Spencer in the Women's and Children's Hospital
July 2023

Why, in 2026, are parents still being told they have limited time left with their child?

My name is Laura Loughead. I'm Spencer's mum. It's been two years since my little boy died, and I still can't make sense of any of it.

Everything was normal before his diagnosis of brain cancer.

Spencer was a cheeky little five-year-old who loved bouncing on his trampoline, and making people laugh with his silly jokes. He was energetic, and so incredibly sweet. The kindest soul.

He was a little brother to Indy, and the two of them were inseparable.

Spencer had only just started school and he loved it. He'd be dressed and ready early, waiting by the door, eager for the car ride and to ask me, countless times, what song was playing. He adored music.

He would often talk about growing up. About the girls at school he loved, Peyton, Octavia, Juliette, Winter and Harmony, and who he was one day going to marry.

Even at five, Spencer knew he wanted to be a dad.

It felt like there was life before that wintery Monday, and a completely different life after. He woke up as a healthy little boy, excitedly getting ready for school and by early evening an ambulance rushed us from Aldinga, lights and sirens to the Women's and Children's Hospital.

I remember feeling calm. I thought it was going to be an illness that a doctor would treat and that everything would be okay.
I really thought Spencer would be fine.
But he wasn't.

We were admitted immediately and taken into the resuscitation room. Spencer was unresponsive. Doctors worked through the night to relieve the pressure building on his brain. Initially, everything was about keeping him alive. We didn't know if he would survive the night, let alone the week ahead.

Sitting on the edge of Spencer's bed the neurosurgeon delivered the diagnosis. Diffuse Intrinsic Pontine Glioma (DIPG), an aggressive brain cancer with no cure. I remember vividly my husband Scott asking how long Spencer would have to live. 'Perhaps a year, maybe less', they said.

I wasn't angry. It was a feeling I have never experienced; complete shock but also so much pain. I can only describe it like I was watching a movie of his life play out in front of me and then having to erase it because I knew it would never happen.

The Palliative care team were introduced to us immediately. It marked the beginning of some of the most difficult conversations. About how Spencer would be cared for at the end of his life, and who we wanted there with him when he passed.

Conversations no parent should ever have.

One minute we were living our normal life with a cheeky, happy little boy who loved music, sport and making people laugh, and the next we were being told to go home and make memories with him.

There was no soft way to hear any of it and, as you can imagine, it was impossible to process. There were so many decisions we never thought we'd have to make.

Decisions about treatment, comfort, what to try, and how we wanted him to be remembered. Impossible decisions.

There was also so much waiting. Waiting in hospital rooms. Waiting for scans. Waiting for results. Waiting to see if something had worked.
Our life became, waiting.

Music was still a big part of his time in hospital. Maybelle, the music therapist would spend time with Spencer, and they wrote a song together. It was a song from the Mario Movie, 'Peaches'. She played their song at his funeral... it felt like a part of him was there with us.

In those weeks in hospital, we were trying to understand what the cancer was doing to him, desperately researching everything we could. It felt like we had to know everything, and it became all-consuming.

We put our complete trust in Spencer's oncologist, Dr Jordan Hansford. He was brilliant, and so down-to-earth. He was honest, he didn't give us false hope, but he was so compassionate in the way he gave us information.

We never told Spencer the exact details, but he knew he was really sick. I could feel his despair. One day he said to me, "I'm a loser mummy. I can't even jump on my trampoline."

That broke my heart.

We had just four months from his cancer diagnosis, to Spencer taking his last breath.

DIPG is cruel. It took everything from us so quickly. Watching what it did to him was devastating. Even now, it still doesn't make sense to me.

In Spencer's last weeks, his room became our whole world. It was filled with his favourite toys - Lego, Spiderman, Star Wars, all the little pieces of life he loved. Indy would sit with him, playing games and building Lego. We were just trying to be together, to find some normality, like how it used to be.

At the same time, Scott and I were managing his pain relief and everything else but trying to still be mum and dad. It was a lot for us to carry, it would be for anyone.

There are so many other kids and families going through this, it's a part of a world we never even knew existed.

Spencer should still be here, bouncing on his trampoline, playing soccer, swimming, and building Lego with his big sister.

We made the decision to donate Spencer's brain tissue to research. If what they learn can help another child, or give another family more time, then that matters.

If the work being done through research can change that conversation, from "go home and make memories" to "you have years" or "there are options", that would change everything. Just one more singalong on the way to school with Spencer would mean so much to me.

I will never be fine. I've learned to live with this because I have to, but I think about him every single day. He had the best little life in his short five years.

Spencer used to talk about when he grew up. About being a dad, about who he was going to marry. He should have had that chance and didn't.

I went from imagining school camps and graduations to just hoping for one more day and while I know this is hard to read, this is the reality for so many families like mine.

When Verity asked me if I would share Spencer's story, I didn't hesitate. Talking about him is all I have left.

During those final months, it was the support around us that got us through. The care, the little things, the moments that made an impossible situation feel even slightly more manageable.

You don't realise how much those things matter until it's your family who needs them.

Thank you for remembering Spencer with me,

♡ Laura