Coroners Act, 1996
[Section 26(1)]

Western  ***Australia***

RECORD OF INVESTIGATION INTO DEATH

Ref No: 42/14

I, Evelyn Felicia Vicker, Deputy State Coroner, having investigated the death of ***(Bethany)****, with an Inquest held at Perth Coroners Court, CLC Building, 501 Hay Street, Perth on 4 November 2014 find the identity of the deceased child was* ***(Bethany)*** *and that death occurred on 27 February 2012 at 10 Watts Close, Boulder, and was consistent with Epilepsy in association with Cerebral Palsy in the following circumstances -*

Counsel Appearing :

Ms I Burra-Robinson assisted the Deputy State Coroner

Ms J O'Meara (instructed by the State Solicitors Office) appeared on behalf of the Department for Child Protection and Family Support

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SUPPRESSION ORDER

The identity of the deceased child is not to be published.

INTRODUCTION

The deceased child (Bethany) lived with her maternal grandmother in Boulder. She had been severely disabled from birth and required a high level of full time care for all aspects of daily living, including mobility, which her grandmother provided.

On the morning of 27 February 2012 Bethany was noted to be awake by her grandmother who turned her onto her left side so she could face the window.

A short time later her grandmother's partner passed Bethany's room and could not hear any sounds. This was unusual so he went into the room and located Bethany, unresponsive, on her left side but with her face turned into her pillow. Emergency Services were called and cardiopulmonary resuscitation (CPR) commenced. Bethany could not be revived.

Bethany was 5 years of age.

Bethany was in the care of the, now, Department for Child Protection and Family Support (the Department) and placed with her maternal grandmother.

All deaths of children in the care of the Department require there be a public hearing, by way of inquest, into the circumstances of the death of the child, pursuant to the *Coroner's Act 1996* (s3, s22(1)(a)), and a Coroner must comment on the quality of the supervision, treatment and care (s23(5)) of the child while in the care of the Department.

BACKGROUND

Bethany was born on 25 June 2006 at the King Edward Memorial Hospital (KEMH) in Subiaco. The Department had been involved with Bethany's parents since approximately 1995 due to their involvement with some of Bethany's siblings. However, in 2006, the Department did not have the protocols now available under the revised Act and there was no pre-birth planning in place for Bethany.

It was known by the medical practitioners involved in Bethany's mother's pregnancy that Bethany would be born with microcephaly, underdeveloped brain, and ventriculomegaly, enlarged ventricles of the brain, from the time of an ultrasound during pregnancy. This information was not automatically passed to the Department in 2006

and the Department was unaware Bethany would be born with severe disabilities. Bethany's mother had continued to use toxic substances during her pregnancy which were thought to have impacted upon Bethany's appropriate development during pregnancy.[1]

The medical disabilities which Bethany suffered from birth included spastic cerebral palsy GMFCS level 5, severe developmental delay, intractable seizures disorder, cortical visual disturbance, bulbar dysfunction, subluxation of her left hip, and as a result she had severe spasticity with no voluntary motor abilities. She needed full support for all aspects of her care, was nonverbal but sociable in that she laughed and smiled at people when she was happy and had some ability to recognise the differences between her sisters.[2]

From the time of her birth until 22 August 2006 Bethany remained in hospital as the only place capable of caring for her. On 22 August 2006 her parents signed a minute of consent orders agreeing to a protection order for Bethany. This allowed the Department to seek appropriate carers for Bethany.

Initially, that was to be with relative carers within Western Australia, but none were available and as a result Bethany's maternal grandparents travelled to Western Australia from

[1] t 04.11.14, p5
[2] Ex 1, Tab 19

South Australia, specifically to take care of Bethany. Due to the level of care required by Bethany her maternal grandparents needed to be trained in the care necessary, and this was done via a group home in Geraldton.

Bethany travelled from Princess Margaret Hospital (PMH) to Geraldton to be trained with her grandparents.[3]

Bethany' s maternal grandmother commenced her training in Geraldton on 1 August 2006 before Bethany was released from PMH. Once she had completed the training and learned how to care for Bethany's needs, Bethany was placed with her grandparents permanently from 14 November 2006. On 13 January 2009 an order was obtained for Bethany's protected care until she was 18 years of age.

The original prognosis for Bethany was she was unlikely to survive beyond the age of two. She frequently incurred serious seizures which seemed to be triggered by respiratory infections and required her constant supervision and monitoring. Additionally, Bethany was unable to move herself and required to be moved frequently to prevent the development of bed sores.

Bethany also had difficulty with being fed when young. Although her maternal grandmother was able to position

[3] t 04.11.12, p8

her and feed her effectively others were not as successful. Bethany's maternal grandmother was the only person who could achieve this level of care and whenever Bethany required hospitalisation there were problems with vomiting and the development of aspiration pneumonia. This again exacerbated her seizures.

In early 2009 a video fluoroscopy study demonstrated Bethany had an unsafe swallow and it was as a result of that she was provided with a nasogastric tube, certainly necessary when people other than her grandparents were feeding her.

By the time of her death Bethany was fed via a feeding tube into her stomach and required to be fed six times a day, each feeding taking as much as a half an hour. It was also necessary Bethany be provided her medications via her feeding peg.

Housing

Following their training in Geraldton the family moved to Boulder where there was family support. Bethany's grandparents also cared for three of Bethany's sisters with the help of one of the maternal grandmother's other daughters.

In 2009 a Department of Housing and Works special purpose home was allocated to the family. This facilitated Bethany's care.

Bethany was originally cared for by the Paediatric Neurologist at PMH, Dr John Silberstein. In 2009 he referred her to the Centre for Cerebral Palsy for, assessment. She was assessed by Dr Anna Gubbay Consultant Paediatrician, and it was recommended Bethany be accepted for services from the Centre of Cerebral Palsy to augment the local support she was already receiving by way of physiotherapy, speech therapy. It was also agreed Bethany would receive assistance from the Disability Service Commission. This allowed access to their Community Aids and Equipment Program, which through the allied health team at the Kalgoorlie Hospital, was able to fund Bethany's medical care and provide the specialised equipment necessary to care for her appropriately in the community.

In 2010 the Make a Wish Foundation installed a spa and heated pool with decking in the home for Bethany's aqua physiotherapy at home.

In Boulder Bethany's paediatrician was Dr Murali Narayanan at Kalgoorlie Hospital and Dr Narayanan attributed Bethany's longevity directly to the care of her maternal grandmother.

Respite

Due to the severity of Bethany's conditions the Department ensured her maternal grandmother was provided with respite care. She was required to take five days respite care per month, with another five days available should she need it. However, the difficulty with providing care for someone as complex to deal with as Bethany, and due to Bethany's preference for the presence of her grandmother, meant her maternal grandmother frequently went for periods without appropriate respite.

On the occasions upon which respite could be organised Bethany attended the Lady Lawley Facility in Perth and it was necessary her maternal grandmother transport her to Perth for respite care, so she could herself have a break.

Due to Bethany's maternal grandmother also suffering health issues in January 2011 an APMH Social Worker expressed concerns about the family's ability to care for Bethany, long term, with her grandmother's declining health. A care plan was put in place on 2 February 2011 to ensure the continued input of many service providers in the Kalgoorlie area to address Bethany's ongoing care needs as she grew older and her maternal grandmother sought more input from service providers.[4]

[4] Ex 1, tab 25

In late 2011, while Bethany was in respite at the Lady Lawley Cottage Facility, she was transferred to PMH on two separate occasions. Initially, on 9 November 2011 she was observed to have an elevated temperature, but was discharged back to the Lady Lawley Cottage. She returned to PMH on 15 November 2011 with a high temperature and this time was admitted.

Lady Lawley Cottage had noted an increase in Bethany's seizure activity and she was distressed and difficult to settle. This was an extended respite period and on admission a previously undetected fracture was found in her femur above the knee. Due to Bethany's very fragile bones this could have been caused with minimal trauma arising out of one of her seizures, or even an apparently insignificant knock. Bethany was transferred from PMH to Kalgoorlie Hospital by the Royal Flying Doctors Service (RFDS) with her leg in a cast. There were concerns prolonged hospital stay would increase Bethany's risk of infection, and consequently her seizure activity, but her maternal grandmother was not confident about caring for Bethany at home while she had a cast on her leg.

On 24 January 2012, following assessment by an occupational therapist, Bethany was discharged home. Her maternal grandmother was confident she would now be able to care for Bethany at home and the assistance of the Goldfields Individual and Family Support Association

(GIFSA) was also incorporated. On her discharge home arrangements needed to be made to provide Bethany's home with a sling and a hoist to assist her family with her movements.

Certainly, from the Department's perspective, this extended period of hospitalisation arising out of the period of respite for Bethany's maternal grandmother, appears to have highlighted the fact Bethany's maternal grandmother was best able to care for her in the long term. The difficulty was her maternal grandmother's health. It was necessary further care options were put in place for Bethany. One of her maternal grandmother's other daughters, Bethany's aunty, was provided with training in an effort to support a care plan involving Bethany's long term care. Certainly Bethany's family of origin, excluding the difficulties for her parents, were anxious to provide Bethany with care and wished to help.

The proposal was for an additional care plan to be put in place from February 2012 for Bethany's ongoing care, with additional support from family member's, other than her maternal grandmother.

It was around this time Bethany was enrolled in the O'Connor Educational Support Unit for the start of the 2012 school year and considerations were made by both the Disabilities Service Commission and the Department as to

equipment which would best assist Bethany with her forthcoming exposure to a special needs educational facility.

Overall, it was clear Bethany's placement in the household of her maternal grandmother ensured she was provided with continuity of care and familiar surroundings. It was clear the whole family was emotionally attached to Bethany, not just her maternal grandmother, who certainly dedicated her life to providing for Bethany's needs.

Bethany's placement with her maternal grandmother was the only reliable, and was certainly the optimal, placement for Bethany with her severe disabilities.[5]

By the end of February 2012 steps were in place to provide a new care plan which would accommodate Bethany's upcoming enrolment at the O'Connor educational facility. Bethany was being cared for by her very attached maternal grandmother and supported by other members of the family.

On Sunday 26 February 2012 Bethany's maternal grandmother was at home with her partner, no longer Bethany's maternal grandfather, and his son. Before she went to bed she ensured Bethany's feeding machine and medications were off.

[5] Ex 1, Tab 25

27 FEBRUARY 2012

On Monday 27 February 2012, Bethany's grandmother went into Bethany's room at approximately 5:30am and realised Bethany was awake as usual. Bethany's maternal grandmother turned Bethany onto her left side, so she could face the window, and then she went back to bed.

A short while later Bethany's maternal grandmother's partner went passed Bethany's door, but could not hear Bethany making sounds as she normally did. Bethany usually laughed and made noises when she was contented. He went into Bethany's room and saw her with her face turned into the pillow. He checked on her and found she was not breathing. He called out for her maternal grandmother.

The emergency services were called and the phone was put on loud speaker so the family could start CPR on Bethany. This was continued until the ambulance arrived.

The paramedics found Bethany lying on a mattress on the floor with her maternal grandmother attempting CPR. The paramedics continued resuscitation efforts but they found Bethany to be unresponsive. Her maternal grandmother was advised Bethany had died.

Bethany's Paediatrician, Dr Narayanan, was informed by Kalgoorlie Hospital that Bethany had died and he advised Bethany's departmental case worker that, from their perspective, Bethany's death was not unexpected, and she was effectively in palliative care. Dr Narayanan consistently commented on the fact Bethany's extended life expectancy was due to the dedication of her maternal grandmother who, with the assistance of the Department and other services, had been able to provide Bethany with optimal care. It certainly would not have been possible without Bethany's maternal grandmother's dedication.

POST MORTEM REPORT[6]

The post mortem examination of Bethany was carried out by Dr Cadden of the PathWest Forensic Medical Laboratory. He confirmed Bethany's appearance to be in keeping with her history of Cerebral Palsy. Her parenteral feeding tube was still in place and the site of insertion was unremarkable and not a cause for concern (infection).

Dr Cadden noticed petechiae over the posterior surface of Bethany's heart and found petechiae on the external surface of her thymus glands. Her brain appearance was abnormal with possible cystic changes at the frontal aspects.

[6] Ex 1, Tab 23

Following further investigations including neuropathology,[7] Bethany's microcephaly was confirmed with gyral abnormalities and advanced hydrocephalus. Toxicology[8] revealed her therapeutic medications and overall, Dr Cadden was satisfied Bethany's death was consistent with her known epilepsy in association with cerebral palsy.

While it had been noted Bethany's seizure activity had improved by 2011 it is clear she was still vulnerable to seizure activity.

CONCLUSION AS TO THE DEATH OF THE DECEASED

I am satisfied Bethany was a severely disabled five year old child at level 5 cerebral palsy. She was unable to carry out any activities of daily living and required full time care. She was cared for predominately by her maternal grandmother, and Bethany's responses when cared for elsewhere, indicated her maternal grandmother intuitively had a good understanding of Bethany's needs, including people to whom she responded, and the need for particular positioning to accommodate her disabilities.

There were no concerns from anybody involved with Bethany's care, of which there were legion, as to the standard of care being provided to her by the Department, through the dedication of her maternal grandmother.

[7] Ex 1, Tab 21
[8] Ex 1, Tab 22

Bethany's case worker was quite heavily involved with the family and all her medical needs were overseen by the Paediatrician, Dr Narayanan, who consistently commented on the exceptional care provided to Bethany.

I am satisfied that at the end of 2011 Bethany's grandmother required a long period of respite care and during that time Bethany suffered periods of infection and irritability, a fractured femur and distress due to the absence of her maternal grandmother. Due to her maternal grandmother's state of health she was not prepared to care for Bethany at home following her discharge from hospital with her leg in a cast and Bethany was cared for in Kalgoorlie Hospital. When her maternal grandmother was confident, both of her health and how that affected her ability to care for Bethany, she was returned home. Further facilities were put in place by way of a sling and hoist to assist with her care and additional training for alternative carers, however, it remained the case Bethany always was vulnerable to a terminal event.

Bethany had been home in the vicinity of a month at the time she apparently suffered a seizure sometime between 5:30-6:30am on 27 February 2012 and died.

I find death arose by way of Natural Causes.

COMMENTS ON THE SUPERVISION, TREATMENT AND CARE OF BETHANY AS A WARD OF THE STATE

It is clear Bethany's placement with her maternal grandmother was an optimal placement for Bethany. Her maternal grandmother's sacrifice in moving from her home in South Australia to care for Bethany in Boulder WA was commendable.

I accept the Department provided considerable assistance by way of funding, respite, and other resources, and was able to access additional input from other support services to help Bethany's maternal grandmother. However, without Bethany's maternal grandmother's dedication Bethany would not have been as well cared for and it is likely she would have succumbed to her natural frailties at an earlier time.

I can only quote Bethany's Paediatrician Dr Narayanan as he described Bethany's maternal grandmother.

"(Bethany's maternal grandmother) has been exceptional in caring for Bethany. She has come across to the nursing team as well as I to be loving, competent and practicable person. Bethany had in turn responded to the excellent care and nurture by thriving and developing new milestones in her development."[9]

[9] Ex1, Tab 25 - Medical Reports Dr Nyaraman 2008, 2010 in DCP files

The supervision, treatment and care of Bethany by her maternal grandmother, following her placement and assistance from the Department, was exceptional.

E F VICKER

Deputy State Coroner

19 December 2014