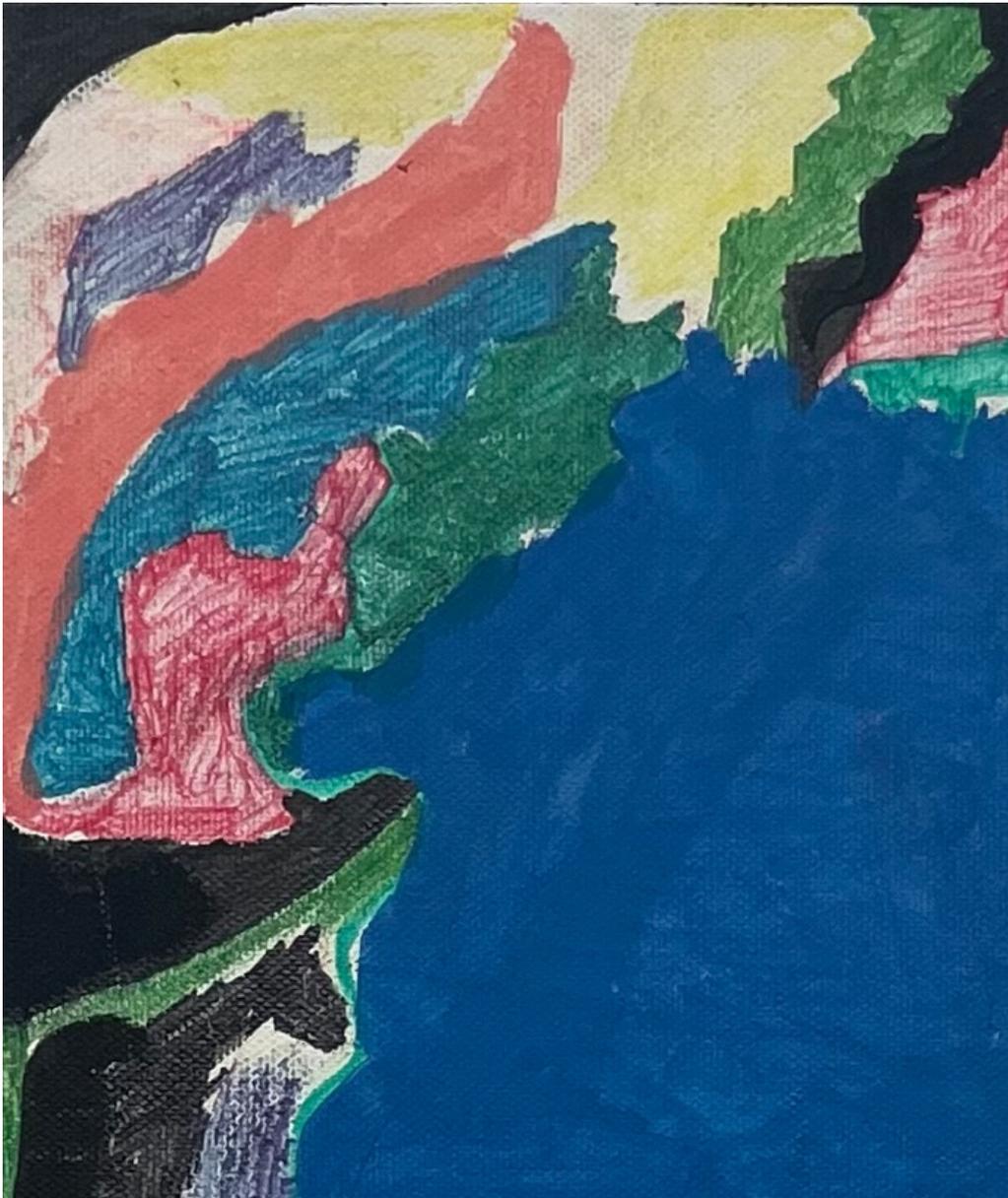


# “Two Brothers in State Care” by Sarah<sup>1</sup>

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<sup>1</sup> All names used in this story are pseudonyms.

<sup>2</sup> Artwork by Dale Scoles

Two brothers, Paul born in 1956 and Ricky in 1964, were institutionalised in two different psychopaedic hospitals in New Zealand. Paul was sent to Templeton near Christchurch at age three in 1959, and Ricky was permanently placed in Braemar, Nelson in 1968 at age four after some earlier respite stays, and was later sent to Ngāwhatu, Nelson. Three other siblings stayed with their family.

The information provided in this account comes from the youngest sibling and only sister, Sarah, who located and met her two 'absent' brothers as adults, post deinstitutionalisation<sup>2</sup>. She

also includes information from her brothers' official files which she obtained from the regional DHBs. The brothers never met each other. The files are extensive and cover several decades, although with some gaps in time and years, and include information about their deinstitutionalisation into agency run group homes in two regions of New Zealand. Between them the two brothers spent over 70 years in state institutions.

Paul was sent to Templeton in 1959 after an assessment from his father and two local GPs, signed off by a JP. The application was sent to the Director of Mental Hygiene,

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<sup>2</sup> Sarah and Hilary wrote this story together.

Department of Health (Dr R G T Lewis) under the Mental Defectives Act 1911, and the language reflected the requirements of the Act which included he was constitutionally 'feeble-minded', 'unable to appreciate discipline', 'attacks his younger brother for no reason' and 'never plays with other children'. He was not toilet trained and there was 'no evidence of emotional attachment to [his] parents'.

Today, these descriptions might indicate a diagnosis of autism, but autism was not widely known about at that time, although 'childhood schizophrenia' was sometimes used. Autism was

not a diagnosis in New Zealand before 1966, when a British child psychiatrist visited and diagnosed some children with the condition. It took many years to be commonly used. (Although, anecdotally, that diagnosis was not used at all in some institutions including Templeton. A psychopaedic nurse who worked for years at Tokanui till its closure in the late 1990s said she'd 'never heard autism uttered there.')

On his application, Paul's birth date is incorrectly recorded in his father's handwriting by two months, an error which would have decades-long implications. His mother is not mentioned apart from a suggestion that

she had toxæmia during pregnancy. That comment about the mother will be repeated throughout his files for the following decades. In a journey of about three months, the boy is apparently sent from his North Island town to Kimberley near Levin, Sunnyside in Christchurch and eventually to Templeton in November 1959. No mention is made of who accompanied him or how he travelled. Ongoing records suggest he is physically well but has 'faulty habits', which is noted on his file for several years.

As a 15-year-old (5 April 1972) Paul had a psychologist's assessment which stated that: 'Testing

indicates that this resident operates at a profoundly retarded intellectual level, although this may be an underestimation due to the effect of an unstimulating ward situation. However, he has reached a level of social ability and development of self-help skills which suggests that he could profit from transferral to Maple Ward and participation in the domestic training there.' He later moved into the large Maple Ward with 33 men at Templeton Hospital, although there is no record of what the 'domestic training' involved. He remained there until deinstitutionalised, after 41 years, with the last batch of residents in March 2000 who moved into an agency-

provided group home in Christchurch.

His sister Sarah was born seven years after Paul was sent to Templeton and she was a toddler when Ricky went to Braemar. This was the local institution, as the family had moved to Nelson. She was always aware of Ricky's existence and remembers visiting him at Braemar when she was a toddler and being scared of the place, though these visits soon ceased. Sarah said there was always 'an atmosphere at home' about Ricky and an unspoken rule never to mention him. She said 'everyone knew my father's volatility at any hint of him, even the neighbours.'

She said she'd 'grown up with an almost evil, sickly feeling around Ricky.' There were still photos of him in the family albums and Sarah said he was 'this gorgeous, curly haired little boy with dimpled, plump arms.' She found it hard to reconcile what she saw with her eyes (including how dotingly he was dressed, and how mesmerised their father, the photographer, had been) and knowing he was 'mental' and had to be sent away. There were also photos of Paul in the albums but Sarah was unaware of the existence of this fourth and eldest brother. She remembers asking her mother 'who's that one again?' as his hair was darker than the other three boys and

her mother would tell her it was one of her other brothers. Sarah said that her parents mustn't have had the heart to completely erase them.

In 1980, the family moved to Australia when Sarah was a teenager. Her mother only told her about Paul's existence when she was in her twenties. The second eldest brother had always known but was told by his parents not to tell the younger siblings.

The parents left New Zealand without a forwarding address and subsequent letters from the institutions were returned. Sarah believes that her parents' motivation for moving to Australia was their

growing fear about deinstitutionalisation and what it might mean for them - would they have to look after their two boys again, now adult men? Would people find out? Etc.

From their historical records, including photographs and their sister's descriptions, the brothers were very similar. They were both healthy attractive children and adults with dark curly hair, and distinct personalities. Neither regularly used words to communicate although they used sounds and gestures. Both were medicated from an early age, and later for epilepsy which appears to develop during adolescence, and they each had an early

diagnosis of 'mental retardation'. The label 'imbecile' was also used for Paul by a Sunnyside medical superintendent on his entry to state care, and 'hopelessly retarded' was used for Ricky by a medical specialist assessing him for entry to Braemar.

The files of the two brothers from the two institutions are also remarkably similar. One major difference is that autism and autistic behaviours are often mentioned in relation to the younger brother from the time of his admission to Braemar. There is even reference to the theories of Bruno Bettelheim, an untrained psychologist who ran an

institution for autistic children in Chicago (from which there were later allegations of abuse of children). He was a popular and internationally read writer and his 1968 book *The Empty Fortress* popularised his theory that cold and distant 'refrigerator mothers' caused their child's autism. The label remained powerful and stigmatising for decades, including in New Zealand, which added to the shame of a diagnosis of autism for families.

As mentioned, autism was a relatively new diagnosis in New Zealand at that time; the Autistic Subcommittee of IHC which would eventually evolve into Autism NZ was founded by parents in 1969.

The Templeton file does not mention autism.

Neither record indicates any access to formal education, apart from a brief note from Templeton, responding to a request from Paul's mother for information on his wellbeing, suggesting he was attending some sort of Kindy activities on site. In the 1960s it was widely considered that 'mentally retarded' or autistic children did not have the capacity to be educated.

The medical director at Braemar found out about the brother in Templeton and in 1974 wrote to her counterpart at Templeton, seeking information about Paul and

the nature of his impairment to try and shed some light on his younger brother Ricky's disability. This request was met with a lack of knowledge and interest from the Templeton superintendent, who wrote back that 'little is known about the boy, he's now 10 years old, another patient brought him to me, he seems covered and small for his age.' The Braemar director also made inquiries about housing the two siblings together in one institution. However, this possibility is thwarted by their father who writes, in response to the proposal, that two of the other three children do not know about Paul and he wants to keep it that way. Sarah says she grew up

sensing her parent's extreme shame about having disability in the family. She said that people in Nelson, including neighbours, her father's work colleagues and members of a suburban club/pub that her parents were regular, long-term members of were aware of Ricky's existence. To have one child with disability known about was more than enough for her parents, and especially her father.

Their father was not an easy person who could be angry and violent and the family were fearful of him. His wife's voice is not recorded in the files of her sons apart from the very occasional short letter sending money, asking about them and if there's

anything else they need. One reply from Templeton to the mother says, 'I am sorry to say' your toddler 'is happy here.'

The official files contain numerous and regular assessments of the boys as they grew into apparently healthy although slightly built young men. There are differences in how they are described depending on who is writing the report and for what purpose. The same incident or behaviour is portrayed either positively or negatively, sometimes reflecting different staff attitudes. Some staff appreciated the character and personality of the boys and there are reports that

recognise that the environment is not right for them, that they need something with more stimulation, individual attention, more space and less populated/crowded areas and more distraction from other residents, but this does not seem to eventuate. Some reports are infantilising and patronising. What would be seen now as autistic behaviours are frequently pathologised. Both boys/men are portrayed as not interacting with other residents. There are references to Ricky particularly enjoying music and the outdoors and as needing outdoors space, opportunities to walk, use swings and tramps, and that

he lost these pleasures when sent to Ngāwhatu (as an adult). One document says that at Braemar, Ricky 'spent most of his time on a trampoline or swing but these have not been available to him at Ngāwhatu' and that since his transfer to Ngāwhatu 'he now shows little interest in walking; when he used to walk some distances.' Another paper, written by the Ngāwhatu Resettlement Project: Independent Service Coordinator states that 'Ngāwhatu was not the best environment for Ricky' but ultimately concludes that 'neither Braemar nor Ngāwhatu were successful with him.'

There are many references in both files to behaviours which to modern eyes look like reactions to sensory overload and many records of bruising and cuts. Extra medication or punishment are often then administered.

There are dozens of incident reports, including about altercations. At one point Paul is injured after running through a glass door, but the circumstances behind this are not reported. There are illnesses that take sometimes weeks to diagnose and reports of problematic behaviour, deemed to be Paul's growing aggression, including his waking early and screaming, which required his being put in the

quiet room and medicated - and that turned out to be physical pain requiring surgery for gangrenous appendicitis, and other times, dental problems, which were eventually identified. It is sometimes complicated by the requirement to get consent from the father who has left New Zealand without leaving contact details.

There are frequent references to negative behaviours around food. Both boys are described as stealing food and fast eaters ('gouging'), and apparently always hungry. From reports it is clear that food was used as behaviour control for punishment and reward. Both were described as having

pica (eating substances that are not intentional food such as leaves).

There are references to dental treatment but when Ricky met his sister, he had no teeth. Ricky's sister Sarah noticed that when she met him after he had been deinstitutionalised into a group home run by a local agency, she saw extensive scarring up and down his back from injuries such as kicks or blows, but there are no incident reports in the records indicating how these happened. There are anecdotal stories from former staff and residents alike, that sometimes residents were coerced into fights. There are stories that patients, like

Ricky, who were bright and energetic, but complex and non-verbal, and likely autistic, were unable to regulate their anxiety and distress caused by a busy, noisy and crowded institutional setting, with its ever-changing staff faces. Such people commonly expressed their frustration and unhappiness by being deliberately disruptive and were in turn punished for 'playing up.' Patients were expected to behave in ways that made sense to the staff but that were often beyond them. It's well known today that many people with autism are overwhelmed by environmental causes and can only react unhappily. Another document on Ricky's behaviour suggests that

‘boredom may be close to the heart of his problems.’

A former Ngāwhatu patient, a verbal man, met Sarah at the group home agency's Christmas lunch, which brought together residents from several houses. He told her, without prompting, that Ricky used to get ‘hit a lot by the attendants, they’d really get stuck into him, they set other patients on him. I don’t know why they were always hitting him.’ Sarah told him she didn’t want to know any more.

The agency staff were aware of Ricky’s scars but these pre-dated their care and the team leader told Sarah that ‘none of us knows what

happened to Ricky in the institutions but they were definitely not from self-harming.’ It was widely understood among some staff that physical violence was a part of institutional life. Some of the staff had even worked in the institutions. Ricky’s voluntary advocate repeated this understanding to Sarah. She had worked at Braemar as a physiotherapist, decades earlier, and knew the stories and fears of goings-on, particularly at Ngāwhatu. She told Sarah it was common to find such scars on former patients and tried to reassure her it wasn’t personal to her brother; he hadn’t been singled out. She told Sarah ‘it happened to so many of them.’ Sarah tried to

explain to her, she could only see her brother in this moment, and couldn't stop getting images of what must have happened to him, and that she found no comfort in knowing it had happened to so many of them.

The decades of charted medication records indicate a heavy regime of drugs for epilepsy, mental illness, behaviour control, and sometimes pain relief. There is a short letter written in 2000 from Paul's primary care physician at Health Link South for his discharge from Templeton to the group home agency. It outlines his medication regime and says 'there has been a problem with his behaviour in the

years I have attended him' and goes on to conclude 'in summary, it appears that his behaviour has been due to his drug therapy.' This physician explains how he/they have been reducing the combination and doses of some of Paul's medications, only in recent times, and have been seeing a corresponding improvement in his behaviour. After deinstitutionalisation and the involvement of psychiatrists from the Ministry of Health, further questions raised about the psychiatric polypharmacy, despite there not being a record of any diagnosis of mental illness, but a comment is made that weaning off any of them might cause new problems. A 2016 assessment for Paul by

a Wellington psychiatrist queries why he has had so much polypharmacy with so little revision over the years, but admits that such drug overuse was normal for years of institutionalisation (even though this is now 2016). His sister would later question Paul's GP's 2021 use of the diagnostic label 'mentally retarded' for him. (As Sir Robert Martin has observed, institutionalisation is more than bricks and mortar, it is also words, attitudes and values.)

In Ricky's case, during his early placement with the provider agency from 1998, another agency is drawn on to assist with his problematic behaviour. The coordinator of

this agency attends and observes Ricky in person and reads some of his historical notes. He reports that Ricky's nursing notes from his early life do not emphasise his agitation which is by now so prominent 'but they do however record the very large quantity and wide variety of anticonvulsant and psychotropic medications he received'. He said that 'these drugs were often in combination and at high dose and sometimes changed frequently'; and that most of the medications were for the control of Ricky's behaviour and moods and 'there are several references to his 'psychoses', obsessive-compulsive disorder and depression are among the

conditions suggested, although no single condition is diagnosed.’ He goes on, that other attempts were made to try and control his behaviour ‘mostly through additional PRN medication and physical control such as locking him behind doors,’ and writes that ‘even as late as 1996, Ricky was prescribed 11 different psychotropic medications, including anticonvulsants and PRN (as required) medications in a single year’ and concludes ‘it may be that his agitation has been acquired or aggravated as a side effect of some of these medications.’ He recommends Ricky ‘needs to have his medication and general health reviewed by

specialists experienced in treating the medical needs of people with autism as soon as possible’ and that ‘while they may not be able to offer insights into Ricky’s moods and behaviour at present, they will be able to review his medication history and his present pharmacological regime.’

This coordinator also notes that the agency’s staff, who know Ricky well, have reported he responds well to different staff, suggesting he reacts differently depending on the individual approach. He said that staff have also told him that Ricky is ‘often free from agitation and challenging behaviour when the other residents are out of

the house' but that 'his mood and behaviour typically deteriorate rapidly when they return.' He says 'difficulties arise when Ricky is forced to share a space with some of his fellow residents.' He writes that as an autistic person Ricky 'may be having sensory integration difficulties' to noises, sights, smells, touches or feelings and that these factors in his environment 'may be the cause of his distressed behaviour.' He refers again to Ricky's Braemar record, which notes Ricky found it easier to calm down when put in his cot on his own, away from others, and when 'his music' was put on, thereby helping him block out other demanding, unpleasant or

irritating sensations around him, including auditory. He highlights that everyone seems to have recognised, early on, Ricky has a clear preference for a quieter, less crowded, predictable and uncluttered environment with consistent support staff and access to space and the outdoors. He advocates that Ricky have staff 'who are well trained in the skills necessary to support a person with autism.'

When Sarah first met Ricky, the agency's team leader told her that when he'd started work with Ricky about a year after his deinstitutionalisation from Ngāwhatu 'he was still on all those horrible medications; they had such a

terrible effect on him.’ He said Ricky ‘rattled with pills when he walked’ and ‘used to just yell and scream and headbang.’ However, under his support team, they investigated Ricky’s medication regime and substantial changes were made. This team leader said ‘it changed his life so significantly - and everyone else’s around him - for the better. His PRNs became less frequent. We had to wean him off his old drugs first, it took about six weeks of pure hell for him and the staff but it made such a huge difference to his life. He just progressed so much in the time I knew him.’

After deinstitutionalisation, Ricky had two independent advocates and they appear to have attempted some vigilance as ‘outside’ people in his life. Ricky’s second advocate was the above-mentioned former team leader at his house who had developed a strong and trusting relationship with him. However, his attempts to keep an eye on Ricky and continue their connection was hampered by the new house leader; she made him feel unwelcome, didn’t involve him in relevant meetings affecting Ricky or share information and encourage and facilitate his ability to fulfil Ricky’s lifestyle plan and goals. His plan recognised that Ricky would benefit from

regular outings to the advocate's farm, but these didn't occur. The advocate was not informed when Ricky was unwell and bedridden and was unable to visit and support him as his unpaid friend. The new house leader also ceased contact and social activities with other agency houses, which left this home of vulnerable people, already in an isolated rural setting, largely cut off from outside contact and view. It left Ricky with no independent person involved in his life.

In Paul's case, it appears that at Templeton, he had an occasional visitor from a local church group. Otherwise, the only people in his life were

paid staff and other residents. There was no notion of 'family'.

This is also the beginning of confusion about the identity of Paul stemming from the incorrect birth date on his file when he was three. His identity appears to have been mixed up over the years with other Templeton residents with similar names.

In about 2011, Sarah, aged in her mid-40s, decided to search for her two missing brothers and find out what had happened in their lives. She said it was a huge emotional and mental undertaking for her, particularly as she was breaking her family's golden

rule of not acknowledging the existence of these two members. She said 'it took me till middle age to feel like I could challenge our father's grip on this part of our story.'

She tried to locate her oldest brother, Paul, and was told that historical records from Templeton were hard to source, that record keeping hadn't been great, and that some of it had been lost or stolen at deinstitutionalisation.

She established that the agency in Christchurch had taken responsibility for the majority of former Templeton residents. But because of the incorrect birth date on Paul's original file and his common name, she was advised by

the manager of the agency at the time that they didn't have a match for her brother's date of birth and couldn't assist her. He did tell her, however, that the agency did have a man in their care with the same name as her brother but that he couldn't possibly have been her brother as he had a different date of birth and parents' names attached to him and had 'already been accounted for.' Sarah understood that this man's family had come forward for him. He told her there had been a few males with her brother's name at Templeton, that Templeton staff may have changed her brother's name for their own convenience so as not to muddle them up and that it

was possible that he may have died. He suggested Sarah try the Salvation Army. She did. They advised her they helped parents and children find each other under adoption circumstances, but didn't have anything to do with separated siblings by disability and institutions. Sarah said that the agency stopped replying to her email pleas for more ideas or information. She was convincingly turned away.

When Paul was committed to Templeton there was no requirement for his birth certificate to be attached to his file. This document was basic proof of Paul's identity. It had his full name, date and

place of birth and his parents' names.

At deinstitutionalisation, Paul, and other residents of Templeton were released to private service providers, like the group home agency, without their institutional record accompanying them. Paul's file contained information about the last four decades of his life but this was separated from him at handover and went into the drawers in DHB archives.

The agency was only given a summary on each person, prepared by a middle party, contracted to write up a 'needs assessment' on them as they left Templeton. His summary outlined his

disability, problematic behaviour, medication regime and provided a hospital number, NZ income support number, community services card and an IRD number. There is a single sentence that summarises his family background and reason for entering state care as follows: 'Was in Levin Farm Hospital pre admission to Templeton in 1959 - continuing screaming, attacking younger sibling.' His father's initials and surname are included on his summary with 'address unknown, no family contact.' Paul exited Templeton with the same (incorrect) date of birth he'd entered with. The full names of his father and mother - which were available on his Templeton file - did not

go with him into community life, nor does any mention of his four other siblings, including his brother Ricky at Braemar. There is little ability for the agency to link Paul with his family members at any future stage - or for them to find him.

At some point, the agency requested a birth certificate for Paul. All they had to go on is an incorrect birth date and his father's initials and surname. Birth Registrations could only have advised them that they did not have a birth certificate matching Paul's date of birth or father's details. Someone at the agency made a decision to accept or take a birth certificate for a completely different person to

the Paul in their care. This other person has the same full name, but an entirely different date of birth and a different father's name. The agency's 'Paul' officially became another person, with another set of parents attached to him for the next 20 years - until it was unpicked by his sister.

Sarah established that Paul's date of birth changed a number of times over the decades. The admission application had the wrong date of birth, his date of birth changed in the institution on some documents, and decades later, the agency had yet another date of birth for him.

By contrast, Sarah was able to locate Ricky easily, by then in his 40s and deinstitutionalised from Ngāwhatu (the institution for adults who had outgrown Braemar). He'd been placed into an agency group home on the outskirts of Nelson. Sarah travelled from Australia several times to get to know him. They enjoyed each other's company and Ricky allowed his sister to sit with him on his special, exclusive mat. Staff observed Ricky had a strong interest in his sister and could sense something special was happening and being shared between them. He welcomed her visits, would smile, sit next to her, seek her out if she moved, sometimes held onto

her as she was leaving the house and would follow her to her car.

While there were some joyful and mending times shared between these two long-separated siblings, Sarah was also getting very affected by some of the more disturbing circumstances around Ricky. These included, not least, witnessing the extensive scars on his back unexpectedly one night. Ricky's voluntary advocate said to her 'I hoped you'd never see them.'

Sarah was also disturbed by the way different staff treated Ricky and his peers. For example, when they shared their first Christmas together,

the particular staff had made a special meal and everyone sat and ate together. It was a real communal celebration. However, the following Christmas, with different staff on, they had another attitude towards Christmas with the residents, and chose to eat separately from them and assumed Sarah would wish to do the same. Sarah was heartbroken. She had worked hard, saved up and travelled a long way to break bread with her brother at Christmas. She said it felt like her brother was being separated out from her again, and she realised that he and his peers would never be seen as true equals by others. She watched as her brother and peers were fed separately 'like cattle' and

apart from those 'in charge'. She began crying and was unable to stop and couldn't eat her lunch. The staff were bewildered to see her so upset but she was not able to articulate how she was feeling. Her brother came and sat next to her and she didn't want him to see her 'losing it' so she drove back to her motel and had a very dark night.

Sarah also found some of Ricky's behaviour distressing to observe, including his headbanging. His behaviour seemed to vary according to what staff were on; he was much more settled with familiar staff. She felt unable to reach and support him and made the difficult decision to

pull back on contact for her own wellbeing. There were staff changes at the house too at this time; Ricky's wonderful team leader was retiring; a new leader was appointed and staff were turning over (as is typical in support work.) Back in Australia, Sarah felt far away and removed. Previous staff had kept in touch and sent photos of Ricky and birthday cards etc, but the newer staff never made contact. Sarah requested to go on the agency's family newsletter list, but never received a copy. She sent Ricky a present a few months before she heard he'd died unexpectedly.

In 2017, Sarah flew to Nelson for Ricky's funeral. He was 52.

He had choked while eating a camellia flower after breakfast (he had no teeth) and could not be resuscitated. Sarah was listed on his file as his only known family member and next of kin. The agency had her email address, phone number and physical address in Australia. However, when Ricky died, no one at the house or the agency office could find her contact information. Ultimately, the agency told her they'd lost it. The Police used Interpol to find her in Australia. But before the police found her, Ricky's two voluntary advocates (former and current) were advised of Ricky's death, and one of them contacted Sarah to share her condolences. This

advocate had assumed that the agency would have already notified her, and was shocked and mortified to realise Sarah was unaware of her brother's death. Ricky's other advocate also contacted her and asked her to call him ASAP. It took two volunteers and the NZ police to advise Sarah of her loved-one's death. The government funded agency with full and paid responsibility for his care was at a loss to contact her. Sarah eventually received an apology from the agency. They put in writing they had failed in their duty to maintain family records and said 'it was not acceptable.' They also said they should have kept in contact as they had a

duty to maintain links with known family members.

When Sarah attended Ricky's funeral and visited the house, she met the new team leader. Sarah noticed that home facilities and opportunities for residents had deteriorated. For example, a large outdoor sundeck area, previously used by residents and staff alike in summer and spring, was no longer used at all. An outdoor swinging seat on the deck, which Ricky enjoyed, was no longer there. The outdoors table and chair setting for the residents to sit and enjoy the sun and fresh air and sometimes eat meals, was gone. A dedicated, small and separate table for Ricky to eat by himself, which he

liked to choose to do sometimes, was gone. The new team leader advised Sarah that he "sat at the table with the rest of them inside." The residents' sensory room was now being used as a junk room. It had previously been a space for residents to go from the main house, sit and have some space and quiet time, listen to music, and one resident liked to play piano. A more rigid approach to supporting the residents had been instituted.

Sarah also established there had been a loss of traditions which had been built up to support Ricky, such as allowing him to make his own toast with marmite before bed - a much prized treat and

calming activity for him. She was also told that Ricky had been wearing incontinent pads all day, and for some time, when he had been fully continent when she'd visited him, under the previous team leader's care (apart from a night-time product). Sarah saw that family photos of herself and Ricky had been removed from his bedroom walls, as had a rug she had purchased for him. She found out that prior to his death he'd been unwell and bedridden, yet neither she nor his advocate had been contacted. She also she learnt from staff and inadvertently from the team leader herself that there had been inappropriate physical contact between the team leader and Ricky, which

had included 'kissing him on the mouth, repeatedly some days', and sitting him on her knee, which other staff had witnessed and said was 'off' and 'unprofessional' for a house leader, who was meant to set the standard towards the vulnerable, non-verbal, people entrusted in their care.

After returning to Australia, Sarah started inquiries into the team leader's behaviour. It resulted in three investigations. The first was an internal review by the agency which determined that the team leader had been kissing her brother on the mouth and professional boundaries had been crossed. However, the agency said

they believed it was more a case of 'misplaced affection' than any dubious or 'sexualised behaviour.' They said it was one of the hazards of the job that staff became 'so familiar with and fond of the people' in their care. They told Sarah the team leader would be facing appropriate discipline but they weren't obligated to tell her what that was. Sarah went to the health ministry (the agency's funding body) and asked them for their view. She posed the question to both the ministry and the agency: What would happen if, for example, a school teacher was found 'kissing' a vulnerable student 'repeatedly some days' on the mouth? Would the

defence of misplaced affection and fondness etc wash?

During this time, Sarah received more incriminating information about the team leader's behaviour in relation to Ricky from some support staff. She continued to relay this information to the ministry and agency management. This led to a second inquiry, and the agency involved a legal firm. The lawyers concluded there was enough evidence to justify further examination and recommended the agency reopen the inquiry.

With the third review, the agency investigated itself again, and advised the

ministry and Sarah that, as a result of its findings, the team leader was no longer working for the organisation. A month later, Sarah found out that this person was still working for the agency and had only been moved to another house with vulnerable people. She contacted the ministry officer, who was equally shocked and said that she too had understood the staffer had been dismissed, period. However, the ministry officer apparently lost interest (it had been going on for a year), and without her support, Sarah decided to let it go too; it was taking a toll on her and she needed to go forward for her own health and wellbeing.

When he died Ricky had no possessions.

Sarah says she felt a tremendous sense of guilt after her brother's death. She felt like she'd let him down, had taken her foot off the brake, and should have stayed in closer contact his last couple of years. She felt hampered by different pressures, including not having the money to visit him regularly enough to make a difference, and her memory of how distressed she'd been on her last visit and decision to focus on her own stability, mental health and life in Australia.

Ricky's body was embalmed, as organised by the team

leader, and while Sarah was involved in aspects of his funeral arrangements, she was conscious of not stepping on his staffer's toes, and was agreeing to things she didn't necessarily understand or want. On the day of his embalming, Sarah tried to stop it occurring, as she felt his body had gone through enough, including a tracheostomy and autopsy, but it was too late, the procedure was underway. The funeral directors encouraged Sarah to see Ricky's body, and on sighting him, she had to be held up by two funeral staff, as she was in shock. She felt riddled with guilt and was inconsolable next to his body and said to him, over and over: I'm sorry,

I'm so sorry. She felt the weight of her whole family having let down this precious person his entire life. She remembered that hands were important to Ricky; he loved to examine her hands and hold them up and turn them over and smile with approval. She asked the funeral staff to see his hands from under the blanket and hoped they'd look the same. They did. She felt much relief and comfort in sighting his hands. She did not want to touch him but gave the funeral staff a sprig of rosemary to place in his hand after she had left the room.

After Ricky's death, Sarah tried, again, to find information about her oldest

brother Paul's fate. It made no sense to her that a little boy who had been entrusted to the state could have just disappeared into thin air. She had a strong feeling he probably had died in care and tried to find some comfort in imagining Paul and Ricky were together. The only information she had on Paul was from when he was aged 10 and the Superintendent of Braemar had sought to bring the two brothers together. She knew he had lived till at least age 10 but was 'otherwise left to imagine the worst' about his 'evaporation'. She thought 'if he has gone, I just hope it was quick'. But despite trying to let it go and live without knowing, she

continued to go back and forth, digging for information.

Although she had never met him in person, she recognised Paul for the strong family resemblance when she came across Gerard Smyth's 1996 documentary on Templeton. She got in contact with the filmmakers and spoke to a father who'd been interviewed in the film. This father had led a parent group during the deinstitutionalisation process. He told Sarah there was a chapel on the Templeton site, still operational today, which had a memorial wall with the names of residents who had died at Templeton. He arranged for someone to visit

the chapel on her behalf and check the wall of names. Paul's name was not on it. Sarah felt confident for the first time that Paul was still alive at closure. Again, it took an informal channel to give her such hope; there was no official agency supporting her quest.

Sarah contacted the agency again and a new manager was in place. She emailed numerous photos of Ricky and asked if he resembled the 'Paul' they had in their care. The agency's staff were apparently shocked on seeing the photos, as they were left in no doubt that Paul and Ricky were brothers. Sarah established the Paul in their care was not in fact

'already accounted for' as he had not had any family come forward for him. She booked flights to meet her brother.

However, after the initial excitement and recognition of their family relationship, which included an email from the manager saying it was a '100 per cent match'; the manager appeared to suddenly change her tone. She told Sarah that the agency required official proof that she is Paul's 'real' sister and did not allow Sarah to see any photos of her brother. This was an unexpected blow. Sarah told the manager that when she'd found Ricky, the agency in Nelson had not required she 'prove' she was his biological sister before

seeing photos or visiting him. The manager apparently replied that the agency's difficulty was that Paul had a different birth date, place of birth, and parents' names attached to him and said 'the onus of proof is on you' to show this official document is wrong. They suggested she do a DNA test - which Sarah rapidly agreed too - and sent her a DNA form with a cost of nearly \$900 and said Sarah would have to pay for it. Sarah said she'd try and find a way. The manager came back again and told Sarah that Paul's GP had refused to do a DNA test on Paul due to privacy laws. She said if Sarah wanted to go forward, she'd need to take out a Court Order, again at her own

initiative and expense, to compel Paul to have a DNA test. Sarah could not afford to do this and lived in another country. She felt utterly demoralised by the response she was getting from the agency, the growing challenges, and the impossible expenses for her. She couldn't understand why the agency had gotten so difficult and why they, and her brother's GP, wouldn't be doing everything within their power to facilitate a family reunion - for a man in their care who had no family in his life, no advocate, no unpaid visitor.

Sarah could not see a way forward and cancelled her flights to meet her brother.

Her tickets were non-refundable. She advised the agency that she was unable to manage it financially or emotionally and was pulling back. She pointed out to the manager that she'd only lost Ricky the year before, had spent much time and energy on the three investigations into the agency's team leader's unacceptable behaviour towards him and that her mother had died shortly after Ricky.

After Sarah cancelled, the manager apparently had another change of tune. She contacted Sarah and says that she wouldn't want to stop a family reunion and that she would waive Sarah having to verify her sibling status and

allow her to visit Paul as his 'unofficial sister'. But she reiterated that 'the onus of proof' remained with Sarah to continue the process of authenticating they were genuine siblings, and suggested that Sarah contact a genealogist. Sarah could not recover the money for her cancelled flights but rebooked again for a future trip. In the meantime she tried, again, to source any information or records which could prove her family relationship to Paul. It bothered her enormously that the agency would not regard her and Paul as true siblings until they had it on a bit of paper.

By a mixture of good detective work and good luck Sarah found a responsive records manager at Princess Margaret Hospital in Christchurch who was able to locate some Templeton archives. The archivist found files for Paul, and with Sarah's extra information about birth dates and parents' names, sourced the correct data from Government records and matched it with the files held for Paul. Ultimately, Sarah was able to prove her family relationship with Paul, once and for all. The records manager contacted the agency's manager directly and asked her to order a new birth certificate for Paul and to dispose of his incorrect one.

She also contacted Paul's GP and gave him Paul's correct date of birth and requested he remove the wrong birth certificate from their surgery. Paul received a new NHI number.

Sarah was now allowed to see photos of her oldest brother and flew over to meet Paul in 2019. She was 53 and he was 63. She visited him twice, then with the temporary Covid border openings in 2021, decided to relocate to Christchurch and is now developing a positive and joyful relationship with her sibling. She is also building trust with his staff so that she can come and go. She encourages Paul's dignity of risk by involving him

in regular community activities such as visits to the markets, cafes, spas at the local pool and helping her shop by pushing the trolley. Sarah has accompanied and supported Paul on visits to hospital, including an operation on a gangrenous toe, for Covid treatment and dental care.

Community Law in Christchurch supported Sarah's successful application to become Paul's legal welfare guardian. Sarah felt it was important to get their sibling relationship on the record after all she and Paul had been through. The agency is now fully accountable for maintaining

Paul's dignity, health and wellbeing.

Sarah wanted to frame some questions and comments for the Royal Commission:

- *Why did the state allow disabled New Zealanders to be admitted to psychopaedic and or psychiatric institutions (often intended for life, as in the case of my own two brothers) without requiring that a copy of their birth certificate go with them and stay with them as proof of their identity? There were hundreds of people placed in these facilities. I understand at the closure of Templeton between the 1990s and 2000 some 465 people were released into the*

*Christchurch community, among them, my brother Paul.*

- Why did the state rely on the word/memory of a father who was committing his toddler to care without requiring the child's mother also be present, at the very least to confirm such critical details as the child's date of his birth?*

- At deinstitutionalisation, why didn't the state provide more, if not all, of the information it had on each person in its care (care that sometimes covered several decades) to agencies at handover? These records had the history of the person - details about how they came into care, their health*

*inventory, who their family was etc. Paul's documents had the names of our parents, both sets of our grandparents, and mentioned the existence of his four other siblings, including our brother Ricky institutionalised at Braemar. The agency was not given this information: Why not? How were wider family members, who wanted to come forward and find their missing loved-one, meant to find them?*

*The agency had no capacity to link the person in their care with their family members at any point. They couldn't cross-reference or verify whether anything they had in their handover summary was faulty.*

- *Why did the agency attach a birth certificate to a person in their care that didn't match the date of birth and father's name they had been given by the state for that person? Someone at the agency made the decision to take or accept the birth certificate for a completely different citizen.*

- *Did the agency seek more information about Paul's identity and family background from the DHB? If it had, Paul's historical files could have been sourced and checked, and the names of his parents and place of*

*birth etc would have been found.*

*It is shocking to me, as Paul's sister, that the agency 'officially' made Paul a different person. If I hadn't uncovered his true identity, my brother would have died and been buried as someone else. How could this happen in the 21st century? Who is responsible?*

At the very least, the State and the agency owed Paul his identity. They both failed to capture and protect this basic human dignity. They also had a responsibility to keep the door open to Paul's right to have a family. They should have realised family members might come

forward for him down the track. This path should always have been accessible. No one was protecting Paul's right to a family.

Also, family members, like me, should not have been hitting dead ends when I tried to find my missing sibling. I had to search, research, hoop-jump, imagine he was dead, pay unnecessary expenses, and go through a mixed-up stressful and time-consuming process to locate and visit my own biological brother. That fact I was on his doorstep, but persuasively turned away, eight years earlier, demonstrates something. It meant our sibling relationship was blocked even longer than it

had to be, and we lost more precious time we might have had together. The inadequate record keeping, record sharing, handover notes at closure and the fake identity of Paul were not of his or my making. Yet Paul and I paid the price for these State and agency errors. We almost didn't find each other at all. Without my persistence and happening upon the 'right' person who knew about the archives - and her willingness to devote time to it, and pulling together scattered information that wasn't necessarily compiled in date or subject order - nothing would have happened.

Paul and I have never had an apology from anyone.

Since finding Paul, the manager has told me the agency can no longer completely trust the information they were given on the people at the closure of Templeton. She wonders if there might be other former residents with muddled identities, birth certificates or family members who are looking for them? The agency still has today former Templeton people who they have no family information on. They have tried in recent times to connect residents with unknown families by drawing up a family tree for them, but with limited success in locating relatives, dead or alive. As highlighted: the institutional record and

wider history of the person did not leave with them at handover.

Sadly, most of the Templeton population are now elderly or have already died.

Meeting Paul in 2019 has been a life changing and meaningful experience for me. My two disabled brothers were real people to me, however silenced and whitewashed. They mattered to me. I believe it was the same for every member of my family, whether expressed or not. We were all incredibly damaged by this loss and family secret.

Just before I met Paul, the agency told me not to expect

too much from him, that I'd get little back, no acknowledgement or interest, that although he'd be aware of my presence as an unfamiliar person, he'd tune me out, that he was hard to reach, hard get to know, that it took him ages to trust people, that he was essentially a loner, didn't like eye contact or physical contact, and was a creature of routine etc. I told the agency I would meet my brother on his terms and accept him however he came.

Paul and I have grown extremely close. Today, I ring the doorbell at his house, and on seeing me, he smiles, rapidly stands up, and comes over to greet me. He reaches

for both my hands and initiates the honggi. His staff say they've never seen him greet anyone this way before. Our mother used to do this to us as children - could he possibly remember? I have no idea. He allows me to give him a cuddle, a back scratch, a hand massage, and actively seeks to go on outings with me. His team leader has told me that she has never seen Paul close to anyone before or even wanting to be, until now. She said that he is happier, a changing person, more dimensional and 'satisfied.' I tell Paul, often, that we are family and that he belongs to me. I tell him he's my friend and buddy too. I celebrated Paul's 66th

birthday with him recently - on the correct day.

I can't fully explain it, but for me, the need to know and connect with my two missing brothers ran deep, no matter how gagged and disjointed the history. I don't think anyone could underestimate the harm that was done to a lot of individuals and families who got fractured this way. It happened to real people like me and my brothers, and it's still playing out in people's lives.

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The files that Sarah has accessed are invaluable. They have revealed details of the lives of two New Zealand citizens that would otherwise have been lost and unknown.

Only through luck and good detective work have they now come into the possession of their sister. But such records are at risk. Health records are required to be held for 10 years and many private providers and NASCs (which are non-government organisations) then shred them. Official government records should be kept but are often a casualty of departmental restructuring, and the varying letterheads in these two files list agency names that are now long forgotten. The status of the Templeton and Braemar/Ngāwhatu records is unclear. If asked for by patients and families they are given to them and no copies kept. They do not appear to

be deposited into a central repository such as Archives NZ.

Good record keeping requirements by staff in the now closed institutions have ensured that a sister has not only found a long-lost brother, but she now knows what happened to two brothers in

two institutions over many decades. These are incredibly valuable records for family, for future researchers and for our disability history. We need to archive what remains. It is one way to provide justice and redress for the distress of institutionalisation and family separation.