

## When the time comes

April 4, 2004

Jay will be four in May, a little fellow on the go, and no idea how he has sustained his parents. He doesn't remember his sister dying two years ago, but he knows her from her photos. Michelle is having a baby in September, she always wanted three kids. She never lets her face drop when she talks, always a shine in her eyes, something like defiance. Her husband Paul wanted to pray throughout the crisis with Jessica, and some people came around to pray, and Michelle thought it was very nice but she didn't see the point. Whatever hope she carried, it wasn't for a cure. Paul kept holding out "for a glimmer".

Paul doesn't talk a lot about it now, the horror, the anger; a lasting trace on his face. They've known each other since they were 17. Paul and Michelle Sutherland. They talk about Jessica — "Jessica" — when she was alive, about the mostly wonderful life she made out of her three years. "But we never sit down and say 'I really miss her today'. There's an unwritten rule that we don't talk about how we're feeling."

Michelle doesn't believe in a god, although she had made an urgent prayer early on, but no more, when she asked the doctor if Jessica would die and he had tears in his eyes when he nodded. Still, she believes in "psychic" events and she's remembered so many things that seem "spooky" and "strange". Michelle says she's the sort of person who reads meaning into things.

"Jessie didn't like playing in the sand pit, she liked it indoors, and didn't like getting her hands dirty. There was a hanging bridge at the park and Jay would try to run over it but Jessica got down and crawled across it. She was petrified of cars. When we crossed the road, she held up her hand like a stop sign. And she was really scared of the birds that came outside her window; shiny black crows."

When I make a face she says, "I know. The bird of death".

"Jessie didn't know what death was. She'd never had a dead pet. I told her she had a tumour in her head that was making her sick. I tried to be direct."

- Michelle Sutherland, Jessica's mother

She remembers, one day in September 2001. Jessica just toilet trained and was proud of it; they were in the bathroom and she said to her mother: "Don't worry Mummy. You'll always have Jay."

Michelle says now: "You just wonder if it's all related. I don't lose sleep worrying about it. I just think about it how it was so strange. It was like she knew she wouldn't be here forever."

Strange also, she says, it was just a few weeks later, Michelle's birthday, October 26, and she'd taken Jay to the doctor for his 18-month vaccination. By the way, she asked the doctor to check out Jessica's ears. She'd been lurching a little, walking as if drunk. Michelle thought her shoes were too small, but why not check her out, anyway?

Catherine Bauld, psychologist at the Royal Children's Hospital, left, and Dr Jenny Hynson, paediatric consultant to the Victorian Paediatric Palliative Care Program.

*Pictures: Wayne Taylor*

The GP didn't bother with Jessica's ears. Instead she started making phone calls, and then told Michelle that she needed to take Jessica to see a neurologist straight away, there was an appointment at Monash at 1pm. Michelle tried to laugh it off, to wait for a couple of weeks, saying "she's all right".

It was on the drive to the neurologist that Michelle prayed her single prayer: "Oh God, let it be all right."

The neurologist asked Jessica to touch her nose. Instead she touched the wall. He then asked if she'd eaten, because he wanted her to have an MRI (magnetic resonance imaging scan) and she'd need to be sedated for it. In the end, it couldn't be done for another four days.

"Do you know what we're looking for?" he asked Michelle.

"Yes," she said. "You're looking for a tumour." And then she said, "She's fine. Look at her. She's fine." Jessica was stumbling by then. In the car on the way home she told her husband on the phone. "She's going to be fine," she told him.

Over the next few days, Jessica stopped walking, her face was dropping, her eye was turning, and at one point Michelle thought she'd had a stroke. She went to hospital overnight but nothing was discerned. Michelle dreamt the girl had five tumours down her spine. Her dream wasn't far off the mark.

Tuesday, October 30, the scan took an hour, and they saw a group of doctors coming down to talk to them. "I thought, 'This can't be good.'" They all went to a little room where Michelle and Paul were told that there was a tumour on Jessica's brain stem, which controls the autonomic functions — breathing and the beating heart, the central nervous system — and they couldn't get all of it out. That's when Michelle asked, "Is she going to die?"

That's when the doctor looked at her with tears in his eyes and nodded. "He said, 'It's all about quality of life now.' I can't remember what else was said. I went down and called my mother."

Three days later the surgeons worked on Jessica for nine hours, not to cure her, but to buy time and relieve her suffering, by taking pressure off her spine that was causing her to thrash around, bruising her legs and her mother's legs. "Without the surgery, she would have been dead within a couple of weeks. They hadn't given us a time, just a guess of eight to 12 weeks. She lasted four and a half months."

Home from the hospital, Jessica moved into her parents' bedroom. "Paul brought in Jessie's bed, and put it next to our double one. It was like one big king-size bed. He slept in Jessie's bed with his legs dangling over the end and Jessie was in the middle, holding my hand. If our hands came apart, we'd find each other straight away."

Six days after the operation, Carol Quayle, social worker with the Victorian Paediatric Palliative Care Program, called and suggested palliative care for Jessie. "I said no way," says Michelle. She had dreadful visions of her daughter drugged and stuck somewhere gloomy. Instead she found it meant that she could care for Jessica at home, and if Michelle and Paul wanted it, Jessica could die there too. The nurse, the counsellor, the music therapist all befriended the family on their weekly visits, especially the nurse.

"She wanted to be friends with Jessica, so if she had to give her a needle or something, it was from someone that she knew."

Michelle was thinking about death then. It scared her, the mystery of it. "It was the palliative care nurse, Paula, who gave me the confidence to look at it head on. I'd wanted Jessica to go to Very Special Kids (a child's hospice and respite home in Malvern) to die. I didn't want her to die in my bedroom. The palliative worker told me, 'She's going to be everywhere'."

"Jessie didn't know what death was. She'd never had a dead pet. I told her she had a tumour in her head and that it was making her sick. I tried to be direct."

"Paul wasn't talking then. I was talking about funerals but he didn't want to know about it. He was looking for something to give him hope. Our GP told me that grief does stupid things to people. You have to leave each other to grieve in your own way."

So Michelle, soon after learning that Jessica was dying, started thinking about funerals, whether to go for a cremation or a burial. One night there was a thunderstorm and she made her decision. With the sound of rain falling and the crash and the brightness she decided she didn't want Jessie lying out there alone on such a night, that she wanted her home, and that's where she is now. "In my knicker drawer. She always went through my drawers. We can't have her out on show."

The four and a half months passed with a sponsored holiday to Movie World and Jessica hating her wheelchair and losing her hair to two rounds of chemotherapy, and no longer able to stand up or talk and then by the end of January no longer able to sit up, and then eating became too hard and so there came the feeding tube, and all she could do was lie propped up on the couch and watch her favourite video, Winnie the Pooh, with her little brother Jay chatting cheerfully in her ear. Sometimes she raised her arms and giggled but that faded too, and all that remained was her smile and her pale skinny legs; looking like an old lady then.

She spent a lot of her time in her mother's arms, her father's arms, and friends came around with meals and it was Paul's job to keep Jay in his routine because Michelle forgot everything but Jessica, that's where she kept her eyes. Some weeks before the end, Michelle and Paul both told Jessica that it was all right to let go. Did she know what they were saying? "I hope to think so, that she did know."

Four days before she died — and she hadn't moved at all for a week and a half, the smile barely there now — friends came over for fish and chips and Jessica was looking a bit sweaty and blue under the eyes. "I put her in the bath, with Jay. She stopped breathing. She turned purple and blue all over and I said, 'Not here like this Jessie'. And she started breathing again. Her eyes were fixed on mine. It was like she was telling me not to let her go."

Michelle knew it was coming. That night, Jessie began having Cheyne-Stokes respiration, where a person stops breathing for some time, only to wake up with a desperate gasping. It's where the expression "croaking" comes from. "I didn't want her to die in her sleep. I didn't want to wake up and feel I'd missed saying goodbye."

Saturday, March 2, she stopped breathing and looked peaceful and they thought she'd gone for good. Paul came in and said her name and she gasped and started breathing again.

On the Sunday, March 3, some friends and family came over. "Suddenly Mum said goodbye to Jess and said she was leaving. She had a feeling of Jessie being crowded." The friends departed soon after, and Paula the palliative nurse arrived. Michelle had been keeping her informed.

Michelle couldn't figure it out, why Jess was holding on. Paul came in and started talking to her about the old house, the life before she got sick. He talked to her about how she'd ridden on his knee in the car as he'd driven into the driveway.

Says Michelle: "We'd been talking all the time about her life since she'd become ill and not before. It was like she was waiting to hear more about her life so she could fill in the missing pieces, because as Paul talked to her her breathing changed, it slowed down and relaxed, and became more peaceful. We could hear her voice in her breath."

The nurse came in, took her pulse and said, "It's happening."

It was 1.10pm. It was a beautiful sunny day. Jay was asleep. Her eyes were open when she died. "If death can be nice, it was for Jessica." Afterward, Paula sent both parents outside while she pulled out the feeding tube. Michelle asked the nurse to help wash the little girl. "I wanted everything to be nice, for Jessica to have her dignity."

They washed her and dressed her in her pyjamas and put her back in the bedroom. "I put my wedding veil on the pillow around her head, because I'd wanted her to wear it when she got married."

"Jay was only 22 months then, couldn't talk beyond a few blurred words. He was asleep when Jessie died and when he woke up he came out to look for her on the couch, I said, 'She died. She's in there.' He got a biscuit and took it in and put it on the bed next to her. He said a few things in Japanese and walked out again. It was good he was that young, I've heard that older kids can end up with psychological problems."

That night, Jessie stayed in her parent's bed. Michelle couldn't look at her. "I was scared. In the morning I played with her hair. I couldn't touch her skin. It was cold. I decided I didn't want to see her again, after she was taken to the funeral parlour. But when I went to the parlour I wanted her, and they said they'd known I'd want to hold her. But I needed a blanket because I couldn't hold her cold."

Michelle and Paul have talked about moving house, but Michelle can't see she'd ever do it. "Jessica walked on these tiles, she touched the walls. She's lived here. If we moved to another house her spirit might come with us but she won't have ever lived there."

Jessie's room is left as it was the day she died, except her bed has been returned to it. Her toys lie on the floor. "Jay goes in there, he plays in there. I don't go in there much. Another child will never sleep there. We might make it a quiet sitting room one day."

"I don't go to her wardrobe. All her clothes are still there. Paul would like to give them to the needy kids. I'd like to have her clothes cut up and made into a quilt. I don't know who will cut up the clothes; I can't do it."

Yes, you think: "I reckon it would kill me if something happened to one of my children." Now research (Danish) has found it is true, the suffering and death of a child will kill some parents.

And you think: "I just hope they're not in pain." Now they know that sick babies do feel pain, and that the management of pain in children is more complex and difficult than in sick adults. And you certainly wonder: "What would it be like when the time comes? I don't think I could bear it."

And the good news here is that death — the death of a child — can be the easiest part of the whole terrible business. It can even be beautiful. There can even be a happiness when it comes.

"Death is not what people imagine. It's a peaceful ending if managed well. A slow fading away," says Dr Jenny Hynson, paediatric consultant to the Victorian Paediatric Palliative Care Program, based at the Royal Children's Hospital. "The first thing we ask when we hear that a child had died is, 'How did it go? We find it goes well in most cases.'"

The VPPCP is an alliance between the Royal Children's Hospital, Monash Medical Centre and Very Special Kids. Half of Hynson's job — along with her small staff — is coordinating palliative care services for dying children and their families throughout Victoria. The other half is conducting research into what those children and families need.

It's still a mysterious arena, the dying child. It's not uncommon for medical staff, social workers and families to fall into disagreement about the best approach to take, because there is often no clear path.

Says Jenny Hynson: "It's a new and developing field of medicine. We still need a solid research base, so we can answer some of the fundamental questions. Like, how do we introduce palliative care to a frightened family? It has such a bad image."

Yes, you might think: "It's giving up and nodding out on morphine, being parked there to die."

Over the past 40 years, palliative care has been transformed from a miserable scene of abandonment and bitter surrender to a more engaged and active pursuit of the best quality of life possible for patients and their families. But most of the research and development of policy and practice has been focused on adults.

In the terminal adult world, most people die of cancer. Less than one third of "life-limited" children have malignancies. Instead, they mostly suffer with things such as cystic fibrosis, congenital anomalies, metabolic conditions, neurodegenerative disorders. Many suffer a complex combination of evils, all unique to childhood; rare conditions seen only once in a lifetime of agony.

Says Jenny Hynson: "We know children still suffer. We're not doing our job if we can't relieve parents by assuring them their child isn't suffering. And we've made significant progress, but there is a long way to go. For a start, we need to be able to recognise that a child is in pain, and that's not always readily apparent. There is a chronic pain may not move around much, may be withdrawn or quiet."

The rub being, kids need different things. "Children in the terminal phase of illness are known to suffer significantly from inadequate recognition and treatment of symptoms, aggressive attempts at cure, and fear and sadness," says Hynson.

Do they need to know what's happening? For you might think: "Well, at least the little fellow won't know what's happening, that he's dying. He won't have that worry if we keep it from him." But the little fellow probably will know — he just won't want to worry his parents by talking about it. Meanwhile, he has a whole lot of worries that he'll take to the grave; what he doesn't know for sure, he'll imagine. Like, Mum and Dad breaking up, or they don't love him anymore. He knows his parents are stressed out too.

Says Jenny Hynson: "There is a real disconnection between what we think is worrying children and what they are really worried about."

She tells the story of a child who wanted to be buried at school because what frightened him most was being forgotten. She tells of another child who never spoke of his death. Instead he left letters and messages with friends to be read after he'd gone, with detailed instructions for some of the letters to be read before the funeral, and others later. Kids will often talk with someone else, but not their parents.

"Research (US) shows children do better when they know," says Hynson. "There is a lot of protectiveness from both parents and kids. Sometimes I wish I could overtake a parent's decision, but in reality that's what she'd been all along. The GP had been consulted to be involved in what's going on, that there should be an open discussion about the issue."

Given that most children die at home (only a small number stay in hospital or go to a hospice) parents need all the help they can get, because they're carrying the load, the day-to-day nursing, bathing, medicating, comforting. In many cases it's a job that continues around the clock, so couples end up living tag-team lives, often for years on end.

"The trauma experienced by parents, siblings and the wider family from the death of a child is profound, with increased potential for complicated grief reactions and impaired long-term adjustment," says Hynson.

In other words, to pieces. Effectively support, the child will have a little death and passing, and the family will never get over it, probably fall to pieces.

"The question is, how do we impact on that?" says Jenny Hynson. "Really, parents aren't asking for a whole lot. They want information. They want us to continue to be with them, and not to abandon them. We can't do what we think is helpful, we must do what the parents tell us is helpful."

But there is perhaps no more closed society than a family watching a child waste away. Often the parents and the children live with their own thoughts, each isolated to some extent from the other.

You might think: "How on earth do they give voice to what they need?" Working with Hynson on the research project — funded by the Bluey Day Council and William Buckland Foundation — is psychologist Catherine Bauld. Since last May, Bauld has interviewed 24 bereaved families (of 60 interviews hoped for). How did they keep going through their lives in crisis?

Catherine Bauld: "We're still at an early stage — we haven't analysed the transcripts or data but a couple of key things are emerging. Quality of life being one of them. But fundamentally there is a real need for families in palliative care to have some hope. Many believe if they don't have hope they've given up. It's really important to have something. I think most families, they hold out for something to shift or change."

But hope for what? A cure; a turning that will not come. There's talk of hope being "redefined" within these scenarios, but this is an area that isn't very well understood.

Bauld points to a UK study that found people with some religious or spiritual belief were found to resolve their grief quicker than those without. "Where it becomes a question of faith."

How do faith and hope retain their relevance when death wins out?

Given that good palliative care is meant to pursue the spiritual and emotional aspects of care, as well as the practical and medical matters, it means that Hynson, Bauld and these bereaved families, part of their work together, a by-the-way issue, is a search for meaning.

It's one of the universal questions: how to construct meaning around terrible circumstances? "We reflect on that on where to look for answers," says Catherine Bauld.

Sometimes one of the children will say something like, "I know it's awful to say it, I know, but life is so much easier now that Hannah has gone." It's not awful to say it, because it's true. Hannah died 17 months ago, leaving the family in a mixed state of guilt and relief, sadness and anger, joy and excitement and a sense of freedom.

Soon after speaking with me, Karen asked Gavan what he thought now, about Hannah being dead. He told her it hadn't sunk in, that he still expected to hear her cry. "It surprised me when he said that, because it's not something we talk about."

We encourage the children to be honest, but they don't really talk about Hannah a great deal. I'd have loved them to go to counselling or a sibling support group, but they didn't want to. They don't want to."

When Karen said she brought Hannah home, ears set low, but then she'd been told there was "something" wrong, maybe Down Syndrome, nothing certain. She had a flat face and small ears, yet in reality that's all the right and happy baby things. They'd decided not to tell the older children, then seven and five, figuring they'd make Hannah part of their lives come what may.

But for five years and nine months, little Hannah dominated the family home, how it was run, determining the family's way of life. And a very tough way of life it was. "Every day was intense," says Karen. "You never knew what was going to happen from moment to moment. Something was always happening. It was very complicated, everything."

At 10 weeks she started having seizures, sometimes jerking rhythmically, sometimes going stiff, for up to 15 minutes at a time, with her eyes rolling upward and to the right. So she was named epileptic. She choked easily, the seizure medication was never right, and at four months a structural problem was suspected. An MRI showed her brain had developed with no folds, a condition known as polymicrogyria, causing profound cerebral palsy. The paediatrician said, gently, "It isn't going to be a good life."

The neurologist said it cold and hard, but Karen still feels his manner when she recalls it: "Don't expect her to have a long life. And don't expect her to learn anything."

Hannah could recognise light and dark, but her brain couldn't interpret input. "They meant nothing to her. I used to call her my little moth, because she was drawn to the light."

Her ears frequently filled up with fluid but she liked music and laughter, and was startled by loud noise. It doesn't seem that she understood language, although she had a language of her own, various sighs and squeals that communicated how she was feeling.

Her tongue muscle didn't work, so she couldn't move food around in her mouth, and she'd choke. At 15 months she had a feeding tube inserted through the abdominal wall, and into the stomach. It sat flush with her belly like the valve on a football.

"I sought it out. I wasn't offered it," Karen says. Of course, Hannah was never out of nappies. She got badly constipated, needing enemas, the big bag, and they used to spread a sheet on the floor because there was no containing it. "Full on, that was the life."

While trying to maintain a routine and set aside time for the older children, Karen and Gavan lived a frantic tag-team life, from crisis to crisis, around the clock, with Gavan doing nights. For older they'd been told to find solutions, new combinations of medicine, diet, anything that would make life happier for their daughter. Instead, she deteriorated, going in and out of hospital 18 times. (At three, she needed orthopedic surgery.)

She would stop breathing for a minute at a time, waking apneic.

Karen and Gavan were never told how long Hannah might live. Says Karen: "It was something that came up in conversation from time to time over the years. We hoped she'd live to be an adult. But I was also worried about how I'd cope looking after her, as an older person."

In mid-2002 — the most horrendous year, with so many things going wrong — their family'd gently suggested they seek palliative care. They hadn't thought of Hannah being a palliative patient, but in reality that's what she'd been all along. The GP had been subtle, hadn't come out and said the time is coming. Karen took it as an "OK" that she could give, that she and Gavan would stop striving to improve the situation. She saw there was no improvement to be found.

In August, Karen became very ill with depression. She couldn't get out, bed, couldn't talk, didn't want to see anybody, didn't go to church (she and Gavan are Christians), she was in a fog. For 10 weeks, Hannah was put into respite houses, including Very Special Kids.

On the day she was due to come home, with her mother feeling stronger — "the medication was finally kicking in" — Hannah broke her leg. The GP had said it wouldn't be the seizures that would kill Hannah, but pneumonia.

Hannah broke her leg on a Thursday, October 24. She was taken to RCH and put in traction. Over six days her chest started rattling, her breathing stalled frequently, at one point for two full minutes, and there was talk now of cutting her throat and feeding a tube into her lung. Karen asked if it would improve the quality of Hannah's life. No, they said, it will probably make it worse. "We said leave her alone. She's been through enough."

On the evening of October 30, Carol Quayle from the palliative care program, having talked over the options with the family (hospital, home or hospice) arranged for Hannah to be transferred to the Very Special Kids hospice. "Home had always been a happy place for Hannah," says Karen now. "I didn't want to look around and see the spot where she died."

Hannah arrived at VSK around 5pm and was put on morphine — the family was told that the drug might hasten death. Hannah always loved cuddles and would complain if they ended too soon, and through the night the family passed her around, holding her and caressing her.

Says Karen: "It was a strange time. The kids were there. They were very quiet. They talk about it occasionally. They knew she was dying. We ordered in pizza. We took lots of photos of Hannah with everybody. The flash went off and her eyes responded."

At 11.05pm, she took her last breath, lying in her mother's arms. In the photo, Karen is smiling. "I wonder what would people think?"

The family stayed in the hospice that night, Karen in bed with her daughter. Gavan and the children left the next day, but Karen stayed on, sleeping the next night in a bed that was pushed against Hannah's.

They moved into a cool room and Karen stayed with her daughter for a week, each night moving her bed a few more inches away from the body. And the children came, and they helped their mother wash her. They painted her lips and her nails, they dressed her and brushed her, and one of them, the son aged 10 then, asked could he put her in the coffin.

I spoke with Karen for maybe eight hours all up. And when Karen says now she's proud of her family, how they came through it, well, all I can say is you don't know the half.

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