Coroners Act, 1996
[Section 26(1)]

Western  ***Australia***

RECORD OF INVESTIGATION INTO DEATH

Ref No: 18/15

I, Evelyn Felicia Vicker, Deputy State Coroner, having investigated the death of ***(MKP)****, with an Inquest held at Perth Coroners Court, CLC Building, 501 Hay Street, Perth, on 29 May 2015 find the identity of the deceased child was* ***MKP*** *and that death occurred on 26 December 2011 at Royal Perth Hospital, and was consistent with Seizure Disorder in association with Long Standing Hypoxic Ischaemic Encephalopathy (known severe cerebral palsy) in the following circumstances -*

Counsel Appearing:

Ms K Ellson assisted the Deputy State Coroner

Mr E Fearis (State Solicitors Office) appeared for the Department of Child Protection and Family Support and Child and Adolescent Health Services

Table of Contents

SUPPRESSION ORDER

That the name of the deceased child not be published and that the deceased child be referred to as MKP.

INTRODUCTION

The deceased child, MKP, lived with her foster parents in Thornlie. 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 foster family provided.

On the evening of 25 December 2011 MKP was put to bed by her foster mother at approximately 11:50pm. Her foster mother checked on her at approximately 4:10am on 26 December 2011 and found MKP face down in her bed. Believing MKP had a seizure her foster mother administered medication and commenced cardiopulmonary resuscitation (CPR) until the arrival of an ambulance.

The ambulance paramedics continued resuscitation and took the deceased to Royal Perth Hospital (RPH) where she could not be revived and was declared dead.

MKP was 15 years of age.

MKP was in the care of the Department for Child Protection and Family Support (the Department) and had been placed with her foster family at approximately 5 years of age.[1]

All deaths of children in the care of the Department require there be a public hearing, by way of Inquest, into the circumstances surrounding the death of the child, pursuant to the *Coroners Act 1996* (section 3, section 22(1) (a)) and a Coroner must comment on the quality of the supervision, treatment and care (section 25(3)) of the child while in the care of the Department.

BACKGROUND

MKP was born on 27 April 1996 in Nambour Hospital, Queensland. She was the first child of her biological mother and her biological parents separated whilst her mother was still pregnant. MKP's mother developed preeclampsia during labour and MKP was delivered by vacuum extraction. She was in poor condition following birth with Apgar scores of 0 at 1 minute; 4 at 5 minutes and 7 at 30 minutes. She was ventilated for 20 minutes and experienced seizures soon after birth. She was transferred to Royal Women's Hospital in Brisbane where a computed tomography (CT) scan of her brain was reported to show possible calcification above the basal ganglia with some areas of hypodensity indicating there may well have been long standing or

[1] t 29.05.15, p7

previous compromise of her cerebral circulation, in addition to acute compromise at the time of her birth.[2]

MKP was transferred back to Nambour Hospital special care nursery on 13 May 1996 where she required further treatment for seizures and was later admitted to the Royal Children's Hospital in Brisbane where a repeat cranial CT scan showed extensive areas of brain damage. Both, clinical and neurological examinations were indicating MKP would probably suffer from severe cerebral palsy. She was provided with anti-epileptic medications and these initially provided relief from her epileptic seizures.

MKP and her mother moved to Perth, Western Australia on 10 September 1996 where her biological mother hoped to have more family support in her care of MKP.

Once in Western Australia MKP was assessed by paediatrician, Dr Somerville, who diagnosed her with significant developmental delay, seizures and severe cerebral palsy, level 5 on the gross motor function classification system (GMFCS) which is the most severe form. It signifies the sufferer has physical impairments which restrict voluntary control of movement and the ability to maintain head and neck position against gravity, is impaired in all areas in motor function, cannot sit or stand independently, even with adaptable equipment and cannot

[2] Ex 1, tab 12

independently walk, though may be able to use powered mobility.

In total MKP had spastic quadriplegia, epilepsy, contractions in her upper and lower limbs, a fixed spinal lordosis and scoliosis (curvature of the spine) and was confined to a wheel chair. She was intellectually impaired and suffered visual impairment and severe aphasia. She suffered repeated episodes of aspiration pneumonia. She eventually required feeding through a gastrostomy tube (PEG) and underwent a repositioning of her oesophagus in 1998 to assist with persistent feeding difficulties with vomiting.

MKP required a high level of support. She could not mobilise and required daily handling, positioning and the use of equipment for feeding, sleeping, bathing and playing. She needed therapeutic programs to maintain her development and prevent further deformities and to provide stimulation.

Lady Lawley Cottage (LLC)

LLC is a service run by the Australian Red Cross and provides support to families with children who have multiple disabilities.

MKP's biological mother was having increasing difficulty coping with her very high care needs and needed respite

both in and out of home. Eventually, following concerns from both her biological mother, Princess Margaret Hospital (PMH) and respite care facilities it was agreed MKP's biological mother was unable to care for her adequately and MKP was placed in the Lady Lawley Cottages (LLC) as a form of respite. MKP's biological mother attended LLC in an attempt to learn how to adequately care for MKP but this also was unsatisfactory and MKP remained at LLC while long term care was sought for her future.[3]

MKP received regular reviews and support from a range of medical specialists and various health professionals including dieticians, speech pathologists, occupational therapists, and physiotherapists. She was assessed for and provided with aids and equipment as needed including splints for her hands, orthotics for her feet and a wheelchair. Her therapy needs were initially met through the Disability Services Commission (DSC). MKP remained at LLC while long term foster placements were assessed for their suitability.

On 12 January 1999 a Care and Protection Order was applied for to place MKP in the care of the State of Western Australia until she reached the age of 18 years. It was issued on 24 March 1999.[4] MKP's care was managed by agreement between DSC, LLC, PMH and her biological mother when she could be located. DSC provided financial

[3] t 29.05.15, p7
[4] Ex 1, tab 13

funding for accommodation and equipment while the Mofflyn Family Care Services (now Uniting Care West) attempted to find a suitable placement for MKP long term. While there had been some potential carers in early 2000 these withdrew and MKP started to receive visits from a care advocate organised through the Citizen Advocacy. That care advocate remained involved with MKP throughout her life and later assisted her foster family with respite care.[5]

In July 2001 Mofflyn Child and Family Care Services arranged for MKP to have home visits with the Murphy family and in September 2001 the Murphys formally accepted and signed a contract to foster MKP. She was discharged to the care of Mrs Murphy on 1 November 2001.

The Murphy family developed a strong bond with MKP. Mrs Murphy, in particular, was able to interpret MKP's limited communication ability. MKP could smile in pleasure, cry or grimace in pain or discomfort and was to a certain extent able to communicate by eye blinking, eye or tongue pointing and, despite having cortical visual impairment which affected her visual acuity, seemed to enjoy watching the television. She was noted to enjoy listening to music and was observed to respond to touch.

Relevant services, PMH, DSC, her paediatric neurologist, Dr Silberstein, and LLC all remained involved with MKP and

[5] 17 May 2001 LLC files

the Murphy family received respite via the Cerebral Palsy Association and LLC as needed. This was regular and frequent due to the level of care needed by MKP.

MKP initially attended Mosman Park Primary School when she was at LLC and later moved to Beasley Primary School which had facilities more suited to her special needs.

Once she was living with her foster family in Thornlie she was transferred to Kenwick School[6] which had a special needs education program. An individual education plan was developed to teach MKP each semester according to her needs.[7] She also attended various events organised through Uniting Care West (Mofflyn Family Care Programme) and other organisations with her foster family.

LONG TERM FOSTER CARE

MKP remained with the Murphy family as her foster family, from November 2001 until the time of her death. With coordinated care arrangements through the Cerebral Palsy Association and LLC providing respite, and her foster family, supported through the DSC which provided access to regular physiotherapy and other necessary aids via her paediatrician at PMH, MKP's many needs were met.

[6] t 29.05.15, p9
[7] Ex 1, tab13, 3

A number of specialists at PMH were involved in her care, and through it all her foster family provided her with a loving, safe and nurturing home environment from which she was able to access both educational and medical needs. It was noted by organisations involved with MKP, both before her placement with the Murphys and following her placement with the Murphys, that her quality of life was considerably enhanced by the presence of her foster family and devotion of Mrs Murphy.

Medically MKP, through the years, suffered recurrent respiratory tract infections, often associated with aspiration due to her medical difficulties. She was provided with medical intervention when possible however, compromises were sometimes needed between different treatments which interfered with one another.

According to her paediatric neurologist, children with cerebral palsy suffer problems as they mature due to the natural increase in muscle power and tone, which occurs with increasing age, tending to amplify their spasticity and its secondary effects on their posture and deformity.[8]

MKP required intensive physiotherapy and orthotic devices and surgery in an attempt to alleviate some of these secondary problems. With respect to her spasticity, muscle relaxant medications had to be used with great care

[8] Ex 1, tab 12

because many of them can be quite sedating and potentially predispose to retention of oral secretions and therefore chest infections, a problem due to reduced mobility. However, the increased muscle tone itself interferes with the ability to protect airways, cough, yawn and take deep breaths and maintain lung volume. Various medications were tried in the case of MKP, but found to be unhelpful.

In July 2005 MKP was commenced on new medication which relaxed her muscles, but did not cause drowsiness or the retention of chest secretions. She was also provided with regular intramuscular injections as a form of muscle relaxant, but very specific muscles needed to be targeted due to her need for a great deal of muscle relaxant. Those which were most likely to enhance her comfort were the muscles selected.

MKP's growth was causing increasing difficulties with her sleep, because of the difficulty with keeping her comfortable. She continued to be susceptible to respiratory infections and it was believed her ongoing requirement for broad spectrum antibiotics therapy, induced a methicillin resistant *Staphylococcus* strain.

As she grew older, so did MKP's medical problems increase. By October 2011 there were concerns with her increased drowsiness, reflected by drops in her oxygen saturations.

MKP had last been seen by her neurologist in May 2011. It was reported she appeared to be intermittently sleepy and in pain which was difficult to localise.

In October 2011 she was diagnosed with the eye condition, keratoconjunctivitis, and provided with treatment. She remained drowsy and suffered intermittent oxygen desaturations to as low as 77%. This was sometimes resolved by a change in her positioning. It was noted she suffered periods of snoring and wheezing which could also be assisted by repositioning. It was felt the deceased was suffering sleep apnoea and this was exacerbated by her increasing weight, as she grew, with restricted mobility.

MKP's paediatrician, Dr Kate Langdon, noted on her October admission to PMH that her conscious level was notably, significantly reduced, and MKP spent much of her time with her eyes closed, with a reduced respiratory drive and blood carbon dioxide levels slightly higher than the normal range. Her obstructive sleep apnoea appeared to be present during the day as well as at night and her increased weight was causing problems with her transfer and care.

Dr Langdon felt it was time to provide a plan for managing a medical emergency situation with all parties involved with MKP and her care.

There was clearly some discussion between the Murphy family and the specialists caring for MKP at PMH in the months leading up to her death. There was some tension between the Murphys and MKP's medical advisors as to expectations for MKP's long term prognosis. The Murphy family were warned the indicators were not encouraging and that it was unlikely MKP would be able to survive long term care, despite their care and attention.

Due to MKP's difficulty with respiratory depression often alleviated by repositioning, Mrs Murphy formed the habit of attending to MKP regularly throughout the day and night to ensure she was positioned in the optimum positions for her wellbeing.

Due to the severity of MKP's cerebral palsy she was at high risk of death for many reasons. The severity of her brain damage interfered with her ability to regulate her physiology and had adverse effects on her respiratory drive, reflex, stomach and bowel motility, temperature regulation and fluid balance. Her mortality risk increased with age due to the inevitable effects of normal growth aggravating the mechanical effects of her spasticity, immobility, and resulting secondary deformities. These all had adverse effects on her comfort and therefore quality of life.

MKP was predisposed to recurrent respiratory infections which could progress rapidly, resulting in respiratory

obstruction and respiratory failure, with her inability to adjust her posture for her own comfort or to maintain her airways without external assistance. Her ability to clear her own secretions and the drive and efficiency of her respiration was compromised due to the combination of impaired central control and the increasingly adverse mechanical effects of her spasticity and deformity with growth.

Following MKP's admission to PMH in October 2011, her lead paediatrician, Dr Langdon, wrote to the Department requesting a multidisciplinary meeting to discuss MKP's prognosis and the ability to deal with her increasing respiratory impairment. The Murphys were attempting to reposition MKP as frequently as possible. This inevitably led to periods of exhaustion for all those caring for MKP. While a meeting was planned it had not been finalised by Christmas of 2011.

EVENTS LEADING TO DEATH

On the evening of Christmas Day 2011 MKP was put to bed by Mrs Murphy at approximately 11:50pm. She was positioned as optimally as possible and Mrs Murphy went to bed. She awoke at 4:10am and immediately went to assist MKP but found her unresponsive and face down in her bed. Mrs Murphy thought MKP might have had a seizure and

administered 5mg of rectal diazepam. She commenced CPR and continued until the ambulance arrived.

MKP was conveyed to RPH but unfortunately could not be revived and was certified life extinct shortly after her arrival at RPH.

POST MORTEM EXAMINATION

The post mortem examination of MKP was conducted on 3 January 2012 by Dr G A Cadden of the PathWest Laboratory of Medicine WA. Initially, following the post mortem examination, the cause of death was given as undetermined, however following ongoing extensive investigations, including neuropathology, Dr Cadden formed the view MKP's death was consistent with a seizure disorder in association with long standing hypoxic ischaemic encephalopathy (known severe cerebral palsy).

Dr Cadden noted prominent scoliosis, apparent microcephaly, pulmonary congestion/oedema a nonspecific finding and cholesterolosis of the gall bladder. The neuropathology showed a number of abnormalities including microencephaly, with features of long standing hypoxic ischaemic encephalopathy. Microbiology showed abundant growth of group B *Streptococcus*, of unclear significance, and toxicology revealed prescribed medications in therapeutic or sub-therapeutic doses.

CONCLUSION AS TO THE DEATH OF MKP

I am satisfied MKP was a severely disabled 15 year old girl with level 5 cerebral palsy which significantly affected her ability to function independently. It appears that while there were difficulties with preeclampsia around the time of her birth, there may also have been problems preceding that which affected her appropriate brain function.

MKP's mother was young and found caring for MKP increasingly difficult until eventually concerns were raised by external facilities as to her ability to continue to care for MKP. Her biological mother voluntarily relinquished care of MKP to the Department for Child Protection and Family Support following her moving to Western Australia from Queensland.

MKP's care was always dealt with by a multidisciplinary medical team to cater for her many medical difficulties, and a combination of services provided by the Cerebral Palsy Association and the Disability Services Commission, working in conjunction with the Department and PMH. Eventually, MKP was placed permanently in the care of the State via the Department and attempts made to find appropriate long term carers to ensure her best possible outcome.

One of the difficulties for MKP and her carers, and those involved with her care, was the fact that as she grew so her difficulties were exacerbated from a mechanical perspective due to her growth.

The Murphy family became her long term carers in November 2001 and MKP remained with that family, cared for unstintingly by Mrs Murphy, Mr Murphy and their other children. There are disarming quotes in the case notes describing case workers visiting the family and finding MKP being cared for by her foster siblings, by way of having her hair brushed, and her delighted responses, and appreciation of the tactile input.

There is no doubt the care and family environment provided by the Murphys ensured MKP had the optimal quality of life for someone with her extremely difficult medical conditions.

She was provided with schooling at schools with special needs facilities and at the time of her death was a student at Kenwick School where she had an individual educational plan concentrating on improving her ability to communicate with other people by her responses to stimuli.

Unfortunately, in the months before her death MKP's ability to physically self-protect from further respiratory depression was impaired due to her growth and mechanical impairment of her already compromised respiratory drive. Concern was

raised by her medical advisors as to her ongoing ability to be adequately oxygenated due to her difficulties causing ongoing desaturation. This, in a child with a brain already affected by long term hypoxic considerations.

Before a medical plan could be implemented for her emergency care should she decline rapidly, an emergency arose on the night of 25 December 2011, and MKP died before a specific plan could be conceived. It is likely the deceased's respiratory depression contributed to whatever circumstances surrounded her death and her propensity to suffer seizures, especially at times of increased respiratory need.

I find death occurred by way of Natural Causes.

COMMENTS ON THE SUPERVISION, TREATMENT AND CARE OF THE DECEASED CHILD

There is no doubt MKP's placement with the Murphy family was an optimal placement for MKP.

The Murphy family's dedication to her care, stimulation and optimal physical input was extraordinary. It is clear the Department, in conjunction with the other services involved in providing resources to the Murphy family to assist in their care of MKP was significant, but nothing could replace the love, support and attention provided to MKP throughout the last ten years of her life. As said by MKP's paediatric

neurologist, MKP *"was in long term foster care with a most devoted and attentive foster family who provided a very high standard of care and advocacy on her behalf"*.[9]

There is no doubt the supervision, treatment and care of MKP by the Murphy family and Mrs Murphy, following her placement with them, was exceptional and allowed the Department to ensure her supervision, treatment and care were outstanding.

E F Vicker
Deputy State Coroner
18 June 2015

[9] Ex 1, tab 12