part of the AfterCare Program, there are clinics for survivors, where a diverse team looks after the many facets of survivorship. There's medical experts — like paediatric oncologists, and a nurse practitioner. There are also psychologists, who work with kids on the stresses of navigating cancer. And a neuropsychologist who helps families with cognitive testing for school and advocating for educational resources. Plus, there's a dietician. And an endocrinologist to provide support around common late effects involving growth and puberty.

**Paul:** So our idea there is to be holistic. This is really a complete 360 look. Not just at, "Do you have any late effects, but how are you doing at school? How are you doing psychosocially? What are your interests, diet, exercise, lifestyle?" So we really try to give a sort of holistic approach to their care, in part, because I think having had cancer and cancer therapy can impact all those aspects, and in part because by the time they come to their clinic, we can't undo the chemotherapies they have. But we increasingly know that a lot of lifestyle decisions can have an impact on their risk for late effects. So we spend a lot of time thinking about healthy lifestyle. Not just because we should think about that in in any child or teen patient. But because that interaction between lifestyle and late effects — not for all of them, but for many of them — is actually quite well established. And is a place that we can actually make a difference.

**Hannah:** Take organs, for example. Research has found chemotherapy can affect a child's heart. As survivors age, having diabetes or high cholesterol can multiply their risk for other cardiac problems. These kinds of findings mean Paul and his team can provide simple suggestions and specific screening recommendations to mitigate issues down the road.

**Paul:** In the early days of this field of cancer survivorship no one really knew what happens when someone who had cancer, when they were 12 turns 20 or 30 or 40 or 50. What happens if you give a kind of chemotherapy or radiation in terms of the long-term outcomes? Does this damage organs or growth? So much of the early research in this area was just around documentation. What's changed or what's evolved more recently is we're thinking more and more about what can we do about it. So how do we take what we've learned over the last decades in terms of how different chemotherapies or radiation or other treatments affect survivors, and can we either make changes to the way we treat patients, give them less chemotherapy, different chemotherapy? Are there medications that maybe can protect against some of the long-term toxicities we worry about?

**Hannah:** Research advancements from Paul's team are also impacting how they follow survivors over time.

**Paul:** In the general population, we know that as adults age, their risk for cancer goes up. That's why there are recommendations, for example, that older folks get colorectal cancer screening starting later in life in their 50s and 60s, or that women get breast cancer screening in their 40s and 50s moving onwards. What we've learned is that some of these things happen a lot earlier in some of our survivors. So, for example, we know that women who get radiation to their chest as part of their cancer therapy have a very much elevated risk of breast cancer. And that breast cancer can happen early, like in their late 20s and into their 30s. That's a period of time in which the general population is not getting mammograms, for example. So much of what we've done is say there's a different set of rules for people who've had cancer therapy, and we really need to be focusing on doing that surveillance earlier. And we've actually shown that doing some of that surveillance so that makes a difference.

**Hannah:** Even before they're transferred to the AfterCare Program, patients are typically monitored by their medical team for several years after their last treatment.

**Paul:** That's the time where we're really working hard to make sure that they don't get a new cancer, and if they do, to pick it up. So a lot of those kids are getting scans every four months or six months or a year to say we just want to be sure your cancer doesn't come back. At some point, that risk goes way down — it may not be gone completely — and that's usually around the five-year mark. And, at that point, *all* patients are transferred into our survivorship program.

**Hannah:** Adrienne's daughter, Rae, was one of those patients. She returned to SickKids for about a year after her final treatment.

**Adrienne:** They were lovely. And that's monitoring for your health and recovery from the stem cell transplant. It's monitoring for secondary cancers, brain injury — those sorts of things. So we had a very positive experience with that. And then we were fortunate that we could transfer aftercare to London, so we didn't have as far to go in the future.

**Hannah:** It's easier to ensure kids will show up for check-ups when they're minors and chaperoned by worried caregivers. But by the time they grow into young adults and transition into the adult health-care system, many of them want to put cancer behind them.

As Paul says, "Kids just want to be kids."

**Paul:** Kids just want to be kids. And so my sense is that a lot of childhood cancer survivors don't want to think about it. They want to go back to normal childhood. And as a consequence, a lot of them don't really want to think about their risk for late effects. And so when we say to them, you know, you have to come to Princess Margaret once a year, you live two hours outside of Toronto, you should drive down, miss a day of work. A lot of them drop out of the system. Although I think these aftercare programs do provide outstanding care, and they certainly see thousands of patients, by far the majority of adults who have had cancer as kids are no longer engaged in the cancer system.

**Hannah:** Just ask Michael Taccone, a former SickKids patient.

I wanted to talk a little bit about your cancer journey. You said you were eight when you were diagnosed with leukemia. Can you talk a little bit more about the type of leukemia and the kind of treatments and just take us briefly through that journey for us?

**Dr. Michael Taccone:** All right. So let's rewind to 1994. Back then, the treatment protocol was a prescribed length of time, which was three years. And those three years were occupied by various combinations of chemotherapies. They also did some radiation at the time for me. Part of it was called the intensive phase, where you'd be in hospital getting more routine chemotherapy and radiation, and then you'd have like a maintenance phase where the doses would dial back a little bit more. And you'd have less side effects, less nausea and these kinds of things from the treatments.

I want to stress that paediatric cancer is very much a whole family disease. The impact that it had was tremendous. The treatments, unfortunately, that we give children that is meant to cure them also comes with not just side effects in the short term but also long-term side effects. And it was quite grueling. Cancer is a lifelong journey. It doesn't just end with cure, and we have to recognize it. All of these other pieces are part of that journey as well and deserve just as much time and respect and effort into treating as that biological disease itself. It wasn't just the treatments that were going on. It was everything else that was happening at that critical developmental time point in your life, the psychological impact, the trauma impact, the stress on the family, the stress on social relationships — all that stuff keeps going with you.

**Hannah:** In health care, empathy is a cornerstone. But wholly understanding the journey of childhood cancer survivors requires more than just empathy — it demands firsthand experience. As more children survive their cancer, some grow up to become nurses, scientists, and physicians, enriching the field with insights formed from their own lives.

**Michael:** Some people call me Dr. Michael Taccone. But I myself am a Senior Neurosurgery Resident here at the Ottawa Hospital. I'm also a scientist. I recently completed a PhD at SickKids, and that's where I got a chance to work with people at SickKids. And the third piece that I'm most proud of is I'm also a childhood cancer survivor. And that's kind of the feather in my cap.

**Hannah:** Given his journey, I wanted to know how Michael describes late effects to cancer patients and families.

**Michael:** The way I like to describe it is kind of if you think of like a sunburn. The immediate effect of going out into the sun is getting a sunburn, and your skin burns for a little while. But the late effect of a sunburn, potentially years down the road could be the development of a skin cancer. Or it could be the development of other types of skin diseases that are not apparent at the time but happen much later, and they're harder kind of to track and to monitor for. And the same thing happens when it comes to chemotherapy and radiation that we give to children. These too have impacts that are not immediately visible at the time that these children are getting treatment. But the impact creeps up.

**Hannah:** Michael also has a special interest in aftercare programs, something he benefitted from greatly here at SickKids.

**Michael:** Where would I be without the support of an aftercare program? It would be a lonely place. It would be trying to face my concerns, my anxieties, my worries alone. I was very much involved in the aftercare program between the ages of 12 to kind of 17, 18, while I was under the watch of SickKids. But once I was supposed to make the transition to the adult version of aftercare, which at that time was at Princess Margaret Hospital, I never went to my clinical appointments. I was in university at the time. I was starting classes. I was learning about medicine kind of at a very rudimentary level. And I said to myself, "If something's going to be needing to be monitored, I'm pretty well-educated, and I know what to look for. I don't need to go to my appointments." And so I just stopped going. Plus, I made the excuse that my life was busy. I kind of wanted to put cancer behind me. I no longer had my parents forcing me to go to the SickKids appointments. And so I kind of fell off the map.

**Hannah:** For many survivors, including Michael, check-ups fall to the side. But what if there was a way to get more people screened for risks in adulthood? Michael and Paul were determined to investigate — together. More on their fateful meeting after this brief break.

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**Hannah:** The AfterCare Program at SickKids is one of only a handful across the province that are connected through a non-profit called the Pediatric Oncology Group of Ontario, or POGO. The group is unique to Canada and tries to ensure that kids and families affected by childhood cancer get access to incredible care and support.

The POGO network also happens to be how Adrienne was able to get Rae's aftercare transferred from SickKids to a hospital in London. And, coincidentally, POGO is where Paul and Michael first met. Their support of the group led to an initiative involving lots of data about childhood cancer survivors and challenges with late effects.

**Michael:** We've been working together ever since.

**Paul:** Michael, who has both the lived experience of cancer and is also a physician, which is incredibly helpful because he sort of has the perspective of a health care system and how it works, has been an incredible partner in that.

**Michael:** I can't tell you how many meetings I've walked into, Hannah, and the first thing I say is, okay, what hat am I wearing today? Because sometimes they want me involved as somebody with patient experience. Then I'm there talking as a survivor, as somebody who's been through it. Other times, I'm there, as a medical expert on whatever the flavor happens to be of that particular meeting. And, sometimes I'm all three: I'm the advocate, I'm the researcher, I'm the clinician, and it entirely depends on kind of what the needs of the project are at that time. I bring that sense of empathy, that sense of compassion to every single opportunity I have to make an impact on somebody's life. Perhaps I was an empathetic person all along. Perhaps it had nothing to do with the cancer experience. But, certainly, there's an impact there where I'm able to know what it's like to be on the other side, and I can anticipate the questions, I can anticipate the worries. And even in the research world, we've been able to ask better questions just by having a knowledge of what that patient journey is like.

**Paul:** I think the most important thing we have done and continue to do and strive to do with all of our projects is to engage folks who have been through this.

**Michael:** Some of the work that I do with Dr. Nathan in population-based research is we're finding better ways to build bridges between cancer survivors and bringing them back into the surveillance programs that are so important for them. And we're using fancy technologies to do that.

**Paul:** So right now, we're about to launch a program across the province that will allow us to reach out to survivors. And we're going to reach out to them and say, you know, we know that 30 years ago, when you were five, you had cancer. We know that you are at risk for certain things and that you're not getting the screening you should get. And we would like to set you up with a program that will make sure you get the surveillance you need. We think we may be able to use all of these different administrative data sources to sort of say, "Who were the kids who had cancer? Which of those are getting the screening they should be getting? Of the ones who are not getting the screening, where are they?" Then I think if we can make that work, it could have tremendous impact.

So I think one of the things that has happened over the last decade or so is we understand more and more about the genetics of these late effects. So we know that you could have two patients who get identical chemotherapy treatments, but one goes on to, for example, get complete deafness as a result of a of a chemotherapy drug. And another kid who got the same chemotherapy at the same age is absolutely fine. And we're increasingly learning that the way your body processes the chemotherapy, or the way your body heals from damage and a variety of other factors — all of these things that are controlled by your own genetics — may be super important in determining who's either really vulnerable to a particular late effect or who's really resistant to a particular effect. And so now we've started to build models where you can input all of these factors up front or at any time and say based on your genetics and some demographic things like age and sex and the chemo you got, this is pretty much your risk of having a specific late effect.

**Hannah:** For children like Rae, who's cancer-free and turning 18 in several years, these precision approaches may help when they strike out on their own — and transition into adult care.

**Adrienne:** So now that I can be confident she's going to be with us for that future, I can confidently say that I want her to be happy and healthy as she lives it. Whatever she chooses to do with the time that we fought to give back to her is up to her, and I support her 100 per cent whatever it is. I have a sense that she's going to be a powerhouse. I think she's going to end up being in a helping profession. She's already talking about science and medicine. But honestly, at the end of the day, that I get to watch her have that future is the gift that I will carry with me. And I want her to have a happy and healthy time doing it.

**Hannah:** From SickKids Foundation, I'm Hannah Bank. Thanks for listening. To support breakthrough research and care at SickKids, please visit [SickKidsFoundation.com/podcast](https://www.sickkids.com/podcast). And if you liked this episode, subscribe and rate us wherever you listen to podcasts.

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