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All for Jane

Six-year-old Jane Kohne loves Peppa Pig and going down slides but as she ages, a devastating form of childhood dementia is robbing her of her mobility and her words. The Tallangatta girl suffers from the rare Sanfilippo Syndrome. Already, she can no longer climb the ladder to her slide and some days, walking makes her so exhausted she will fall to her knees. Soon she'll transition to a wheelchair. Despite the cruelty of their little girl's reality, and her progressive deterioration, mum Jill and dad Andrew say there is no looking back. They live for each day, and each day's mission is to bring as much joy into Jane's life as they possibly can.

SOPHIE BOYD report,
more **JAMES WILTSHIRE**
pictures: **WEEKENDER**

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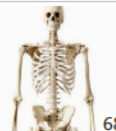
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weekender.



TRUE LOVE: Jill Kohne, with her daughters Annika, 3, and Jane, 6, who has Sanfilippo Syndrome. Picture: JAMES WILTSHIRE

HOPE FOR JANE

Six-year-old Jane Kohne has a heartbreaking form of childhood dementia.

Slowly the disease will rob her of her movement, words and eventually her life.

Her mother Jill spoke to SOPHIE BOYD about her darling girl. P32-33

COVER STORY

weekender.

FREE: Tallangatta's Jane Kohne loves exploring outdoors, but slowly her mobility is deteriorating.
Picture: JAMES WILTSHIRE



LOVE IS IN THE SMALL THINGS

Jill Kohne had never heard of childhood dementia until her daughter Jane was diagnosed with the heartbreaking condition that's slowly robbing her of her words and movement. SOPHIE BOYD reports.

AT SIX years of age, the world should be expanding and opening up to Jane Kohne.

But Jane's world is getting smaller. Her development is going backwards.

The Tallangatta girl who loves Peppa Pig and her pet dog Alli, has an extremely rare form of childhood dementia called Sanfilippo Syndrome-B which affects her central nervous system.

The condition causes progressive fatal brain damage. There is no treatment or cure.

Already Jane's mobility has deteriorated. Some days she can no longer dance along to songs by her favourite Wiggle, Emma.

The few words she once knew are mostly all gone and soon she will transition to a wheelchair.

About three years ago, Jill Kohne received

a diagnosis no parent wants. She felt sick.

The prognosis was devastating, children with Sanfilippo Syndrome have a life expectancy of just 12 to 20 years.

But having a diagnosis meant Jill and her husband Andrew finally knew what they were dealing with.

Ever since they've had one goal - to appreciate every moment with their darling Jane.

"Even though things are really, really tough... if we can just make every day really nice for Jane, or part of each day, I think we've done our jobs," Jill said.

"I do often think she's six years old, she could be halfway through her life... but I don't focus on it.

"I'm very mindful that we could have her taken away from us at any point.

"I've found you just need to live for today. "It's those little things, if she wants to sit

on my knee and give me a cuddle or she wants me to sing a song in the morning and I'm running late for work, I really don't care.

"It makes you really appreciate her for who she really is... if she's happy, I'm happy."

Finding out Jane had a genetic illness was made all the tougher because Jill and her husband Andrew had been desperately trying for another baby after the heartbreaking stillbirth of their son, Harry.

Sitting in the doctor's office after Jane's diagnosis, the physicians started to talk about family planning, Jill's heart sank.

The doctors said both Jill and Andrew possessed a recessive gene which meant any future children they had could also have Sanfilippo Syndrome.

"I thought I was pregnant and four days later we confirmed it," she said.

"It was really tough, you've got this devastating news about one child, you've already had a still born at 36 weeks - full term...

"I had a lot of mixed emotions about being pregnant again."

Luckily, nine months later baby Annika Kohne, now 3, was born happy and healthy, without Sanfilippo Syndrome.

Annika adores her older sister, but is too young to understand the difficulties Jane faces.

"She knows Jane is sick, we've said she's sick, but she just keeps saying we'll take her to the doctor and he'll give her some medicine," Jill said.

"How do we explain it to her? We can't do it. It's just going to be with time."

Little Annika is full of empathy and if Jane starts screaming because she can't communicate her needs, Annika tells her mum Jane is sad. For Jill it's agonising seeing her happy girl upset and unable to say why.

"It must be really tough and must be really frustrating for her not being able to express what she needs," Jill said.

"When she's happy she beams the world but when she's not OK we all know about it. It could be something as simple as she wants a drink and it's a zero to 10 meltdown if we don't get it to her quick enough.

"She just can't indicate that she would like a drink or she's thirsty or she's hungry."

Jane loves being outdoors, staring at the hills around their Tallangatta home, and watching cars drive past.

weekender.



She likes Peppa Pig and kicking balls along as she walks.

"She loves the Wiggles, the Wiggles are our saviour at 3am in the morning when she's not sleeping," Jill laughs.

Sadly, as she ages and loses mobility many of Jane's favourite activities have become too hard. Some days she has trouble walking and her hands have curled.

"She used to be able to draw the dog, she'd be able to hold a pen or a pencil whereas now she wouldn't be able to," Jill said.

"Her favourite thing was going on the slide, but she can't even climb up the stairs to the slide anymore because she hasn't got the strength in her hands.

"I don't think she misses out because she doesn't know now."

Jane, who attends Belvoir School, is also completely deaf in one ear and has limited hearing in the other. Over the years Jill has embraced sign language and picture boards to allow Jane to communicate.

But as Jane's strength has waned she's lost the ability to lift the velcro pictures off the board so the family are looking to explore eye gaze technology.



ABOVE: Jane Kohne, 6, riding her bike with the help of mum Jill and little sister Annika, 3, while dogs, Suzie and Alli watch on.

LEFT: Four days after finding out her daughter Jane had a rare genetic condition, Jill Kohne found out she was pregnant with Annika, 3. **Pictures: JAMES WILTSHIRE**

BELOW: Jane Kohne with mum Jill. Jill says Jane's diagnosis allowed her to focus on the little things.



"We don't worry about where we've been, we just worry about where we're going," Jill said.

From the time Jane was born Jill sensed something was different about her girl.

"She used to snore really, really loudly as a newborn, I thought it was extremely odd," Jill said. "She'd snore louder than her dad."

Jane had three older children and knew the usual developmental milestones.

When Jane was 2, Jill became deeply concerned because her vocabulary wasn't growing and she rarely strung two words together.

"She would only ever retain about 10 words," Jill said.

"The words she'd already learnt she'd forget when she'd learn a new one."

Jill began pushing for a diagnosis and luckily, Jane's paediatrician went to university with a Mucopolysaccharidosis doctor and thought to screen for the rare syndrome.

Without that stroke of coincidence Jill isn't sure they ever would have gotten a correct diagnosis.

"How do they know where to start looking?," Jill said.

For Jill and Andrew the world of missing enzymes, metabolic diseases, facial dysmorphism and childhood dementia was uncharted territory.

"It's taken lots and lots of time, just time," Jill said. "We're never going to get over it."

"At first it's shocking, it's distressing. How on earth are we going to get through this - how is my child? What is it going to do to our family?"

"You've got all these emotions but I think you get to a spot where you just think 'OK, this is what we've got'."

"I'm glad we've got a diagnosis because many kids probably go undiagnosed." Jill has begun a Hope for Jane Facebook page and campaign to raise awareness of the rare condition in the hope it may help others get an early diagnosis.

She also wants to raise money for research into the extremely rare disease.

Jill isn't sure a cure is likely in Jane's lifetime, but she's hopeful a treatment could be found to improve Jane's quality of life.

For now, she's focusing on the little things, the good times, and making every day count for her smiling girl.