

## Inquiry into Health Services in Tasmania

12 August 2017

Ms Natasha Exel  
Inquiry Secretary.  
Parliament House.

HOBART TAS 7000

To whom it may concern.

I am writing to submit our experience with the Health Service in Tasmania.

We have had reason to be involved with the Launceston General Hospital and other allied health departments for over two decades, since the birth of our son, for some minor medical issues when he was a toddler and then most significantly when he contracted (suspected) Acute Viral Encephalitis at age six, in 1998. As such, frustratingly, we have seen the health system struggle under demand while both Labor and Liberal have been in Government.

While at no time during extensive hospital stays, and outpatient care have we ever had reason to be disgruntled with the personal care offered to our son - restrictions have no doubt however seriously impacted his health outcomes.

During the acute stage of his illness, tests that were routinely done in other jurisdictions were not carried out, we were told at the time that "They were not needed and the tests are very expensive." Testing such as metabolic screening were only done late into his illness. Genetic testing was never undertaken until Jeremy was included in another study by a mainland professor to check for SCN1A mutations.

As I write, Jeremy remains undiagnosed and during that acute stage of his illness, when his life literally was hanging in the balance it was always a great frustration to us that those tests and many others were not done.

Jeremy was airlifted to the Royal Children's Hospital in Melbourne, in an induced coma in an effort to save his life. Upon our return to Launceston and the Launceston General Hospital he continued to make grounds and eventually after just over a month we were allowed to take Jeremy home.

Jeremy was severely brain injured, however his MRI was reported to us as essentially normal. His needs post illness were high and his medical care was demanding on our entire family. Jeremy displayed extreme behaviours where he was a danger to himself, his younger two year old brother and to us, his parents. His generalised tonic clonic seizures at that stage were occurring approximately twenty times a day with hundreds of partial seizures as well at the GTC's. While he was ambulatory he needed assistance, and while his speech was making grounds (not as clear as before his illness, he was a very bright child) it was obvious he was struggling. He was at that stage, far too unwell to return to school which would happen for half days some months later.

Considering his age, his brain injury and the impact that had on him Jeremy was not offered post illness support, he should have been offered extensive therapies to aid him in his recovery.

Jeremy was not offered rehab services. He was not offered Physical Therapy, Speech Therapy or access to an Occupational Therapist.

We were handed his medicines and told to go home and love this new little person that aside from his looks in no way resembled the child he was before his illness.

In desperation we contacted (OAK I think it may have been called back then?) Child Mental Health Services here in Launceston, where we were told "We have no experience with Encephalitis, we cannot help you" Naturally we were devastated as a family at breaking point we were turned away.

Thankfully we did eventually find a brain injury service some time later - who helped us navigate our new life with a brain injured son.

We were fortunate that Jeremy did have the best neurological paediatric care with the visiting Neurologist from the RCH. We are also eternally grateful for the exceptional care offered to him over the years from his Paediatrician John Dunstan.

However, being thankful for good care does not deny the fact that our son was left untreated and unsupported which did drastically effect his health outcomes.

With the relentless seizures, and "mystery" relapse episodes Jeremy started to decline. His seizure control worsened, the side effects from four and five anti-convulsants at a time and his "weird illness" as his Neurologist Lloyd Shield described it eventually started taking its toll. As a young family we were exhausted, and worried and struggled to help our son.

Our sweet bright child, started to lose his battle. The words he spoke became less and less, and he drifted further into himself and further away from us.

If at this time, he had access to services these outcomes might have been different. If he had a diagnosis his treatment may have differed. Potentially we have been treating Jeremy all these years for seizures when there is most probably an underlying condition that should have also been treated.

However, Jeremy was put in the too hard basket and because we had learned through experience to cope with intolerable hardships on our own - he was just left to our care.

Of course, this is a very long time ago now but as you can see what leads us to our experience with the health system and services now is not a road where confident, well financed services protected our son.

Up until last year and after two years of treating Jeremy with cannabis therapy he was very stable and we rarely had need to see his neurologist or visit the hospital.

Earlier this year there was a decline in Jeremy's health to the point where one morning I took him into the ED at the LGH.

As usual, the triage, and nursing staff were excellent. The doctor on the floor was obviously very busy and was rather flippant when it came to my concerns for Jeremy. Busy doctors rarely have time to take in a medical history that spans two decades, so I do not blame him for his lack of attention.

We had some bloods done, a CT and X-Ray of his fused shoulder and then we left. Jeremy did not improve and I asked for a tele-health appointment with his Neurologist, Wendyl D'Souza. At the end of that appointment he informed me that as he was no longer funded to visit Tasmania he did not feel comfortable caring for Jeremy over Skype. To our amazement, this exceptional neurologist that specialises in epilepsy is no longer funded to

visit out State. Considering the dire state of neurological services in Northern Tasmania losing Wendyl is devastating to many Tasmanian patients.

So, we sought a neurologist appointment as an outpatient at the LGH specialist clinics. We were not prepared to put Jeremy under the care of Dr Koshi, personal experience with another family member had warned us that the doctor was severely overworked, Wendyl agreed that Dr Koshi was almost impossible to contact concerning patients. We asked for the referral to be written so that Jeremy could see Dr Simon Bower.

At the same time we asked for a referral to see the Orthopaedic surgeon, Mr Butorac, who performed the arthrodesis on Jeremy's right shoulder to get his opinion on the hardware in Jeremy's shoulder.

We received notification of Jeremy being placed on the waiting list letters for these outpatient appointments in the same week. Both letters advised a lengthy wait for an appointment. I called the Specialist clinics and was told

For Category 1 Neurology the wait for an appointment was approximately twelve months - and that it is difficult to say when an appointment for Dr Bower would be as "He only comes into the clinic as a favour there is no set schedule"

For Category 3 Ortho the wait for an appointment was twelve months and possibly longer.

As Jeremy was very unstable we found these wait times completely unacceptable and I researched Dr Bower and found he visited the Longford Medical Centre bi-monthly. We made an appointment to see him there, and in four weeks we were seen.

For Mr Butorac we asked the referral be instead written for his rooms, where we would have to pay to see him privately, rather than at the LGH Specialist Clinics. We were seen within four weeks.

Our experience with complex dental care unfortunately was no different with our son experiencing increased seizures because of a broken wisdom tooth he was expected to wait three months just for an appointment to see a specialist dentist to assess his teeth.

To attempt to rectify this we made many calls to the dental clinic, had his GP send a letter to support the urgent need for an appointment. Eventually in desperation sent a direct message to Michael Ferguson on Twitter, to which he responded. Jeremy was seen to, and his tooth was extracted under

general anaesthetic at the Mersey. Under no circumstances is it acceptable to expect a medically fragile person to wait months for specialist appointments because they are simply unable to sit in the dentist chair for an examination.

Finally, and perhaps most distressingly I would like to address the situation concerning medicinal cannabis in Tasmania. We engaged Mr Ferguson in 2014, to express our desire to see cannabis therapy be legally available to our son, and all Tasmanians who either use or seek relief from medicinal cannabis.

After absolutely no positive response from the Government we contacted Tasmania Police concerning our son's treatment. No person would doubt that this was a ridiculous situation, that in order to get the attention of a Health Minister one should have to seek advice from Tasmania Police.

In his whole life, enduring his medical complexities never once have I had to engage a politician and the police for permission to use a safe and effective medicine. The lack of understanding and compassion from our Government in this area is disgraceful.

We have begged the Government for a legal, affordable and safe cannabis medicine to be made available to our son for over three years.

Now as his health fails, and we illegally cultivate cannabis to try and alleviate his suffering, we are still forced to beg and we are at risk every day for operating illegally to ease his suffering.

Minister Ferguson is not approachable on the subject of cannabis therapy, he is ignorant to the existing science and one can only assume as to why this is the case.

Our experience within the Health System has always been fraught with frustration that Health is funded inadequately and that Government(s) often have no experience "on the ground" as a patient. As the carer of a patient in this system for over twenty years we expect that health be a priority, that how well the system is or isn't working should be transparent to all. Patients should be given the opportunity to share their experience which should be listened to and most importantly health never be used as a political football.

Lyn Cleaver

