



A survivor's story

From the Australian Cancer Survivorship Centre

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'Some days it was really hard'

Kylie and Matilda Pretty's story as told to Meg Rynderman OAM, a consumer representative with the Australian Cancer Survivorship Centre.

I had wanted to tell a story from the perspective of a parent of a child with cancer; what I encountered on a recent visit to the Pretty home in Geelong was that story and so much more.

Kylie Pretty is the mother of Matilda (Tilly), who at the age of 3½ was diagnosed with acute lymphoblastic leukaemia (ALL). I learned about Kylie's experience as Tilly's carer but also listened to Tilly herself, who is now 18.



Tilly, aged 5 years, 2008

Tilly had been unwell, with seemingly unconnected symptoms, for several months. One Saturday, while Kylie volunteered at the kinder fete, "My husband rang and said, 'Tilly's really not well,' so we took her straight to Emergency at Barwon Health and she had a blood test".

Kylie's description of the emotional chaos of the Emergency department would be familiar to many. "It was Saturday afternoon and there were footy injuries and all these people and there were no spare rooms, so she was on a chair having her blood tests in this hallway. An hour or so later, a doctor came and told us that she had leukaemia and they weren't sure which sort."

After a night in Geelong Hospital, Tilly was transferred to The Royal Children's Hospital (RCH) for a definitive diagnosis then four weeks of intensive chemotherapy.

"In some ways, knowing what was wrong was a bit of a relief because we had gone through the past months thinking, there's something wrong; we don't know what," Kylie said.

"One of us stayed with Tilly all the time and her grandmother and her aunty met us there. A few years earlier Tilly's cousin [Charlotte] had gone through cancer treatment – we had been at the RCH a lot in Charlotte's little life. So, we kind of knew what it was like."

Weekly and then monthly tests, oncologist visits and involvement in a research study followed over a two and a half year period, with early morning trips down the highway from Geelong to Melbourne. "That was a huge day and we'd try to make it fun as much as we could. We'd have nice food and I'd take my dad (Tilly's grandfather) with me or my uncle. Someone would always come with one of us."

Kylie and her husband, Stuey, had a second child, 2-year-old toddler Alice, who also needed their love and attention, "so we tag teamed – one of us would stay with Tilly and the other one would be with Alice, so that she had someone to care for her".

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Children receiving a cancer diagnosis often travel to Melbourne from regional Victoria for treatment. When Tilly was no longer an inpatient at RCH, a shared care arrangement was commenced with Geelong Hospital.

Returning home for treatment elicited conflicting emotions for Kylie. "We weren't that familiar with the Geelong Hospital knowing a lot about cancer treatment. It was early days back then – they were doing some work with children, but I really wished that we lived in Melbourne because I felt really confident with the RCH."

Kylie recalled that her attitude changed with time. "As soon as Tilly had a temperature she needed to be in the hospital ... that was really scary ... but then having had time to be at home and having the confidence to go to the Geelong Hospital, we got to know them really well and that was fantastic. I think every time we'd call the paediatrician, he'd call ahead [to the hospital], and we didn't have to really spend much time in Emergency."

While her mum's recollections were vivid and emotions are still close to the surface, Tilly has vague, disconnected memories of this time. "I feel like I remember being in the hallway waiting to find out. I remember being in an ambulance one time. I definitely do remember, more in Geelong hospital than there [at RCH], always Starlight [Foundation] people would come in, volunteers coming in or the clown doctors, people doing music therapy, a person who played the harp. I remember that a lot, all those people coming in to make it better and easier."

Tilly also remembered gifts from Make-a-Wish. "I really wanted a swing set, I could have asked for anything in the world, but I wanted a swing set and they [Make-a-Wish] surprised me, as well with a trampoline."

Many of the support services for children and families are based in Melbourne, but Kylie was pleased to learn of their reach. "I think that was a bit of a challenge being in Geelong, we sometimes think being in regional there's not as many supports but ... I picked up a flier for Very Special Kids. Peggy was the social worker and she was fantastic. She'd help us and we had a support worker who was a volunteer – Elizabeth would look after the girls if I needed some help."

When Tilly was too sick to go to kindergarten, Kylie recalled, "We got in touch with Challenge [a charity that supports children and families living with cancer]. We went to the playgroup there for a year or so because Tilly was so sick. I suppose at the time it was difficult for her to go to kinder, so we'd drive to Melbourne for the playgroup and take the girls there and we'd go to the market after or go for lunch or Mum would come."

Beginning at school, Camp Quality volunteers performed a puppet show for Tilly's class to teach her classmates about cancer. "The school were all over it – they would have parent support group meetings regularly with us to talk about how Tilly was going. They'd want to know about how Tilly was going medically but also about her educationally. And that continued until pretty much grade 4 or 5 ... then she was able to access some tutoring from Ronald McDonald Learning, which was wonderful."

Kylie explained that, when they were older, the girls went to camps organised by Camp Quality. "The girls went off to their camps and had carers. They were there together and that was really important because it was also about Alice and not just about Tilly being sick."

Tilly remembers feeling and acting like a regular kid. "I didn't really think that I needed everyone to know [about my cancer diagnosis]. As I got older it was something that I never really thought about. I just forgot about it. It was never really on my mind."



Tilly (aged 18 years), Kylie, Stuey and Alice, 2021

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While child-centred cancer organisations were supportive to Tilly and her family, Kylie recalled so many instances where it was the emotional and practical support of family, friends and colleagues that was the most touching.

"I was so overwhelmed, but I got through that with all the support. Friends would drop over a curry and rice and beautiful food." Staff at Kylie's workplace conducted a raffle and gave the family \$1000 in petrol vouchers.

That assistance, together with her relationship with husband Stuey, helped Kylie get through those difficult years. "He's a rock and he's positive and strong. It broke his heart too to see Tilly so sick ... I think we became a pretty good unit together in being able to support each other; we just made it our thing ... and Stuey's work were great as well, they said, 'Take time when you need time'."

Kylie spoke of her faith and how she managed to cope despite being overwhelmed during Tilly's treatment and recovery. "I think asking for help was really important. Some days it was really hard, you'd be hearing about children who hadn't survived and worry that it might be you ... during that time I kind of crashed, I suppose early on it was scary not knowing and not being able to control what was happening. I went to see my doctor and she was really supportive."

Tilly has recently completed the RCH paediatric long-term follow up program. She is pursuing a career in nursing at Australian Catholic University. She reflected on those years, literally a lifetime of check-ups, follow-ups and blood tests.

"I remember when I first had to do those yearly things, they told me 'you'll stop when you're 18' and I was like, 'Oh my gosh, that's so long, I'm going to have to do this forever'; and now I don't have to do them anymore."

Ongoing follow-up care and surveillance with a local GP is key for survivors of childhood cancers. Kylie spoke of the importance of young people being advocates for their own health.

"Tilly has a GP here in Geelong that she has met with for the follow-up, [who] has all of Tilly's information from the RCH and they recommend that the young people continue to do that because they're looking for long term effects as well from the treatment." said Kylie

Kylie explained that her life had changed as a result of Tilly's illness. "It's not about things I've done but it's about being a person that can tell a story and share a story. So, I became the regional representative for the Children's Cancer Centre at RCH ... because what I've been through as a mum has made an impact on how I can relate to other parents who are going through difficult times. I became an advocate because I was passionate about things getting better for regional families."

Sharing a scrapbook full of photos and articles, Kylie explained that Tilly became the face of childhood cancer in Geelong. "We seemed to get asked to have our photo taken a lot for different reasons and we just said yes to all of them. Because we wanted to just provide hope for other families."

Each regards themselves as cancer survivors. Tilly said, "We did this thing called Relay for Life. Every year you get a sash, survivor or carer and I got the survivor one. I think that, even from diagnosis, you are surviving cancer. You haven't passed away yet, so you are surviving. So, I would say I'm a survivor". For Kylie, "I suppose I saw myself more as a carer but, now that I'm thinking about it, yeah, definitely a survivor as well."



Tilly, aged 16 years, 2019

Tilly and Kylie offered advice to families finding themselves in a similar circumstance:



For parents:

- you can't do it on your own
- reach out for support – ask for help
- take time for yourself
- take one day at a time
- eat well – eat!
- exercise



For kids:

- have a good support system
- have people around you
- 'I don't know how anyone could do it alone'

Further information

✚ **Peter MacCallum Cancer Centre**
petermac.org

✚ **Australian Cancer Survivorship Centre**
petermac.org/cancersurvivorship

✚ **Peter Mac information for children, adolescents and young adults** petermac.org/services/cancer-information-resources/children-adolescents-young-adults

✚ **Australian Cancer Survivorship Centre survivor stories** petermac.org/services/cancer-information-resources/survivor-stories

✚ **Royal Children's Hospital information for patients and families**
rch.org.au/rch/patients-families

✚ **Paediatric Integrated Cancer Services**
vics.org.au/pics-about-us

✚ **Cancer Council** 13 11 20

✚ **Cancer Council information for children, teens and young adults** cancervic.org.au/cancer-information/children-teens-and-young-adults

✚ **Barwon Health** barwonhealth.org.au

Support services

✚ **Challenge** challenge.org.au

✚ **ONTrac at Peter Mac:** petermac.org/ontrac

✚ **Very Special Kids** vsk.org.au

✚ **Ronald McDonald Learning**
rmhc.org.au/ronald-mcdonald-learning-program

✚ **Camp Quality** campquality.org.au

✚ **Canteen** canteen.org.au

✚ **Make a Wish** makeawish.org.au

✚ **Starlight Foundation** starlight.org.au

✚ **Relay for Life** facebook.com/RelayforLifeAustralia

✚ **Redkite** redkite.org.au



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