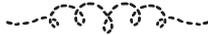


Imagine you have an itch, but your hands  
are too scrunched to scratch it.  
You have something to say, but you  
can't talk, so no-one listens.  
There's nothing you can do.  
You're locked in.  
Like me.  
Ava.



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# chapter one

My sister, Nic, keeps secrets. Big secrets.

Like the talent show.

We should have figured something was up when Nic started bashing away on her drums again. She never used to practise, then suddenly she was at it day and night. But, like everything with Nic, it took us a while to work it out. Dad only solved the puzzle when he saw a list of performers in Nic's school newsletter.

As soon as my driver, Sam, drops me home after school, Mum and Dad bundle me into the car. My heart's thumping on the way there – half-excited, half-worried. Nic's going to spew when she sees us. There's a reason she's kept this a secret.

We stop on the way to get a large strawberry milkshake – to keep me quiet while we watch – and when we get there,

my parents hold me by my elbows to steer me through the crowd. We find seats in the front row, where Mum and Dad perch on chairs either side of me, their faces glued to the stage. They're so excited to see Nic perform it's like they have *Team Nic* signs in their eyes.

Behind us, the hall is jammed with restless high schoolers, grumbling and elbowing each other while they wait. But they turn their attention to the stage when someone steps out from behind the red curtain.

My big sister, Nic.

Despite the death stare she throws us, she looks great in her new sparkly sneakers. I want to cheer for her as she settles in behind the drum kit. If she and Mel win today, they'll make the interschools for sure. Which could lead to the nationals, and Nic's first time on a plane.

Dad holds the straw of my strawberry milkshake while I take a soothing sip. I squeeze my hands together.

*Clench, squeeze, clasp.*

The crowd hushes. Someone's bracelets jingle behind us, and a crow caws outside.

Mel, Nic's best friend, walks onto the stage, her guitar slung around her neck. She smiles a wobbly smile and we're close enough to see her top lip sticking to her braces.

*Clap, clasp, clench.*

Mel stops in front of the drums, and after a quick glance back at Nic, she places her fingers in position on the neck of her guitar.

*Good luck, guys. You'll nail it.*

Nic pretends not to see us as she begins to count: 'Five, six, seven, eight ...'

Mel starts singing. Nic's sticks fly over the drums. I almost forget to breathe. One verse down, now the chorus. Nic reaches for the snare drum. I know exactly how she plays it. I could be up there, playing along. Two beats on the bass drum, then smash on the cymbal—

The crowd starts clapping along.

My clenching hands grow clammy.

*Don't scream, don't scream, don't scream.*

I try to focus on the takeaway cup full of strawberry-flavoured milk, cool against my side. Dad's wedged it between his hip and mine, and my clasping hands means my elbow keeps brushing against the straw.

The second verse is perfect. Another chorus. Mel takes a step to the left, one to the right, then does a small wiggle of her hips. The guitar wails as she belts out the final chorus. The whole crowd is on their feet, clapping and stomping and dancing along.

My chest heaves. *Too loud. TOO LOUD.*

Before I can stop it, my hand jerks out and whacks the milkshake.

*CRASH!*

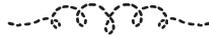
The music stops. Pink milk slides down Mel's cheeks. She's staggering back, almost tripping over her guitar lead, her mouth open with shock.

But that's not the worst of it. My heart plunges as a piercing scream echoes through the hall. Kids cover their ears. Teachers squint to the rafters, looking for the world's biggest cockatoo.

But it isn't a cockatoo.

It's me, Ava.

Nic's biggest secret.



'Nicole, you know Ava didn't do it on purpose,' says Dad later that evening. 'It was a milkshake, not the end of the world.'

We're in the bathroom, where Mum's loading my toothbrush with toothpaste and Dad's helping to hold me up. Nic stands in the doorway, her eyes red and blotchy. Nic never cries. To her, this is the end of the world.

'Come on, love. Ava just got spooked, that's all. No-one will even remember.'

They talk like I'm not in the room. Or like I'm deaf. Which is one thing I'm not. I can't talk, and sometimes I can't swallow, but Rett syndrome hasn't affected my hearing.

*You know I didn't mean it, Nic.*

Rett might have twisted my body, my hands and my fingers, but it hasn't twisted my brain.

*Please, Nic. You understand. Right?*

But Nic doesn't say a word. She stares at her phone, like I hardly exist.

Dad's wide smile usually makes everyone around him feel happy, but he's not smiling now. His lips are straight and his eyes are sad, like he knows he can't fix this. His forehead crinkles as he tries to mend the impossible. 'Nicole, honey,' he soothes, supporting my weight so Mum can tuck the toothbrush into my mouth. 'People can see Ava is different. The kids at school will make allowances for ...'

Nic stares at Dad like he's a squashed toad that's been left in the sun. Mum sees and slide her lips to the left and squeezes them together. Nic calls this Mum's chook-bum face. Her lips grow more and more puckered the longer Dad tries to reason with Nic.

I don't utter a sound. Instead, my hands squish together. My twisted hands aren't much use for anything – they can't press buttons or hold a pen. The only thing Rett fingers can do are curl around each other, pulling palms in close, creating the perfect space to make squishy, farty sounds that fill the room.

*Squish, clap, squish.*

Not a talent I'm proud of.

Nic lifts her head from her phone and glares at my reflection in the bathroom mirror. My mouth's full of foam. A sliver of toothpaste drool hangs from my lips.

Nic's nostril's flare. 'Ava,' she hisses, 'stop it.'

Mum and Dad take a collective breath. I wish I could say sorry, but instead my hands just keep squishing and clasping together.

I was a healthy baby when I was born, but when I turned two and didn't talk and could hardly walk, the doctors said maybe I was developmentally delayed or on the spectrum. But that didn't explain my wobbly legs and clasp hands. Until, after years of specialist appointments and frustrating dead ends, my GP ordered a blood test for a genetic mutation called Rett syndrome. Rett girls are mostly crooked and small for our age. Our muscles don't work properly and we ache when we sit for too long. But that's not the hardest part.

Rett girls like me can't talk.

It's the worst. Not talking makes my head pound. It makes my hands clasp. My face sweat. Not talking is like being trapped underwater. You're screaming for someone, anyone, but no-one can hear a sound.

When scientists in America bred mice with Rett syndrome, they cut up their brains and found the only part that worked normally was the part that controlled the eyeballs.

So now I focus all my energy into my eyes and try to say something like, 'I'm sorry, Nic. I'm sorry I screamed at your talent show.'

But my eyes can't communicate that. By the look on Nic's face, they've said something more like, 'Eat your brussels sprouts.'

I stare down at the bathroom taps. The tag on my pyjamas itches the back of my neck. The bathroom light hums, and outside a bored dog yaps.

‘Ava would love to talk,’ says Mum – more to Dad than to Nic. ‘She’d ...’

Too late. Nic has stormed down the hallway and slammed her bedroom door, which sounds like a train hitting bricks.

Then everything’s quiet again.

Dad pats my back. ‘Don’t worry. She’ll come good; she always does.’

Mum wipes my chin clean of toothpaste and holds a glass of water to my lips.

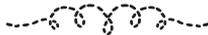
*Squish, clasp, squish.*

Will she, though? Will Nic ever forgive me? My shoulders droop. The sharp, minty smell of toothpaste makes me feel sick.

‘Come on, you,’ says Mum. ‘Don’t give it another thought.’

Mum and Dad help me into bed, where I lie down. My pillowcase fabric is soft and it’s good to take the weight off my aching back. But my iPod speakers buzz and my stomach clenches.

*Next time I’ll do better, Nic. I promise.*



I lie in bed, listening to Nic on her phone in the hallway. ‘Yeah, exactly,’ she says. ‘I literally could have, like ... What? Yeah. Mel, I know. Tell me about it.’

Mel and Nic talk about boys and music and movies and everything else that matters when you’re nearly fourteen.

*Imagine what we could talk about, Nic!*

There's silence for a moment. I look at the animal pictures Mum's stuck up for me on the walls, listening to Nic's uggies scuff against the floorboards as she heads down the hall. Then she's in the kitchen; I can hear her clicking the pens by the fruit bowl. 'Want to come over this weekend? Yeah, awesome. And Bella? Yeah, good, okay. Pizza? Movies ...?' The pens click again. There's a sigh, then, 'Huh? No, of course not. I'll get Mum to take her out.'

That's me she's talking about. Me, who lives here too.

*Can't I stay home and watch movies with you, Nic?*

I already know what they'll choose: anything with singing or dancing. I like musicals too, but Mum and Dad still choose *Finding Nemo* and *Surf's Up* for me, even though I'm almost twelve.

'Okay, cool. I'll text the others. Bring your straightener?'

Nic's curls jump out of her head like springs from a mattress. Luckily Mel is the champion of hairstyles, and whenever she comes over Nic's bedroom ends up looking like a beauty salon. Nic's hair goes from crimped to flipped-out to beachy, the styles changing as often as the costumes in their favourite movies. Sometimes Mel offers to do my hair, too, but Nic tells her, 'No, Ava doesn't like people playing with her hair.'

I sigh. It's not Nic's fault she can't understand me, but that doesn't make it better.

*Maybe one day, Nic, we'll hang out like other sisters do.*

## chapter two

The next day's a school day, so everything's a rush. I'm in the shower, with Dad standing at the shower door, holding my hands to make sure I don't slip, while Mum reaches past him to wash my hair. The rose shampoo tastes like perfume. The groaning pipes fry my ears. The smell of wet skin, the stinging water ...

I squeeze my eyes tight.

*Don't scream, don't scream, don't scream.*

Mum and Dad are soaked by the time they help me out. The towel scrapes like sandpaper and my arms hurt as Mum pulls them through the sleeves of my school shirt.

*Don't scream, don't scream, don't scream.*

I try to concentrate hard on the bird pictures in our

bathroom – animals in my bedroom, birds in the bathroom – and I clamp my lips together.

*Don't scream.*

I shove my fist into my mouth. But it doesn't work. A massive scream bounces off the bathroom walls. Mum ignores it, tugging up the legs of my track pants while I hang on tight to Dad's hands. Once my pants are on, Dad sits me on a nearby stool to finish dressing me, while Mum goes to get my breakfast ready.

'I know, I know. You're hungry,' Dad says.

*No! I'm NOT hungry.*

Suddenly I'm like a toddler having a meltdown in the supermarket. I don't mean to lash out. It's just ... sometimes the frustration is so strong my arms and legs do things I'm not expecting.

'Mum will get your brekkie soon,' Dad says gently, catching my arms as they try to hit him, 'and then we'll get you off to school.' He scrunches up his nose and pulls a funny face.

I don't smile. It's not about brekkie. It's not even about the shower.

*I don't want to go to school.*

But Dad doesn't understand. He starts singing silly songs as he pushes a sneaker onto my left foot. 'Nobody loves me, everybody hates me, I'm going to eat some worms,' he warbles. 'Fat ones, skinny ones, little bitty itty ones ...'

Dad can't sing. Not for nuts. But I don't laugh. Not today.

My regular teacher, Hayley, left to have a baby last term, and the stand-in teacher doesn't understand me.

*I don't want to go to school.*

Dad changes his cheery tune. 'This old man, he played one, he played ... Hey!'

I've kicked. Hard. My sneaker's gone flying across the room. But Dad's practised at not reacting, and keeps singing. 'He played knick-knack on my drum ...' He calmly pushes the other sneaker onto my right foot.

*Don't make me go to school, Dad. Have you even seen the time-out room? It's the worst place in the school.*

He's lacing my shoes up while I try to headbutt him, but he knows how to avoid me, and finally both shoes are on. He's half-humming another silly song as he leads me to the kitchen, and part of me wishes he'd just shout. If he and Mum slammed doors and yelled like Nic, then maybe I could yell back, and then we'd be even. But when they're being nice and patient, it just makes me feel worse.

*Sorry, Mum. Sorry, Dad.*

Mum's already got my toast on a plate when Dad helps me onto a chair. 'Hey, Ava,' Mum says. 'Vegemite or peanut butter?'

Funny how she always asks.

*Jam, please.*

But she spreads my toast with Vegemite. Like always.

Part of Rett is that my muscles, even my swallowing muscles, are weak. When I can't swallow my food, I

choke – a lot – so Mum and Dad take turns to watch me while I eat.

It's Mum's turn now, while Dad has a shower, and this morning I try extra hard to swallow without choking. There's enough tension in the house today.

'Nicole, we're leaving in ten minutes,' Mum yells down the hallway. 'We need to go as soon as Ava's taxi arrives.'

Nic finally wanders into the kitchen, yawning as she texts. Her hair's unbrushed and she's got on a crumpled school shirt.

'Looking a little sloppy there, Nic,' Mum says. 'Didn't Dad just do the ironing?'

Nic glares at me from under her curls. 'Why don't you talk to Ava about being sloppy?' she mutters.

I don't have to look to know my dribble is making wet patches down the front of my red school shirt.

'What's up?' Dad's fresh and clean, wearing his black *Air-Conditioning Solutions* work shirt, and smelling of tangy men's deodorant.

Mum points to Nic and raises her brows.

'Do your mother a favour,' Dad says. 'There's an ironed uniform in the laundry.'

Nic pulls a face, but disappears down the hall.

'Thanks, hon,' Mum says, running a hand through her hair. 'I'm not in the mood for drama. I'm sending those plans off for the Byron houses this morning ...' She pauses while Dad kisses the top of my head. 'Goodness knows how

many hours I've spent on them. I'll be glad to see them go.'

While Dad spends his days fixing people's air con, Mum designs fancy houses. When they couldn't get me after-school care, they asked our neighbour Henry to help build an office in our garage, making a space for Mum's desk and printer where the lawn mower used to be. Mum designs all sorts of new buildings in her garage office while I'm at school, so someone's always here when I get home.

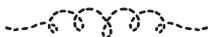
'And they'll be brilliant,' says Dad. 'As always. Have a good day, guys. Bye, Ava.'

*Bye, Dad.*

Dad's work ute roars off just as Nic reappears in the kitchen. She's wearing the ironed uniform and her hair's been pulled back into a messy bun with two long strands hanging around her face, like she just got out of bed. Perhaps that's the look she's going for.

Mum doesn't comment on the hairdo. 'Hurry, honey, go get your bag. The taxi's nearly here.' Mum grabs her car keys and handbag, and helps me into my wheelchair just as my maxi taxi pulls into the driveway.

'Perfect timing,' Mum says as she steers me towards the taxi's lowered wheelchair ramp. 'Morning, Sam. Thank you. See you, Ava.'



The kids in my school arrive either by bus or by taxi, so the parents have no way of finding out how deadly boring

school is. I tried taking the bus, but the smell of the diesel fumes and the thud of the engine made me vomit. Now Sam comes to drive me, taking me in my wheelchair and loading me via his special ramp. While Mum and Dad only use my chair when it's too far for me to walk, the teachers at school are worried I'll fall, so they keep me firmly strapped in at all times.

'How's it going, porcupine?' Sam asks. 'Another day in paradise?'

*I wish.*

Sam ran a kebab bar back in Greece, but here in Australia he's an approved taxi driver for people with a disability. I'm glad he's my driver. He sings along to 70s music in his cab, and unlike Dad, Sam's singing is pretty good. But I don't care about singing today. I need to talk about Nic, and how I'm sorry that I screamed at her concert. And about Mum and Dad, and how hard it is for them to look after me.

But of course I can't. When Sam looks in the rear-vision mirror, he sees what he always sees: a crumpled, twisted kid with a head that struggles to stay upright. He sees hands that won't stop clasping, and long threads of drool staining a red school shirt. So Sam keeps driving, tapping his fingers to the music and complaining about the traffic. Like he does every school day. Like absolutely nothing is wrong.

Except absolutely everything is.

By the time we get to school, my lungs are heaving and

my vocal cords are primed. If I can't talk, then I'll scream. Scream and scream and scream the whole place down.

But then I spy Wendy, our stand-in teacher, at the gates. She has short, army-style hair and stands with her hands on her hips, making the muscles on her arms pop out.

*Sergeant Major Wendy.*

Her voice punches over the throb of buses waiting to unload. 'I'll take Ava,' she bellows as Sam lowers me down on his ramp.

My stomach swirls.

*Squish, clap, clench.*

*I don't want you to be our teacher. I want Hayley back.*

But I'm helpless in my wheelchair – the classic sitting duck. If only I could unclasp my hands and wheel myself away.

*That's not going to happen.*

Instead, I grimace on the inside as Wendy marches my chair down to our classroom.

Brandon's pacing the floor when we get there, his sound-cancelling headphones firmly on his ears. He flaps his hands in front of his face, like his tongue is on fire, while Derek sits at his desk, saying, 'Yes, please' to everything. Freya's white-blue eyes just stare blankly at the ceiling.

No-one's in the time-out room. Not yet.

'Sit down, thank you, Brandon,' says Wendy, her voice too loud. Our classroom is a jumble of pictures and crazy

paintings, with anything breakable placed up high. The lights are too bright, the carpet too swirly, and the air too thick with the smell of antibacterial wipes.

Wendy locks the classroom door so Brandon can't escape, and then sits on a small stool with wheels, skidding over to show us each a laminated card. The stool's wheels roll like thunder over the lino.

The first card has a black-and-white picture of a stick-figure person waving their hand. It looks sort of like the 'men' or 'women' symbols you see on toilet doors, except instead of the person having their two arms stuck out straight, one hand is raised and waving.

'Hello!' belts out Wendy. 'Hello, everyone. What do you say, Brandon?'

Brandon takes the card and gives it back to her.

'That's right, Brandon. Hello.' Wendy gives him a lolly.

'Yes, please,' says Derek.

The cards are coming closer. My twisted fingers won't unclench.

'How about you, Ava? Hello, Ava. How are you today? Happy?' She's showing me a card with a yellow smiley face. Wendy's morning coffee is stale on her breath. 'Use your words. Ha-ppy, Ava?' repeats Wendy, pushing the card close to my face.

*I'm not blind.*

Hayley, our regular teacher, understood that I couldn't unclasp my hands. She never made me pick up things,

and would talk in a quiet singsong voice. Hayley tried different ways of helping me, even borrowing a Dynavox, a heavy white box with a screen showing lots of symbols. She spent ages loading the Dynavox with different pictures and pages, but the screen needed to be pressed, something my twisted fingers couldn't do.

So Hayley returned it, and told me not to worry. She said that one day there'd be a better way, but in the meantime we'd just have to make do.

But Wendy's nothing like Hayley. She doesn't understand about my useless hands. She keeps shoving the card closer and closer. My arms throb – I can't move them. A strangled scream escapes.

'I see. In one of our moods today, are we?' barks Wendy. 'Let's try Derek. Good morning, Derek. How are you?' She waves the 'happy' card in front of Derek. He grabs it and gives it back to her. 'Yes, please,' he says.

Wendy erupts. 'Well done, Derek. Good talking, Derek!' She pushes a lolly into his outstretched hand, and keeps going around our group.

Everyone except me gets a lolly.

We move on to a storytime session, with lots more card-waving and squealing from Wendy.

None of the cards show anything I want to say. Who cares what colour the lion is in the *Dear Zoo* book? Who cares where the monkey is? I, for one, want a proper book, not one for toddlers. And two, I need proper cards that say

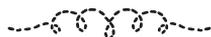
useful things like, ‘Nic, I wish I were a better sister’ and ‘Mum and Dad, I’m sorry I’m so much work’.

But cards like that don’t exist.

*Don’t scream, don’t scream, don’t scream.*

I don’t want to go in the time-out room. So, instead, I sag in my chair, hot tears welling in my eyes.

*I’ll never be able to say what I want to say.*



After school that afternoon, Nic tells Mum that she’s organised a sleepover for the weekend. Mum’s only half-listening, concentrating on reading my communication book from school.

‘Mum!’ Nic repeats. ‘Can Ava go to Henry’s on the weekend?’

Our neighbour Henry and his wife used to look after me when Mum and Dad got stuck. But Henry’s wife died a few months ago, and Henry’s too frail to care for me on his own.

Mum’s frowning at something Wendy’s written in my communication book, presumably about the cards and me not participating in class.

‘Mum?’

Mum sighs and closes the book. ‘Nic, Ava’s your sister. Your friends can still come over while she’s home.’

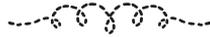
Nic rolls her eyes. ‘Yeah right,’ she mutters.

‘How about Dad and I feed Ava dinner while you and

your friends watch a movie?’ Mum suggests. ‘We’ll be out of your way and by the time you’re done, she’ll be all tucked up in bed.’

*Bedtime straight after dinner? I’m not five, Mum!*

Nic agrees and the sleepover is on.



The following Saturday, I watch all of *Happy Feet*, and then *Finding Nemo*, while Mum and Dad prepare the house for Nic’s friends. I’ve watched each of these movies at least a thousand times, but it’s not like I can sit Mum and Dad down and say, ‘Stop treating me like a baby.’

Mel’s been Nic’s best friend forever, so she knows about me, but Nic’s invited two other girls and is eager to impress them. She wants any sign of me to be hidden – every surface wiped and disinfected in case I’ve dribbled on it.

*I’m not contagious.*

When the *Finding Nemo* credits roll, Dad comes in and turns off the TV. He smells vaguely of bleach and he’s holding a bottle of Windex and a dirty rag. ‘You have to be good tonight, okay? Your sister ... well ... you know how she is lately.’

I’d nod if I could, but I can’t. Instead, I will myself to behave. *I won’t let you down, Nic. Not this time, I promise.*