

On behalf of Kat's family I would like to thank you all for coming today to commemorate our Kat's life.

I will honour Kat by telling her story.

Eirini, her Greek name that means peace, was born on the 23rd of April 1984. From her earliest years, her personality was evident. She was bright, energetic, enthusiastic, vivacious, flamboyant and loved to perform. In infant school she would whip off her basketballer's skirt and do a cape dance that delighted Miss Parsons. When she came home from school and all the other kids would play in the backyard in their uniforms, she would appear in orange, purple and leopard print, off the shoulder, split up the leg and accessorised. She could also be very strong willed, which is another, nicer way of saying difficult. But I was proud that she would one day be a leader and a confident, independent woman.

In primary school she had a great circle of friends, but a mild dyslexia affected her confidence. In high school she excelled academically. She loved learning and her teachers loved her. Unfortunately at this new start in life she was not growing properly and needed to have daily, painful injections of growth hormone. Her short stature, delayed maturity and precocious abilities made her a target for bullies at school and there was no group that accepted her. This was a prolonged, wretchedly miserable and heart-breaking period for her. School in Narrabri was no better. Some kids called her Urini, hence her decision to change her name to Katerina. It was then too that she started experiencing vision problems. Investigating this involved a lumbar puncture that was botched, excruciatingly painful and dreadfully traumatic. But even worse than the physical trauma was that she felt that we neglected her emotionally. This physical and emotional trauma came to dominate and cloud the rest of Kat's life, much as she struggled to overcome it. She had only recently been making headway to resolve these issues with the help of Sophia, her cousin and life coach.

In 2000, for senior high school she transferred to Newtown High School of the Performing Arts. She found a good friend and acceptance. She was in her element and began to flourish. She took up saxophone and Tim, her music teacher, became her best friend in the category male. This was the year of the Sydney Olympics and, as a promotion, Newtown Gym was offering a two people for two weeks for free trial. Kat bugged and pushed a very reluctant mother into going with her. The first class we did was conducted by the remarkable Liz Lowasser and we were both hooked. And then came the devastating diagnosis of MS. By the end of 2001, her HSC year, Kat was using a walking frame and unable to sit her exams. Nevertheless, she qualified for Sydney Uni. At her Year 12 graduation, she was awarded the Outstanding Effort in Visual Arts Prize and was given a standing ovation by her form, which raised \$1000 for the MS Society on her behalf.

Kat still struggled along to the gym for longer than was reasonable – me lugging her walking frame up the stairs in stages for her, Liz modifying exercises for her, but, honestly, her commitment and her technique put the rest of us in the class to shame. But that was Kat. She always did her best at anything she was doing. Even when she could no longer go with me, she was very proud of the fact that it was her idea. The gym is a lifelong gift that Kat has given me and she inspires me to maximum effort every class I take.

Kat deferred uni for a year and did a Computer Skills for Business course at TAFE. She also volunteered at the local organic food co-op Alfalfa House. She applied to Centrelink for a mobility allowance but was knocked back twice because she didn't have the "right" combination of education, work and volunteer hours. Kat took her case to the ombudsman, who ruled in her favour. Interestingly, the next

newsletter from Centrelink detailed the new guidelines to qualify for mobility allowance in line with the outcome of her case. She was very proud of taking Centrelink on and winning. She would do this again a few years later and, no surprises, she won then too – that must be some kind of record. I knew that strong will of hers would come in handy.

Living close to Sydney Uni was a lucky break, as Kat was able to drive her electric wheelchair there to go to classes. The Carillon Rd chemist we used at the time would remark about seeing her flying along. She was very striking to catch sight of because she had such perfect posture, always sitting erect, or, to quote my friend Andrew Benson who spotted her coming up to a set of pedestrian lights, she had “chutzpah”.

At Sydney Uni Kat studied history part time, one unit a semester. It was my privilege to be Kat’s reader/writer/researcher for her studies. Having library skills, I was competent in the research department, but having a science degree from decades before and no essay skills whatsoever, as she would often remind me, I was somewhat of a liability. This was Kat’s second big gift to me. I hadn’t studied history in high school and reading for her at uni, I fell in love with the subject. The uncanniest thing was that when it came to selecting courses, and even choosing from say a choice of forty essay topics, we always independently chose the same option. I would hold my breath, wondering what kat’s choice would be, worried if I would cope with something I was not interested in but every time we would be delighted and congratulate each other on our excellent choice.

Unit by unit, Kat’s results improved from credit to distinction, and finally, all high distinctions. However, in early 2008, Kat’s health had deteriorated and reluctantly she discontinued her Bachelor of Arts. In May 2008, her father was checking her bank account and asked if she knew where a \$500 deposit came from. She had no idea. The next day Kat received a letter advising her that she had been awarded the 2007 Walter Reid Memorial Prize. This prize is awarded annually to students enrolled in undergraduate degree courses, including honours, in the Faculty of Arts or the Faculty of Law, and is based on academic merit. I told you she was bright.

No longer at uni, Kat needed a creative outlet and she found Creative Youth Initiative (CYI), and the amazing art teachers Irene and Jane. I worried that, with her poor dexterity, her efforts would embarrass her. Far from it, when the end of year exhibition was mounted, Kat’s works were extraordinary and sold well. I’m still kicking myself for letting some go, but she needed to know that it was not just family that admired and desired her artwork and were willing to pay for it. The second semester of CYI, Kat’s weight plummeted dramatically to 32 kilos. She was at death’s door and was hospitalised and given a PEG tube to deliver a high calorie total diet fluid directly into her stomach. Eating was no longer a pleasure. CYI graciously broke the rules of only two semesters and let her come back to continue her art, for which she had a passion. It was at CYI that Kat met Katy, her best friend: female category, and that Kat started needing full time carers.

No more CYI, Kat was once again proactive in pursuing a creative outlet and found Sydney City Council Pine Street Studios and started pottery. Once again, I was apprehensive about her efforts (you’d think I would have learnt) but she didn’t need to use a potter’s wheel. She made uniquely beautiful hand built pots. When that was no longer an option for her, she was encouraged by Ant, the teacher, to paint pots and she developed her own signature style and palette of colours. Kat’s third gift to me is her beautiful artwork and pottery that we have throughout our home. Many of you also have been gifted one of her pots.

Even this became too hard as her arms lost all function, but in the meanwhile Kat had been writing poetry and because she had a carer and a visitor who had musical backgrounds, she started songwriting. Four of her songs her friends have recorded for her. Just recently, she finished writing a duet with her friend Marc, that one day I would love to hear.

One of Kat's passions has been theatre, ever since her 10th birthday when I took her to see Phantom of the Opera. She was entranced. Over the last decade, Kat and I have made ourselves regulars at many of the "off-Broadway" theatres like Darlo, Seymour Centre, Enmore, Newtown, New Theatre, Sidetrack, Factory, Parade, The Old Fitzroy Hotel and The Comedy Club to mention a few favourites. One year we saw 74 productions – once a week, every Saturday, and many during the Comedy and Fringe festivals. Kat was well-known and loved by the theatre managements, and in three instances was the first to use their wheelchair lift. Where there was no lift, the crew would each take a corner of her manual wheelchair and carry her Queen of Sheba style, or even better do the newlywed lift and carry her to her seat. Kat was treated like royalty and made to feel very special, often meeting the cast. We always booked front row seats and if audience participation was part of the show, she was invariably the unpaid performer. Kat, the theatre was your fourth gift to me. Over the last two years, our visits to the theatre dropped off steeply to none, with so many admissions to hospital and as the pain of getting there and sitting through even a great show increasingly outweighed her enjoyment. In the last month of her life, even lying in bed was too painful, but anything else was worse.

Kat loved company. Many of you will have happy memories of Kat because you brought happiness into her life and I have so much to thank you for that. But in fairness to Kat and for you to understand how courageous and uncomplaining she was, and what her life was like when you weren't there to lighten her load, I'm going to read a poem that we collaborated on a few years ago. Hopefully hearing this you will understand how hugely important was your contribution to her happiness and sense of self-worth.

I stumbled and fell 'til I couldn't walk at all.
My arms got weaker, my right hand a claw.
Going out is all anxiety and doubt,
Never knowing when bladder or bowels will give out.
Did I mention the trouble with my eyes,
Even the familiar I don't recognise.
Exhausted and tired I can't stay awake,
Night time insomnia, trauma I can't shake.
I wake each morning with a curse, groans and tears
For the dreadful realisation that I'm still here.
Though I have good friends that visit and care
Still it's 24/7 pain and fear.

It's not my fault my body's a mess.
It's not my fault I live with MS.

No surprises I don't want this semblance of life
Just regret I was never a mother or wife.
Never finished uni or had a career,
Never danced at parties or got to drink beer.
No boyfriends or lovers, no chance for hangovers,
No driving a car, or life in countries afar.
All those things one takes for granted
All those things that I have wanted

I have had none and so I cry
"I hate my life" – do you understand why?

But I'm hanging on, I'm still here
with my life so lonely and full of despair.
You get one life and though mine is shit
I'm too scared to put an end to it.
It's not so much that I want to die
I want to live, I want to fly.
If wishes could cure
Then I'd have one for sure,
But holding to hope just prolongs the agony
And the pointless question "Why did it have to be me?"
For the pain and frustration you have shared with me
Thanks again and forgive my refrain
It's not my fault my body's a mess
It's not my fault I have MS

So when the time comes please let me go,
Not that there's much left as you well know.
I love you and thank you for the time that we shared.
Remember the good times and the pain I'll be spared.
And if thinking of me makes your life seem the better,
Then I'm happy to do that from the hereafter.

But this is not how you would have experienced Kat because when she was awake and you were around she was funny and wise and compassionate and interested in you. Kat, thank you for this your most precious gift of all – realising what are the important things in life.

Before I pass on to others to tell their stories of Kat, I would like to leave you with one short anecdote, and I'll start in the oh-so-familiar way that Kat always used to preface a story she was about to tell – "oh, it was so funny". So

Oh, it was so funny. Kat had been admitted to hospital and was in emergency in a very confused state. I was extremely concerned because she had not been coherent for hours. Finally, a young male doctor from neurology came down to see her. He took her hand and leant in close and said "Can you tell me your name, sweetie?" Kat looked him over and said, in her best Mae West voice, "My name is Kat, but you can call me Sweetie". That's when I knew she was ok.

Finally, to all Kat's carers, but especially her current carers, Mohamed and Nick, and similarly all her friends, especially Sally, Daniel and Marc, and Leanne who found them for her, and her very special GP Dr Linda Mann, I have nothing but wholehearted gratitude. I would also like to recognise the unconditional support that my colleagues Jenny Parker, Wendy Rafter and Wendy Tuxford have shown me throughout Kat's illness.

Kat, you would ask me "Mum, are you proud of me? Have I done enough?" My darling Kat, I couldn't be prouder. You have done more than enough – I suspect more than most. I owe you so much.

Kat, Eirini, Peace. Peace at last.