

## PINEAL CYSTS — TREATMENT

### *Grievance*

**MR D.A. TEMPLEMAN (Mandurah)** [9.53 am]: Minister, my grievance this morning is about the urgent need for government action to assist Western Australians suffering from pineal cysts. Today in the gallery, along with her parents Lynda and Peter, is 15-year-old Cortney Vinten, a young Mandurah woman. Since the age of two Cortney's health has been like a rollercoaster ride. Constantly suffering from debilitating migraines, Cortney was referred to specialists at Princess Margaret Hospital for Children for treatment and management. In 2008 an MRI found what was classified as an incidental pineal cyst on her brain. Remarkably, the family was not even informed of this incidental pineal cyst until a few years later. Two more MRI's were performed on Cortney in 2012 and 2013, which reported that her pineal cyst was stable, but the symptoms, including the migraines, continued and, in fact, intensified. Cortney's health has deteriorated rapidly and in July 2013 Cortney had a ventriculoperitoneal shunt inserted to help relieve the hydrocephalus pressure in her brain and behind her eyes. Delays in treatments have resulted in Cortney having permanent damage to her retinas and most of the time she is now reliant on a wheelchair due to balance issues and because she is easily exhausted. Cortney now needs to be home schooled in Mandurah and cared for around the clock. All Cortney wants is to live without pain and for her symptoms to be understood and real treatments given that actually help her.

Over the years Cortney and her family have been back and forth countless times from Mandurah to Princess Margaret Hospital for Children in Perth for appointments and assessments. Her parents, Lynda and Peter, tell me that they get very frustrated and distressed when medical professionals tell them, "Sorry we can't fix her; take her home and bring her back if she doesn't get better or keep bringing her back until we get it right." Peter and Lynda tell me simply, "We want our beautiful girl well again".

There are many other people in the state and around Australia suffering with this condition. Some have been lucky enough to have their cysts removed by renowned Sydney-based surgeon Dr Charlie Teo. Teresa Hope, who is also in the gallery this morning, had a pineal cyst removed in November last year and, thankfully, is now on the road to recovery. But like many others seeking surgery, there was a financial cost for Teresa. It cost her over \$40 000 to get to Sydney, have her cyst removed and recover before returning home. In desperation, Teresa and her family sought out Dr Teo to relieve her of an almost unbearable life prior to her surgery. Teresa had become wheelchair bound because of severe balance problems and surgery was her only option.

Cortney Vinten wants to be relieved of the pain and suffering she is experiencing now as a young woman. Cortney and her family live now in hope that either Dr Teo in Sydney or Dr Dong Kim in Houston, in the United States of America, will offer Cortney surgery to remove her pineal cyst. The family itself has already started fundraising to try to raise the money for this to happen. But minister, what does Cortney, her family and other sufferers and their families want of the government? What do they want of the Minister for Health and the medical fraternity? Cortney's one wish is to prevent others from going through what she is going through. They want the government, through our public health system, to recognise a pineal cyst for what it is—a pineal gland tumour—that can be symptomatic regardless of its size. They are pleading for improved education around this illness in medical teaching institutions and hospitals. They want to ensure flexible health care plans are tailored to the individual sufferer's needs. They want doctors and medical professionals to listen to the patient talking about their symptoms and they want to be heard on the medical care they want and need, especially if they have exhausted all other options.

Families need financial support to get the treatment and support they need, including access to the best professional knowledge about treatments of these cysts. If the best minds are in Sydney or Melbourne, we have to do everything possible to ensure people like Cortney have access to that expertise. Minister, Cortney, her family and other sufferers and their families need hope. They need to know that what they are experiencing is understood and that in a wealthy state like Western Australia young women like Cortney will be assisted so that she can live a healthy, happy life into the future. At the moment, it seems that it is left to families to try to get the treatments and support they know their loved ones need, and it is left to them to try to research the condition to find solutions for themselves because they do not feel that they are heard or understood here. The stress and the sheer frustration that these families experience every day are clear, but I fear it is not fully understood by those in a position to help.

It is a plea of desperation that I present to the minister today on behalf of not only Cortney, but also other people suffering from this condition. I want to thank Cortney and her mum and dad and her brothers for coming here today. I thank Teresa Hope and her family members and supporters who are also here today and the other people who are here to support the families who are going through the suffering that their loved ones are experiencing. On behalf of Cortney and her family, and the many sufferers and their families in Western Australia, I plead with the minister to take a personal interest in these people's plights and that he respond to their requests with urgency and compassion. The families in the Speaker's gallery this morning deserve that understanding because they are

living with a very, very difficult and exhausting condition, and I think they deserve to be understood. I look forward to the minister's response.

**DR K.D. HAMES (Dawesville — Minister for Health)** [10.00 am]: First, I would like to recognise Mrs Vinten and Cortney and their supporters in the Speaker's gallery. I probably need to start by describing pineal cysts. Pineal cysts sit within the middle of the brain in the pineal gland. It is called that because it looks like a pine cone. These cysts are very common. At autopsy, up to 41 per cent of people are found to have a pineal cyst. Indeed, scans show that 10 to 15 per cent of people have a pineal cyst. They affect men and women in a ratio of three to one. Generally, they are under half a centimetre in size and cause no symptoms at that size. Beyond that size, they can cause symptoms. They can cause obstruction to the cerebral aqueduct, which increases pressure within the brain and causes a range of symptoms. Cortney's cyst is 0.6 centimetres, so it is just over the size at which these cysts cause symptoms. Generally, the reason doctors do not start operating on everyone who has a pineal cyst is that they are very common. As I said, they affect 41 per cent of people, so the member may well have a pineal cyst; and, if he does not, I probably do. Therefore, doctors do not operate on people because they are mostly symptomless. Even if the cysts are a slightly bigger size but are not blocking the aqueduct, they do not cause any symptoms. Generally, the cysts become more prominent in people in their 20s and 30s, who show symptoms. They shrink in size as people get older, so they are less likely to cause symptoms.

Clearly, Cortney has lots of symptoms and they are a reflection of increased pressure; indeed, she has had a lumbar puncture. For the record, I have sought permission from the family to talk about her condition, which I would not normally do. Cortney has symptoms. She has been seen regularly, as the member said. Lots of specialists have had a look at her; indeed, she has written to Dr Teo, who has an international reputation for operating on things that a lot of other people would not. I gather that he has declined to do the surgery. Normally, the surgery required is not all that complicated; in the old days, it used to be. Surgeons used to have to open up the head to do that surgery; now it can be done endoscopically. They go in with an endoscope, put a needle into the cyst and drain it so that it no longer causes pressure.

I have spoken about Cortney's condition to Professor Bryant Stokes, who, as the member knows, is a neurosurgeon. He is also across this condition. By the way, it is listed as a neurodegenerative disorder in the letter that the member sent me. It is not a neurodegenerative disorder. There are about 31 different diseases that are neurodegenerative disorders, but a pineal cyst is not one of them. It is, in general, a simple cyst that sits within that gland in the middle of the brain. The specialists who have been looking after Cortney and doing those scans do not believe the cyst is causing her symptoms. They have the capacity in Western Australia to operate on these cysts, and, in fact, they do on occasions, particularly with larger cysts and when they believe that the cysts are causing the symptoms. I am not questioning the symptoms that Cortney has. Not all her symptoms are caused by the pineal cyst, which is the clear view of her parents. She has other symptoms from other conditions. I looked through her list of medications to treat hay fever, asthma and other conditions. Clearly, the cyst is not causing the full range of her symptoms. Clearly, there is something wrong. However, medicine is not an exact science and it is not always possible to determine the exact cause of somebody's symptoms.

Professor Bryant Stokes has spoken again to Dr Lee, the eminent neurosurgeon in this state who is looking after Cortney. She is an excellent specialist who has a reputation of her own. She is of the view that the cause of the range of symptoms is not the pineal cyst, as is the neurologist who has seen her for her symptoms over the years leading up to now. Dr Lee will contact Cortney's parents again in the near future. Dr Lee is actually sick today and is home unwell. Professor Bryant Stokes, the director general of the Department of Health, has spoken to her at home today. Dr Lee remembers Cortney very well; she remembers her condition very well. She will do her best to try to find what is causing Cortney's symptoms. At the end of the day, a 0.6 centimetre pineal cyst that, as I have said, occurs in 41 per cent of the population may cause some of those symptoms, but probably not the full gamut. There are other causes of the increased pressure within the spinal fluid. I have little doubt from reading the information that the increased pressure within her spinal fluid that was found at the lumbar puncture is causing a lot of her symptoms, but that does not mean that the pineal cyst is causing them.

**Mr D.A. Templeman:** But you can understand the frustration.

**Dr K.D. HAMES:** I do understand the frustration.

**Mr D.A. Templeman:** It's a drain on any family.

**Dr K.D. HAMES:** It is an extraordinary problem for any family when doctors are not able to find a cause. These are very highly qualified specialists who do not rely on the internet for their information. They have vast experience in managing these cysts, because, as I said, they are very common. It is not an issue of the state not having the resources or not having the people with the expertise. As the member can see, even Dr Teo, the eminent world specialist, has said that he is not prepared to proceed with her surgery. We need to try to find the cause. If the cause in the end is unknown, that will not stop treatment. The treatment is the shunt that she has to relieve the pressure, because that is the only symptom that a pineal cyst can cause. It can cause only increased

pressure within her brain fluid, and that shunt is there to treat it. The symptoms can be treated even if the cause is uncertain. Dr Lee will be in touch and will do her best to try to follow through and reassure the family that she is doing her best.