

Submission
No 625

**INQUIRY INTO HEALTH OUTCOMES AND ACCESS TO
HEALTH AND HOSPITAL SERVICES IN RURAL,
REGIONAL AND REMOTE NEW SOUTH WALES**

Name: Mr Timothy Burge
Date Received: 14 January 2021

Partially
Confidential

I am a 65-year-old resident of Deniliquin NSW and our local Health authority is Murrumbidgee Local Health District which covers a vast amount of southern NSW. The Deniliquin hospital is the 3rd largest in the MLHD after Wagga and Griffith.

In 2010 at the age of 54 I was diagnosed with a rare autoimmune disorder Xanthogranuloma. I was treated by 2 Melbourne professors and both highly esteemed in their fields. I underwent 2.5 years of treatment at Cabrini Oncology in Malvern. I was monitored by both Doctors until March 2019 when I was given an all clear.

Late in 2019 I relapsed and was again diagnosed with Xanthogranuloma along with another rare disorder IgG4. I returned to Prof. care for treatment in January 2020 with monthly treatment at Epworth East Melbourne. Prof. declared from the outset that I was not able to have the treatment in my local rural area as they were not up to the task & he had no jurisdiction in southern NSW and would not be able to supervise treatment. I was also classed as a leukaemia patient and Deniliquin was not allowed to treat Leukaemia patients

With the onset of Covid-19 it became increasingly difficult & risky to attend Melbourne for treatment. Along with the other 1000-1500 oncology, immunology & haematology patients in this area of NSW I was faced with ceasing treatment which many did, and some have now suffered the ultimate consequence, (figures of 1000-1500 are supported by NSW Can Assist, Peter Mac and after extreme pressure, MLHD head of oncology)

My wife Shirlee, a long-standing health advocate for this area intervened and contacted Peter Mac Clinic in Melbourne and asked for a Deniliquin pop up clinic to be arranged for the NSW patients who normally seek treatment in Victoria due to lack of facilities in southern NSW and due to so called reciprocal border rights. Peter Mac were extremely interested and acted quickly stating they had their eye on this area because of the large volume of active cases related to our postcode and surrounding postcodes and were prepared to set up a pop-up clinic. The attached correspondence relates how that was almost achieved and how our local MLHD intervened at every stage to veto and put an end to the suggestions going so far as to tell Peter Mac, "there were only 41 patients in this area" and that they were in the process of re-certifying the tender. They admitted to not having enough staff and at every confrontation, insisted they were in the process of employing oncology nurses as far back as 2018. The last oncology nurse resigned in December 2019 due to lack of support and the stress of her job – MLHD then organised a visiting O/N to travel from Griffith when the credentialed Albury Border oncologists were due to visit which was supposed to be bimonthly - this dwindled out and the patients all had to go to Albury or interstate. During COVID-19 this became impossible sometimes with the border closures to even enter Victoria – subsequently many patients gave up treatment or were put on long waiting lists as Albury was not able to accommodate the massive demand. Patients have succumbed earlier than expected and a close friend aged in his early eighties is currently on his last battle – one of his last trips to Victoria involved the following.

6.00am Car trip from Deniliquin to Tocumwal 78kms where he walked across the bridge into Victoria assisted by a policeman. Collected on other side by a relative who then drove him to the outskirts of Melbourne 270km and put him in a taxi to a Peter Mac clinic in Box Hill he received his oncology infusion was discharged late afternoon by taxi to the outer drop off point recollected by the relative who then drove him to the Tocumwal border where he was escorted by the police back across the border he returned to his home around 11.00pm at night and over 700kms later – if that's the best our health system can offer we have a serious issue.

I was finally allowed to have a haematology infusion at Deniliquin Oncology in September after lengthy & excessive organisation by Prof. [redacted] only to be told that my December infusion could not be held at Deniliquin. This was done in Echuca and again organised by Prof [redacted]. He told me that if we had managed to set up the Peter Mac pop up clinic I could have been accommodated here in Deniliquin. In the course of my wife's discussions with MLHD Head of Oncology where the NSW President of Can Assist was present she suggested that this area of NSW so dependant on cross border health services should not come under the same tender & credentialising processes that are applicable further into NSW. I draw this to the attention of your inquiry because for too long now we have been treated like a metropolitan suburb of Sydney. Our guidelines and practices are based on metropolitan practices and are ordained and conceived by individuals who have never been out to this corner of NSW and are blatantly unaware of the decisions made over the years and the dreadful impact withdrawing services has had. We have no daily transport services that enable us to seek treatment in a larger centre such as Wagga or Albury in a timely fashion. There are No daily return bus services to any centre in NSW or Northern Victoria that allows us to seek treatment and return in the same day. Pre covid a VLine Melbourne bus left here at 7.00am returning at 10.00pm at night with only a 5 hour window to get to specialist and back to the depot for the return journey. This was a tight schedule and sometimes patients were stranded in Melbourne overnight trying to find accommodation.

We have 2 community transport cars however they were not operative during COVID-19 due to the risk to the "Volunteer" drivers most aged over 70 and most with no first aid certificates.

The downgrading of our local hospital over the years has resulted in a mass exodus across the border into Victoria for services that were once normally provided here and with no accountability to provide by the NSW Health department and with no statistics kept by that authority which has allowed them to continually refuse to reinstate vital services here as they say there is no one out here warranting or requiring the services. The Oncology fiasco regarding the Peter Mac pop up clinic is a prime example of MLHD hiding behind the incorrect figures they provided to Peter Mac to ensure they do not have to outlay further funds to update our facility. In a nutshell they withdrew services – we seek those services across the border under our own steam – they have no record of this, so they refuse to provide any better services. They then rely on their own low usage records which are blatantly incorrect and skewed to maintain the facility at the lower usage statistics. Peter Mac, Fight Cancer Victoria and Can Assist NSW all agreed there are approx. 1000-1500 patients yet MLHD cited 41 – this a gross discrepancy by any standard and while they present figures like this to the Health Minister we continue to survive with little or no services. This is a severe disadvantage to the 20,000 residents in this area that have little or no services. This was very apparent during COVID-19 and the border closures as we had nowhere to go and Albury was inundated and unable to cope with the influx.

The future at this stage in relation to COVID-19 looks uncertain and so I urge NSW Health to finally admit that there is a large population in this border area of NSW who are far too reliant on Victorian facilities that can be closed to us in hours as was the case on NYE when Victoria imposed the lockout in the afternoon and closed the border at midnight. People requiring oncology or operations across the border that week were totally abandoned and had to cancel appointments thus pushing them further back on waiting lists.

Deniliquin should have a Cancer centre that services the immediate 20000-40000 (extended area) people that would access it. A current impending upgrade to Deniliquin Hospital cites a 3-chair oncology clinic. My wife and the Health action group she is part of have challenged MLHD over the size of the service saying they believe it should be at a minimum an 8-chair clinic. MLHD refuse to be

swayed citing their 41 number and saying we do not warrant anything larger. They refuse to acknowledge the real statistics that cross the border due mainly to MLHD's inability to hire and maintain qualified staff. A senior administrator at Deniliquin Hospital insists has oncology staff coming since 2019 to service the Oncology department yet they have never eventuated 2 years later. They maintain they have been recruiting all this time, yet we still rely on a visiting oncology nurse from Griffith. The recruitment process that MLHD has in place again is based on a metropolitan example. They offer no extra incentive to procure specialised personnel so the services remain out of reach to most and only those with private health and a thick wallet can access services elsewhere – this system needs to improve, and I implore your committee to address these oncology, immunology, and haematology shortfalls urgently as the people of this area of NSW are seriously disadvantaged and impacted to the point of dying early due to lack of available resources or due to inadequate services and pathetically low levels of staff.

The real statistics prove that we require a full-time functioning Cancer centre/clinic in Deniliquin to service this area of NSW anything less is a band-aid solution. We need to be able to accommodate the specialised service for leukaemia patients, so they are not required to travel long distances. We have a more than adequate airport at Deniliquin and if we cannot accommodate the specialists and specialist nursing personnel on a full-time basis then we need to fly them in.

My experience during this 11-year episode has been exasperating to say the least as I have a Nurse yet they refuse to work under the conditions provided by MLHD as they believed them to be unsafe and unacceptable – whenever they complained via the correct procedures they were ignored. Allegedly cancer chemicals were kept in a fridge in the men's changing room, something patients also attested to. Allegedly staff say they were bullied and told not to make waves to the point they resigned as mentioned and have never been replaced. MLHD administrators complain and say they advertise yet cannot get staff again as mentioned there is no carrot or incentive to work out here staff are treated the same as metropolitan however in a rural under-resourced area they are expected to perform well above their city counterparts.

It's my belief that the Deniliquin Hospital should in some form have governance by at least someone from this area – we are governed by the Board of MLHD none of which reside in Deniliquin yet we have the 3rd largest hospital. As stated those governing have no idea of the circumstance and disadvantages we suffer in this area and obviously are not interested or they would have instigated rectifying procedures. We were once governed by a local Board and in those days ran at a profit as we were not carrying the extra burden of highly paid administrators that appear not to have our best interests at heart. Their focus is and always has been Wagga and Albury but should have also been the redevelopment and enlargement of Deniliquin Hospital to cater for the residents of this area approx. 20000 not counting Moama who usually use Echuca facilities however during Covid closures had to use Deniliquin this surged the population to almost 40000.

I attach correspondence regarding oncology services in Deniliquin some dating back 2 years.

My wife and other health related interested parties have fought with MLHD for years over the real statistics out here that MLHD refuse to acknowledge and continue to ignore so I ask NSW Parliament to take note and rapidly do something about this dire situation. It has been proven without a doubt that local administrators and those up to the CEO of MLHD have blatantly ignored the proven existence of cancer/immunology/haematology patients for years in order to hold an already ridiculous budget in place. This costs lives and at some point they and the board need to be made accountable and stop lying to the Health Budgetary Committees and the Minister regarding actual

figures in this area of NSW. They seem to believe that we can pop over to Wagga at the drop of a hat – it is 250kms away over some of the worst roads in NSW that are perpetually strewn with dead kangaroos. It is safer to travel to Melbourne 300kms and higher quality service. The NSW Health Minister recently donated over a million dollars to the Peter Mac Cancer clinic in Echuca – that tells us he is only focusing on Victoria servicing us yet when the border closes as it did again on Monday this week again it can take up to 5 hours to travel 100 kms to Echuca. Minister Hazzard and CEO of MLHD have been made aware in the past of the sometimes, poor attitude and behaviour of Victorian Health Staff, who abuse and reprimand NSW patients saying we are clogging up their system. They refuse to acknowledge or address over 4 years of strong and sensible requests to fix the system.

I have attached correspondence between relevant parties over the past year. The correspondence belongs to my wife Shirlee and she has allowed the use of the information.

Kind regards

Timothy Burge

List of attachments

Item A Original correspondence with Peter Mac Clinic Melbourne

Item B Notes by _____ in response and in relation to upcoming Zoom meeting

Item C Meeting briefing summary

Item D Summary of the Zoom meeting

Item E Summary of later meeting with MLHD & Can Assist NSW