

Mayo Clinic News Network

Treating more than the disease: Giving kids with cancer Brighter

Tomorrows

Video	Audio
CONNOR JOHNSON Cancer Survivor	“I was 13 and we went in for a eye checkup just ‘cause I was having headaches and I was vomiting too so we just went in to – to the eye doctor to get checked and he scheduled an MRI for the next day and that’s what diagnosed me.”
	The diagnosis: Something no 13-year-old should ever have to worry about.
	“I was pretty much in shock because I would have never thought that I would have got cancer. But yeah, I just really couldn’t grasp my mind around it.”
	Connor Johnson had medulloblastoma; the most common form of brain cancer in children.
	His parents were just as shocked, but had little time to consider the implications of their youngest child having cancer.
CURT JOHNSON Connor’s Father	“I mean, it was – it came on so fast that there was no planning. There was no thinking. It was just we knew we had to do it, you know, to try to save his life. So we just went in with a mindset of, okay, one step at a time. Brain surgery.”
	And thus began the most terrifying and painful time in the Johnsons’ life.
	“Well, the brain surgery, I think it was six hours and after that, I think a couple weeks later, I went to proton beam and we did 30 sessions of that and then after that we did chemo for 46 weeks and we’d go, like, every week for that

	and it's been pretty tough but gotten through it. "
	But there were times he questioned whether he could get through it.
	"Well, going into surgery they said it was, like, a 1 percent chance of dying and at that time, I thought that I could – I could die, but I haven't really thought that I was going to die. I thought that I'd get through it, but I was – I was never sure."
	Fear of the odds, however small, loomed large for Connor's parents too, even as they tried to distract Connor from them.
	"Well, I think any parent will tell you that they'd trade places with the kid – their kid in a heartbeat. I mean, you wish you could be in their place and feel their – feel the pain instead of them. But it's – it's pretty emotional. You try to – you know, I used humor a lot to keep them upbeat and positive and you try not to show your emotions and cry and stuff in front of them as much as possible, but there's times when you do. But you just try to keep an upbeat, positive attitude and – and just wish for the best."
	Dr. Shakila Khan is a pediatric hematologist and oncologist at Mayo Clinic in Rochester, Minnesota, and was part of Connor's medical team.
	She says extensive research and great participation in clinical trials have drastically improved the numbers for childhood cancer outcomes.
	But she says doctors like her have also come a long way in learning how to treat the patient, and not just the disease.
SHAKILA KHAN, M.D. PEDIATRIC HEMATOLOGY ONCOLOGY Mayo Clinic	"I mean, we treat the child as a whole. I usually tell the parents that we are part of the same team and are – you know, they are part of our team. It is a multidisciplinary team and we also include them so that we can take care of the child as a whole, not only for the

	chemotherapy. And attitude makes a big difference. I've seen – I've been doing it for a long time – positive attitude helps.”
	But staying positive while going through such a traumatic time can be difficult for the patient and the parents.
SHERRIE DECKER Co-Founder, Brighter Tomorrows	“When you hear those four words, your child has cancer, your life just comes to a screeching halt. Matter of fact, when the doctor tells you those four words, you don't hear anything the doctor is saying for the rest of that particular conversation. Everything is a blur. It is your worst nightmare and when all you know of cancer is death, you think immediately that's what your child is going to go through and that's where our minds go right away, but that's not always necessarily the case.”
	Sherrie Decker knows all too well how it goes.
	Almost 20 years ago, she went through it with her daughter, Shanna.
	“It's very true that when you look out the window and you watch the rest of the world moving on, just the cars moving down the street, the people moving through the courtyard, you think how can they go on with their life when our life has come to an absolute standstill?”
	Decker says it's a lonely time.
	That's why she and four other mothers of kids with cancer started Brighter Tomorrows.
	“And what we learned is that even though it was hard for the parent, we had to provide that – that hope for that child because they're always looking to the parents' eyes for that. And so that's why it's really important for parents to have a place to go where they can seek re – you know, be re-invigorated a little bit by other families that are going through the same thing and that's where the organization plays a big part is

	bringing another family into the room that's already done this and helping that family get a grasp on what they have to go through."
	Brighter Tomorrows steps into these families' lives when they need them most.
	It starts with a comfort kit full of things like snacks and toiletries they might need for long stays in the hospital...as well as some financial assistance during treatment.
	They offer a safe place of understanding for parents to meet other parents, patients to meet other patients, and even siblings to meet other siblings all going through the same thing.
	It's a mutual understanding they can only find in others living under the same dark cloud.
	"Yeah, because they'd, like, tell you their experiences, and it'd just help you through it a little bit."
	And perhaps most importantly, they host monthly events for the kids going through treatment to look forward to.
	"You know, I mean, it always helps if you, you know, have things to look forward to, but kids are very resilient. I have to tell you, they just deal with things much better than adults."
	Curt Johnson thinks it's made all the difference for his family.
	"It probably – you know, the treatments and everything would have been the same. But the positive mindset was definitely strengthened by going to Brighter Tomorrows and just being able to talk to other people that are going through the same thing you are: The same fears and emotions and hopes."
	For Curt and Connor, it's been a daunting journey through treatment.
	But they've had little victories along the way to celebrate; each one making the effort to stay positive a little easier.

	They believe it was part of a cycle in which the positivity led to more victories to celebrate.
	Connor made it through brain surgery.
	Then, after 30 sessions of cutting edge proton beam therapy, Connor got to ring the bell.
	(rats of bell)
	“It kind of surprised him how many people were there, but ringing the bell, I mean, was pretty emotional.”
	Then, instead of going to school, playing baseball, or hanging out with his friends, Connor pushed through 46 weeks of chemo therapy.
	And after more than a year of treatment, Connor is now cancer-free and heading back to school with big plans for his future.
	“I’m thinking of being in the – the medical field and because people don’t realize that life is so precious and, yeah, I’m just thinking that I want to help people later in life.”
	“Grasp every day like it could be your last because a kid going through cancer, it may be their last, but just be positive about things. You know, hug your kid. That’s first and foremost. Just hug them and love them.”
	For the Mayo Clinic News Network, I’m Ian Roth.