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Abstract
A fragile life

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The span of a butterfly’s life is dependent upon season, size and species, but the average length that an adult butterfly will live is a month. Caterpillars in the northern hemisphere tend

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to hatch in the summer whilst their cousins in the south hatch in spring. Drinking flowers, they live in the sun.

The Orchard Swallowtail Butterfly’s adult life is spent floating languidly in the search for nectar. Commonly seen in the gardens of Sydney, it is a ponderous beauty. Those giant wings cloaked in scales of black, red and white don’t move as fast as other butterflies. Their admirers have just enough time to witness their passing.

Like the Orchard Swallowtail, Zoe was a spring baby. At 11:44 in the morning of the 22\textsuperscript{nd} of September 1999, Zoe Emma Crews was born and in the arms of her mother, she enjoyed her first breaths.

In the early hours of the 23\textsuperscript{rd} of October 1999, in the arms of her father, Zoe Emma Crews gave her last.

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In a dusty garden in southern Sydney sits Trudi Crews. Twenty-nine with blonde hair and a wicked sense of humour, she is the “cool aunt” to her three nieces, wife to the equally wicked, curly-haired Matt and mother to Jack, one, and Zoe, 31 days.

Today she is at home. So is Zoe who left hospital a week earlier. She still has her feeding tube; feeding Zoe can take a while. Too much food and her stomach doesn’t cope. For now though, Zoe is happy.

A baby girl like every other and no other, Zoe can never see the sun. One gossamer eyelid is a hammock. It floats, bruised and delicate. The other is a pillow; plump. It tenderly protects her only eye.

Soft damp baby fingers curl under soft damp baby palms. Thumb, index, middle, ring and a pinky. And then just one more.

Around them, the backyard slopes downwards from the bush while bindis, stones and prickly grass fight for space underfoot. The sun is out and Trudi sits with her baby. The two of them, blonde and strawberry-blonde, watch as a big black butterfly makes its way through her garden. Trudi wonders if it is a sign.

Hours pass. There’s something wrong – Zoe’s small limbs, usually knotted and tight now rest easily. They are loose, unfurled. It’s harder for her to breathe. Trudi and Matt ring the doctor.

“You might be going back to the hospital,” the doctor says. They are told to keep an eye on her.

Not one but two sets of eyes rest on the baby as her parents watch over her. She sleeps in an old car seat bassinet to stop her rolling onto her back. A few rooms down her older brother sleeps calmly in his bed, taking in luxuriously deep breaths and the dreams of a one-year-old.

Shadows lengthen and disappear as the night crawls into early morning.

One a.m.

Matt’s parents are called. Matt, Trudi and Zoe need to get to the hospital. Jack sleeps on.

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The clash of organic and inorganic sounds, sights and smells of the St George Hospital emergency room. Zoe’s skin is turning blue. Her lungs.

Then to the Children’s Ward, where a team of nurses and doctors are waiting to save the little girl.

Outside, wind gathers.

Matt, Trudi and Zoe stay in a darkened ward as doctors and nurses come to visit, checking on them. It’s a procession of stethoscopes and sympathy.

One of them gives Zoe an injection, to help her. It’s a helpless situation, but the doctors can make Zoe at least more comfortable.

For her parents, there is no injection.

*****

Patau Syndrome: A well-defined set of congenital defects in humans caused by the presence of an extra chromosome 13. Also called trisomy 13 syndrome or D, trisomy syndrome. The median survival time is 3 days and the incidence is 1/10,000 live births. The condition was first described in 1960 by Klaus Patau and four colleagues.

A Dictionary of Genetics (8th ed.) Oxford University Press

Babies born with Trisomy 13 are rare. A bitter cocktail of terminations, miscarriages and stillbirths take care of the majority of fetuses. In the social media vernacular, these babies are known as angels and princesses. Stillbirths aren’t stillbirths – they are born sleeping.

For the babies that survive, they could live with any combination of:

A cleft palate.
Close-set eyes that may fuse into one.
Poor muscle tone.
Extra digits.
Low set ears.
Small head and brain.
Skeletal abnormalities.
Scoliosis.
Undescended testicle.
Scalp defects (missing skin).
Seizures.
Respiratory difficulty.
Congenital defects.

Of these babies, 10% will meet their first birthday.

Online, they are referred to as miracles, fighters, super iron men, troopers and again, angels. Pictures of powdery pink newborns, babies and sometimes toddlers are posted. Everyone agrees they are beautiful.

But when they die the language changes once more. The word “death,” is missing. Babies are lost. Babies gain their wings. Babies are let go and then send precious gifts, healthy babies,
months or years later. The day of the baby’s death is the angel day. It’s the language of a club that no one wants to join.

*****

In 1999, I was five years old. I had just started school, I had two blonde sisters, an enthusiastic imagination and from September to October, a cousin named Zoe.

When Zoe died, it didn’t make sense. I had drawn pictures of a fairy princess with orange hair, and had written with spikey letters, “Dear Matt and Trudi, I hope Zoe gets better soon, love Lucy.” To me, it didn’t make sense that a baby could die. She’d only been a month old, after all.

*****

The 27th of October 1999, at St Patrick’s Church in Sutherland is a typical spring day. Tucked away from the road, there is shade from the gum trees, while the church itself sits low in the ground, dipping under at points. Birds click and whirr and inside tendrils of sunlight trickle weakly through stained glass windows.

The mourners arrive. Sun bounces off zippers on dresses in red, green, yellow and blue. Others wear black, but not many. A few of the mourners haven’t seen Trudi or Matt for years.

They talk quietly, look up, blink, and swallow. Shake hands, look up, blink, and swallow. Painfully. I stand with my Dad and wonder why everyone is so sad.

Family and friends pour into their aisles. Sniffing, coughing, shuffling and then stillness as Matt and Trudi enter the church. Trudi has Jack’s hand, but the coffin is small; Matt takes Zoe down the aisle alone. It is an echo of another father-daughter tradition.

People rub their eyes. Maybe it’s the springtime pollen.

Mourners shift, sweat sticking to their backs while throats, already constricted continue to swallow desperately. It’s Matt’s turn. He grits his teeth as he places his speech on the lectern. The wood is solid under his palms.

Burying Zoe is the worst thing that will ever happen to Matt.

He takes a breath.

“Firstly, thank you for all coming on this special day. It’s fantastic to be able to gain support off so many friends.”

Matt’s best friend is in London. He wishes he were here.

“Our darling Zoe was born just over a month ago at St George Hospital. She was a special little girl who received wonderful care from our new friends at the hospital who we can’t thank enough. She had beautiful strawberry blonde hair and was as tenacious and stubborn as anyone you would meet.”

When Zoe cried, it was different to other babies; not a bawl - a whimper. He would worry about her when he went to sleep.
The congregation blinks soft smiles of encouragement.

“I’m sure she has taught a lot of people in her short time with us about how precious life and family are and how these simple things that most of us take for granted should be cherished.”

His Nan is here today, but his Pa is not. He died weeks before. Zoe’s health was precarious. Matt couldn’t go to the funeral.

“Trudi and I are disappointed that we only had a short time with our beautiful angel and that we were unable to show her the life experiences we wished. We are comforted, however, that there are some very close friends in heaven that can take on this parenting role for us.”

His voice is starting to splinter. Small shards of it are caught in everyone’s eyes.

“My Pa, Zoe’s Great Pa, can teach her to fish and play snooker,” he continues,

“Trudi’s Pop can teach her to paint.

“Great Pop Crews can make her a rocking horse.

“Harold can teach her how to make and enjoy beer and Laulie can teach her how to have a good laugh, entertain crowds and thoroughly enjoy herself.

“And there is a big bloke up there called Uncle Wally who will take her under his wing and educate her in the finer points of rugby league and the importance of being a fanatical Parramatta supporter and more importantly show her the love and affection on behalf of her Mum, Dad and big brother.”

A crack. His voice is cracking.

“Trudi and I would like to show our gratitude for the support we have received over the past month from all of you, especially our close family and for the love you showed and gave to our little Zoe. Another thank you to our local doctor, Dr. Nair, who supported us and our family as a professional and a friend.”

When Zoe died, he had felt something that was almost relief. She was out of pain. He wasn’t though. Nursing her to sleep was awful. Awful. Awful.

“Finally, to all those kids or those who have kids, the next time you’re in the garden trying to find fairies, if you look close enough, you will see a beautiful fairy with a pink dress and strawberry blonde hair called Zoe.”

He sits down. Voice broken, his heart has too.

*****

Perennially colourful, Woronora Cemetery rebels against its purpose. With a circumference of 2.4km - a route for runners, dog walkers and children on tricycles – native birds show off besides greying tombstones and rabbits dash along names and rusting plaques.

Roses with roots wire upwards and roses without roots surrender to grass that is always slightly damp. Up and over the hill to the west, the cemetery runs into the bush. From here, the
sunset will illuminate the flowering graves, signalling to the caretakers that it’s time to shut the gates.

As the cortege threads through the cemetery, the sun climbs towards midday. This is the last stop before the wake. At the crematorium chapel, they pull up.

Once more, the mourners sit, listening. There are prayers and poems.

It’s not long now.

The tiny coffin with yellow roses, beanie bears and babies breath is taken through to another room. In a few hours, Matt and Trudi will have the ashes. These will be buried in the Rose Garden and in return the couple will hold onto a rose and a white sprig of babies breath that over time will dry. The strawberry blonde thatch of hair they keep will always be soft though.

******

Butterflies, once hatched, do not fly away immediately. They can’t – their wings are damp and undersized. They need to pump them full of hemolymph, blood to a butterfly. Until then, they are completely vulnerable. They will hang upside down, waiting until they are strong enough. Then they will fly away.

The Monarch Butterfly, however, has an advantage. Orange and black with white freckles, they are beautiful. To predators, these colours signal that the butterflies are poisonous. They stay away. The Monarch Butterfly will survive.

******

Simone Payne is the type of friend who will sneak alcohol into a maternity ward for a friend. She’s a midwife – so it’s almost okay.

She has a voice that leans towards laughter and a face that matches. With big eyes and brown hair, she bears a strange resemblance to the babies she delivers.

She and Trudi have been friends since they were five-year-olds at St Patrick’s Primary School. Together they graduated primary school, high school and studied together as nurses at St George Public Hospital. “Best friends” doesn’t even come close.

A few days before Zoe is born, Simone rushes back from Melbourne to Sydney. Her sister, Nicole is pregnant and the doctors think her baby has Trisomy 18, a sister condition to Trisomy 13. Simone has a nasty feeling that something is badly wrong with Nicole’s baby. She’s at her sister’s house when her mobile rings.

“Oh, I just wanted to let you know that Trudi had the baby.” It’s Matt.

An unexpected, unsettling sound. He’s crying. The sound crackles through the phone line.

“What’s wrong?” she asks.

A pause.

“There are a few issues,” he says.
“She only has one eye and she’s blind in it. She has six digits on every limb and they think her brain is really small.” His voice is distorted by distress.

“Matt, I’m in Sydney,” Simone says. “Do you want me to come over?”

“No.”

It’s an odd moment for Simone. She’s deeply concerned, however a strange, loose thought is unspooling in her mind. I’m not Trudi’s true best friend anymore, it says. That’s Matt now. It’s comforting nonetheless; this is how it should be.

Matt’s still talking.
He’s telling Simone that Zoe doesn’t have any reflexes. Her medical training forces unwilling understanding upon her. A gag reflex is the most basic, she thinks. It’s a root reflex.
If you don’t have that you can’t survive.

“It’s really bad,” Matt says.

“I know.”

“Can you ring everyone?”

She just wants to see Trudi.
The friends are called. Two days later she visits Trudi and the baby. Zoe, she thinks, is an old soul.

The next day, Simone returns to St George Public; this time with her platoon of girlfriends. Inside the maternity ward, it sounds warm and feels quiet. The medical staff is busy but unobtrusively so.

“It’s rest period,” a nurse informs them.

“We’re here for Trudi Crews,” Simone says. Authority and kindness all mixed up. She knows what she can get away with.

“Come on in.”

The girls, emboldened by the fact that they have alcohol in a maternity ward, are showed into Trudi’s room.

“I don’t want to see that,” the nurse says – pointing to the champagne, beers and rum.
A few moments later she returns with glasses.

As she leaves, she shuts the door behind, leaving Trudi with her friends. Trudi is tired. So tired. Tests are still being done on Zoe who is living hour by hour. And physically, Trudi just gave birth. But it’s nice to see her friends.

They all have a drink to the birth and a toast to Zoe.

*****

Before becoming a midwife, Simone was a nurse in the Children’s Intensive Care Unit. She did some of her best work there. There is a limit, however, on the number of children’s funerals a person can attend. Simone knew she was too close.

As a midwife, she gets drenched in human emotion daily. There are labouring mothers certain they are dying – they can’t fathom that pain so severe could mean anything other than
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death. There is the terror of the unready and the excitement of those who are. There is grief too. But mostly, it’s a joy that looks bloody, feels sweaty, smells earthy and sounds like a baby.

The luckless few without a healthy baby will have choices. To terminate or carry? C-section or vaginal delivery? Resuscitate or let the baby go?

As a midwife, Simone avoids C-sections for miscarriages or stillbirths if she is able to. A vaginal delivery will leave an emotional scar but a C-section will leave a physical reminder too.

The delivery will also be done with as little sedation as possible, if she can. It helps for the mothers, she says, to feel the physical pain of giving birth. The emotional pain that they’re in is matched by the physical.

It’s also the only time a mother and partner will have with their child.

“Who are we to take that away from them?” Simone asks.

“We don’t want them drugged, we want them to be able to remember.
This is the only time they have with that baby.
The ones that hold their baby, they know that they’ve had a baby.
They’ve held their baby.
They do much better than those that don’t.”

On October 15th, communities remembering their departed babies light candles. The ceremony is known as the Wave of Light.

As 7pm touches the time zones of the 50 states of America, South Africa, the UK, Costa Rica, Canada, Puerto Rico and Australia, candles are lit in parks, homes and cemeteries. They burn for an hour, giving enough time for the next time zone to light theirs.

At the Woronora Cemetery event, I watch from the back. Families and friends move around me, shuffling into seats. They offer wet smiles to one another. They offer them to me too. They must think I’m a young mother.

How strange and sad. I smile back.
There are poems and violins, prayers and doves, balloons and watercolour skies. A man and a woman are a few rows in front of me. His hand is on her shoulder, his arm holding her close. They don’t move, the whole nightlong.

At the end of the ceremony, I meet two women. One blonde and one brunette, both well dressed and both fairly young. They are mothers of children both dead and living.

Melissa is 39 and pregnant. 22 months ago, her daughter Jordan died. Sometimes when her other daughter is sleeping, she is reminded of Jordan. An expression, a shadow or a sound; she’s not sure why, but sometimes she sees them both.

“Our daughter had a true knot in her umbilical cord that she just made herself.” Her words fall out like marbles, smooth and heavy - she doesn’t mind talking about it, as long as she doesn’t have to think about it.

“We couldn’t have picked it up if we’d tried. There’s nothing we could have done.”
Her friend, Doris, 29, is sitting with her. Her baby Alyssia Grace died in May. The doctors don’t know what happened. Neither does she, really.
She looks down, a brown bobbed head. Her voice throbs. “It’s probably the most scary death; to think that you are mourning somebody who you don’t know very well.”
“You don’t know the colour of their eyes, the sound of their voice.”

******

Trudi’s room is peach and beige, gentle and unassuming. Zoe is in the Special Care Nursery. Matt and Jack are at home outside of visiting hours. Her room in the maternity ward is not shared with any other mothers – probably a sensitive decision on St George Public’s part. It’s just her. However, it isn’t completely silent. Just outside is the nurse’s bay. The sounds of medical jargon and occasional personal talk slips in under the door; it’s a language that Trudi understands.

It’s two days since Zoe was born. As Trudi wakes, she wonders if today they’ll find out the diagnosis. Maybe Zoe will make a small improvement. Maybe she’ll have to be resuscitated again. Maybe this will be Zoe’s last day.

The hospital never stops. Doctors, patients and visitors walk by the small white room that Matt and Trudi are taken into. Table and chairs, plain and hard are the only things in the conference room. It’s a fishbowl - windows from the corridors on either side look in. An odd design choice, Trudi thinks.
Her mouth dries and her heart echoes in her stomach as their paediatrician, Dr Scarf closes the door behind them and sits down. He has a kind face and dark hair that is beginning to turn grey. Trudi and Matt look at the doctor. The doctor looks at them and breathes out slowly.
“She’s not going to get any better,” he says.

What’s with these windows, Trudi thinks. Everyone can see right in.
“It’s the full trisomy,” he continues. It’s so cold in this room. There’s no colour.
“What does that mean?” Matt asks.
“We don’t know how long she’s going to live,” says Dr Scarf.

Matt feels his future being flipped inside out and upside down. Things that weren’t meant to be in it are there.
“Oh god.”

“Okay,” Trudi says. “I understand. So what do we do now?”
The doctor’s eyes are wells of sympathy. Trudi looks into them. She has a sick feeling that she knows what he’s about to say.
“Well, we’ve come to the time where you can make the decision if you want her resuscitated or not.”

Oh god.
“We’ve done it a few times now and we will keep resuscitating her, if that’s your choice.”

Trudi’s mind takes her back to her days as a nurse. Medical staff are rushing past. Something is beeping in a room not too far away. She’s sitting on a squeaky leather chair with
families of loved ones in terrible states. They breathe in the processed air and look up at the lights, before she asks them the exact same question.

I can’t believe this is happening, she thinks. To us. Now it’s happening to us.

“Or, we can leave her be. Just see what happens. We would just make sure that she’s as comfortable as she can be.”

The day before, Zoe had stopped breathing again. Sitting in that little room, Matt remembers peering through the window of another room. The doctors are there, pressing hard, listening, looking, lifting and then pressing again. It’s not nice. It’s got to be hurting her tiny body.

Trudi and Matt look at each other, turning over the impossible choice in their minds.

“We won’t resuscitate,” they decide. “If it happens, we’ll let her go.”

“Oh,” says Dr Scarf. He pauses. Looks at them. “A lot of families, at this point, choose to have a priest baptize their child.”

“Oh,” they say. What else are they going to do? They’ll see a priest.

Trudi won’t remember it, but Matt will lose his religion. He can no longer put his faith in a God that put his family through this pain. Now, he doubts if there even is a God.

*****

The priest baths Zoe that day. Seven days later, her father baths her for the first time. Two days after that, it’s her mother’s turn. They both agree; Zoe enjoys it.

The warm water laps around Zoe and Matts hands. Her limbs loosen slightly and she breathes easier in the steamy air.

The soft smell of baby soap floats upwards as Trudi pushes back Zoe’s wet hair. Matt and Trudi look at each other. They were best friends before they were partners. This isn’t going to pull them apart.

The nurses watch the family, smiling. Zoe is doing better than they hoped. Maybe she’ll go home soon.

*****

There is a difference between a cocoon and a chrysalis. Cocoons, woven with the caterpillar’s own silk are reserved for moths. Soft and homely, they look the way “cocoon” sounds. A chrysalis too, looks like the word; glassy and unyielding. They are made out of the caterpillar’s molted skin, smoothed and hardened into a crystal shell. Inside, the pupa is safe.

In the chrysalis, the caterpillar undergoes a radical transformation. It turns liquid. A butterfly elixir. Out of this, the butterfly creates itself. Some butterflies remain in the chrysalis for years; however most will emerge after a few weeks to a month.

The Common Crow Butterfly will stay in chrysalis for about two weeks. At first, it is a cream colour, however, a day after forming, the chrysalis will develop a silver sheen.

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The chrysalis gains lustre, until eventually it looks like a drop of watery gold. It’s not really metallic though. Layer upon layer of transparent skin has created this gloss. Beneath this, the almost butterfly can be seen.

*****

It’s the 16th of June 2001 – two years since Zoe, and Trudi and Matt are back at St George Public. They’re in a delivery suite, Trudi’s giving birth.

The room is hard, shiny and clinical. There’s no music playing, and Trudi wishes she were in the birthing centre. It’s more relaxed there and what she really needs now is to relax. She’s a heavily pregnant bundle of pain and nerves.

Contractions are coming harder and faster, waves that tighten as they move up and down her stomach and back. In the brief moments between the contractions, she wonders if the midwife knows about Zoe. She’s not giving Trudi the reassurance that she is internally begging for. She is just so offhand.

The labour pains intensify and Trudi pushes away her concerns about the midwife and the room. She focuses on her breathing and Matt focuses on her. She has to get this baby out.

She doesn’t cry out but her breathing is hoarse. In, out. In, out. In, out. She can’t think of the pain. In, out. In, out. In, out. Her breaths are deeply husky, bordering on groans. In, out. In, out. In, out. She’s on the ground now, the feel of the unyielding concrete on her palms and shins barely registering. In, out. In, out. In, out.

And then everything that was In is Out.

There’s a shock of curly brown hair and a baby follows. One motion and he’s in her arms. He’s beautiful. He’s going to be Billy. Quiet, serious Billy who will go to school in Burraneer Bay, keep snakes as pets, play rugby league on the weekends and name a blue-tongue lizard ‘Gumboot.’

Matt, in a blaze of euphoria, sees the mass of dark hair – more hair than Jack or even him, and wonders vaguely if Trudi has been too friendly with the milko. But Trudi isn’t ready to celebrate yet. Billy isn’t crying and his lips are purple. Too purple to her nurse’s eyes.

“His lips - is he okay?”

Just be healthy, she thinks. That’s all I want.

“Yes.”

“Is he okay?”

“Is he going to be okay?”

We did all the tests.

“Yes.”

“Is he okay?”

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“He’s fine. He’s fine.”

“But his lips – he’s okay?”

Please.

“He’s okay. He’s healthy.”

“He’s okay.”

“He’s okay.”

He’s okay.

He’s going to be okay.
Zoe going home with Trudi and Matt.