

Thank you honourable members of the Queensland community cabinet for your time today. I am here as someone who provides hands on support to families and patients from rural, regional and remote areas whilst attending Brisbane or regional hospitals. I currently live in Brisbane, but first lived in Bundaberg when I moved from Victoria to Queensland in 2003, have lived in Biloela and now in Brisbane.

In 2006 I had my second child here and as an ex Bundaberg resident have formed relationships with many patients and their families from Bundaberg region. I welcome the opportunity to address their concerns at this community cabinet on a local level.

Many of the families I support require it long term, whether staying in Brisbane or travelling frequently for medical appointments. Many are from the Wide Bay and Fraser Coast region.

This is all about real Queenslanders, like [REDACTED] and [REDACTED] who are with me today. Their son [REDACTED] requires multidisciplinary medical teams due to his medical complexity. They are required to travel to Brisbane for regular check ups and follow up appointments and sometimes unfortunately under emergency circumstances. They are the people who make me so passionate about my work, and even more so when preventable healthcare bungling adds to the already enormous stress of being the parents of one or more sick or dying kids.

Before I commence with facts and figures I would like to state that there are 3 children who I know and have provided support for, who have encountered delays for surgery and or follow up treatment at Lady Cilento Children's Hospital and have since passed away. 1 was from Maryborough and 1 from Bundaberg. (2 of the 3 passed away 1 month ago yesterday) The fact they were delayed in receiving treatment and have passed maybe coincidental however I want you to consider while I speak with you that sadly for some children, delays in medical treatment can or may be fatal or life altering and the effects of the delays or treatment may not be medically evident in the immediate but can be over time.

LCCH - Lady Cilento opened it's doors to its first patients on Nov 29th 2014. On this same day both Royal Children's Hospital (RCH) and Mater Children's Hospital (MCH) were decommissioned and closed for business. Lady Cilento is the only public pediatric hospital for all of QLD and Northern NSW. Mater private children's hospital is limited in the services they provide to their private patients and also rely on using and accessing Lady Cilento Children's Hospital. Our Qld hospitals are reliant on LCCH, this is why more than ever our Govt needs to listen to the families and take steps to resolve issues.

On behalf of sick kids and their families, I earnestly and respectfully request the honourable members here today under the leadership of our Premier to

- ★ Improve access to Patient Travel Subsidy Scheme (PTSS) particularly at both Hervey Bay and Bundaberg Hospitals, including working within the guidelines of PTSS and offering the services described in the patient brochure
- ★ Improve turnaround times for reimbursement of PTSS payments (waiting 6 months is unacceptable when documents state allow approx 30 working days)
- ★ Consider changing the approval requirements for an extra parent to travel as a second escort when the child is seriously ill or having life threatening treatment
- ★ Consider allowing local families to fly to Brisbane in one day where possible (within reason) to avoid staying overnight, reducing the time families are away from home and or without income, taking into consideration the physical and mental benefits to some of the sickest children in the state, especially those with a medical request to fly.
- ★ To publicly acknowledge the hardships families have faced as a result of the LNP opening the hospital too soon
- ★ Investigate the health outcomes for those who have experienced delays and cancellations
- ★ Conduct a review and hold accountable those who are responsible for allowing LCCH to open before it was clinically ready in order to identify the problems and also to gain the trust of those who have experienced responses like "minor problems" or "teething problems"
- ★ Ensure systems are in place to prevent delays when a child is requiring transfer to LCCH via RFDS or Careflight from Regional and Rural Hospitals keeping in line with the Australian Charter of Healthcare Rights
- ★ Grant special consideration for those whose loved one has been transported by RFDS or Careflight to be offered where possible the fastest and safest mode of transport (including flights) to be by their loved one's side when they are transferred to Brisbane
- ★ Seriously consider creating positions within Queensland Health and QCH that offers a "rural connect" support worker available specifically to those who are travelling to city and regional hospitals who can provide understanding of the situation and identify the services required.
- ★ Work closely with the staff unions and reps and clinicians to allow open discussion of issues needing to be addressed to improve the safety and well being of both clinicians and patients

Under the LNP government, parents were not only to be made out to be lying when they went public about a hospital that was not ready to open, witnessing untrained staff at the only medical facility for their child, were also labelled as teething problems. Despite the "Teething problems" a clinical review was conducted into the first 14 days of operation including the transfer of inpatients from both RCH and MCH.

The review findings stated -

"- This Report presents the findings of the Clinical Review in alignment with the Children's Health Queensland goals for transition, that: 1. No patient is harmed 2. Patients and families feel (are) safe 3. Staff feel (are) safe."

"Although a combination of factors generated an unparalleled level of complexity and risk, **no serious adverse events causing long term harm occurred** on the day of the move or during the first two weeks of operation of LCCH"

"There were approximately **150 media items** during November and December 2014 related to the opening of the Lady Cilento Children's Hospital. Ranging from radio interviews, newspaper and other print media, the content reached audiences across Queensland and **was consistent with the matters raised through submissions**, interviews and focus groups, and was not formally included for analysis."

"Of the 69 submissions assessed, more than half (52 per cent) were categorised as compliments and provided positive statements about the new hospital's facilities, the professionalism of staff and the delivery of patient and family centred care:" **-(AN ALARMING 48% WERE NOT COMPLIMENTS)**

"However, 22 per cent reported a less than positive experience resulting in **minor harm**, which was predominantly short term distress. "

"There were **77 issues associated with the delivery of clinical care** (figure 19), 43 per cent were positive and **57 per cent were negative**. The 'Other' subcategory included references to clinical communication with families, equipment, nutrition, patient and family centred care, and privacy. "

"**Clinical care was also felt to be affected by staff not familiar with the specialty or environment where they had been allocated**. The late allocation of nurses to their respective locations was concerning for both them and their colleagues, and some incidents reported by staff related to the inexperience of the team relative to the specific conditions of patients in their care. "

See heat map Diagram with red dots - issues or concerns far outweighs favorable or complimentary and **does not reflect 52% compliments**.

The Minister for Health Cameron Dick published a media release statement in response to the clinical review -

"Mr Dick praised the efforts of staff, management and families **who ensured patient safety was not compromised** during the commissioning and opening of the hospital.

"It's now **important that we listen to hospital staff and families** about what has happened and learn how we can do better which is something Lawrence Springborg refused to do," Mr Dick said."

Children's Health Queensland website the following info was provided via several video statements from CHQ in response to the findings of the Clinical review

- To summarise Susan Johnston

Video 1

"The Board was very pleased to receive..... and welcome the review"

"..(the review was).....in response to some media reporting around clinical care"

"**what was pleasing to us is the findings no instances of substantial harm or temporary harm to children during first 2 weeks of operation**"

Video 2

(LCCH) "**was opened when we were clinically ready to open it**"

"**we went through long process of assessing readiness**"

The CHQ board and Executive team along with the Health Minister were more focussed on convincing the public that there was no patient harm as a result of a hospital with:-

- **faulty phone and computer systems**
- **shortage of beds and staff**
- **providing untrained staff to medically care for children in specialties they are not familiar with**
- **delays in administering medication (6-9hrs for pain relief)**
- **no bins throughout the building including the Oncology ward and no hazardous waste bins**

██████ and ██████ can explain to you how delayed appointments and faulty administration services has compromised the health care of their son, especially when they see approx 7 different specialists and have only seen 2 of these specialist departments since opening in Nov 29th. Prior to that they were regularly travelling to Brisbane and now it seems they have dropped off the radar, they can tell you how travelling in a car or by train for 5 hours to arrive and be told they can't be seen or weren't aware of the appointment are then sent home with another 5 hour journey, they can tell you how it physically and mentally tires their son.

However The Minister for Health did state "A clinical review into the first two weeks of the Lady Cilento Children's Hospital has raised serious questions about the processes leading up to the opening."

The Minister then announced a review to be conducted into the commissioning of Lady Cilento but the purpose of the review " **would focus on identifying lessons for future major projects.**" it was not to ensure the best possible health care for the sick kids of QLD and NSW, it comes across it was so the Govt can do better than the LNP at opening a new hospital.

Sadly the Commissioning Review revealed many concerns. With many breaches of health regulations, legislations and even OHS. Reports of untrained staff, cancelled appointments, lost patient records, lost referrals, shortage of beds, cancelled surgeries and medical equipment missing, reflecting an unsafe hospital.

It was even revealed in RTI's that most of the clinical readiness assessment forms that were to be signed off prior to Nov 29th Opening, were actually signed off during the period that the media and public were stating their concerns that this hospital opened too early and was not ready, were signed off during Dec 5th 13th mostly. (see sample of RTI)

With all the evidence, the complaints, the review findings, and even the concerns and complaints that have come from the staff and unions, there are still many changes needing to occur, we are still waiting to find out who made the decision to open the hospital 2 months earlier than planned, and why the hospital opened earlier than planned, there has been no honest acknowledgement of how a **faulty operating hospital** with such **dysfunction** could and can and has caused short and long term patient harm. The Govt and CHQ have not acknowledged that delays in transferring to Brisbane due to lack of beds like one Hervey Bay infant experienced, can and has caused harm. This baby was requiring urgent surgery and was waiting at HBH for a transfer for over 24hrs, upon arrival was rushed into surgery, not only is this compromising the well being and health of this baby but it is isolating the baby from the only specialists who can treat her who are approx 400km away. To not even be able to ensure the best and trained speciality staff are close by in the event of a "worse case scenario", again this is an area that both [REDACTED] and [REDACTED] can share with you and how these type of situations can affect their Son [REDACTED], as all his treating specialist's are specialised pediatricians who are not available in the local region.

Patient Travel Subsidy Scheme - via Patient Brochure PDF doc

The purpose of the PTSS is to assist patients, particularly rural and remote patients, who are required to travel more than 50 kilometres from their closest public hospital when the specialist service they require is not available at their closest public hospital.

Your local hospital will provide travel subsidies for the **most clinically appropriate** and cost-effective mode of transport. Generally, the cheapest form of commercial transport (bus or rail) will be subsidised **unless you are approved for a more expensive mode of transport (based on a clinical need and/or if commercial transport is unavailable).**

In the unfortunate case of requiring return transport for a **deceased person, a relative will be provided** with a subsidy equivalent to a **full economy airfare**, to the nearest airport to the deceased person's normal place of residence.

One night's commercial accommodation may be arranged if you would be travelling by car for more than 600 kilometres or for more than eight hours in one day. You would need to discuss this with the PTSS officer at your local hospital prior to travel.

Escorts are automatically approved where you: are under 17 years of age; or need assistance to travel safely following sedation, parenteral analgesia or requiring oxygen. If you do not meet these criteria, the approving officer will consider the following conditions for approval of an escort: Will you be unable to look after yourself where you are going? **Will someone be needed to participate (or trained to participate) in your physical care or rehabilitation?** Is there anyone where you are going that can assist you in these ways?

If your local hospital is booking your travel and accommodation, you will be contacted to **discuss the most appropriate travel itinerary and accommodation options.**

Families in the Wide Bay and Fraser Coast regions have very similar concerns and complaints in regards to accessibility to PTSS,

For example while the tilt train is undergoing maintenance the diesel train is operating reducing the access by rail to Brisbane especially for those who are requiring disability seating. I know 2 of families from Hervey Bay and Bundaberg with children in wheelchairs who were unable to access disability seating on the train that arrived or departed closest to their appointment time to be told that they would have to catch the train to Brisbane a day or 2 prior in order to access the services their child requires, but they would be responsible for the cost of their accommodation, despite the documentation stating "Your local hospital will provide travel subsidies for the most clinically appropriate and cost-effective mode of transport. Generally, the cheapest form of commercial transport (bus or rail) will be subsidised unless you are approved for a more expensive mode of transport (based on a clinical need and/or if commercial transport is unavailable)."

One patient was booked on a flight to Brisbane (with a specialist request to fly) was approved for flights, was told the PTSS office had decided they had to catch a train, the train had one avail seat and Mum is required to travel with her child, after many discussions as the plane ticket had been cancelled and the train did not have enough seats they now had no way to get to hospital in time for their appointment as they do not have a license. And even when they offered to catch the tilt train the day earlier than planned they were told they must provide their own accommodation and PTSS doesn't pay for family holidays. (\$180 per night). Instead they had to ask a friend to drive them Brisbane and the friend was not approved for accommodation subsidy.

During July and August I provided support to a Mum from Bundaberg who's baby was born preemie. The reason I was supporting her was because she was not informed of her rights and the services she could access while in Brisbane.

This mother who is also undergoing mental health care was sent home to Bundaberg because she was not aware that the initial travel approval for 2 weeks accommodation could be reviewed and extended until her son was discharged. She returned home leaving her 2 week old baby in the Neonatal Intensive Care Unit. As a result this had a huge impact on the mental health of the Mum and left her son with out a mother to care for him or be close by in case of an emergency.

Once we connected Mum was back in Brisbane, her son had deteriorated and was now waiting for a bed at LCCH to have the urgent surgery he required. Mum was now under the care of the Mental Health Unit due to the stress of being away from her baby, unfortunately by the time surgery was able to be done, baby had deteriorated and was no longer able to have the surgery he required. Sadly one month ago today, this little baby gained his wings.

Mum was needing to go home after her son passed so that she could be at his funeral, it was argued by the Bundaberg PTSS that the mother was not entitled to a flight home, despite the mother quoting the above text from the brochure. "In the unfortunate case of requiring return transport for a deceased person, a relative will be provided with a subsidy equivalent to a full economy airfare, to the nearest airport to the deceased person's normal place of residence. "

It took many calls to several departments to finally have the flights approved, but by this time the grieving family had enough and needed to have Mum back in Bundy asap so the baby's father drove there and back in one day to bring her home.

This Mum lost her son, she also lost 2 weeks of her son's short life, due to a lack of support and information given to her, as a result her mental health declined and was restricted to time with her son. And then was put through further stress with PTSS during the days following his death.

██████████ and ██████████ have been told they will not be approved for accommodation and must catch the train home on the same day (departs 5pm) they arrived if there are no more appointments for the day, this puts alot of pressure on their day as often clinics are running several hours behind and they may miss their train leaving them to then have to organise accommodation and travel to get home. They have also being told they will not be approved for flights, "One night's commercial accommodation may be arranged if you would be travelling by car for more than 600 kilometres or for more than eight hours in one day. You would need to discuss this with the PTSS officer at your local hospital prior to travel."

I am sure you agree these examples reflect the need for the Govt to consider reviewing some of these policies as there are times when parents will both need to attend appointments, whether it be due to needing to learn **how to care for and treat their child** or because **bad news maybe given** while in Brisbane and **one parent requires the other to not only support their partner but also ask the important questions about their child's health**, in these situations **serious consideration should be given** to a second escort, obviously there will be others who are attending a routine check up and may not require the second escort. (Much like what was made available to the survivors of the Ravenshoe explosion) many families do and have faced similar tragedies only it was one patient not 19 patients.

Changes need to be implemented for approval of flights, if there is an appt for early morning the travel office should take into consideration the extra expense of accommodation if travelling the night prior and the effect on the child's health and education when travelling by rail or road as to plane, perhaps the Minister could introduce an assessment based on families situation in regards to loss of income because of travelling to Brisbane, some families are taking time off work without pay so they can attend one or 2 appointments in Brisbane but are required to stay overnight due to the times of the appointments and access to train or road travel when they could be home in one day reducing the loss of income.


PTSS is a fantastic scheme but unfortunately it is not always accessible or granted and is not always providing the service it was intended to do, I hear from so many parents about the delays in reimbursements taking upto 6 months or more, I have had parents calling me distressed because a simple request according to the information brochure is denied and then the family are accused of expecting a holiday. These families did not chose to have children with serious illnesses and nor did they ask for their treating specialists to be in Brisbane, they also did not ask for a singular pediatric hospital. Parents of sick kids may have a smile but often they are just like ducks, above water they seem calm and underneath they are paddling frantically to keep their head above water and then when it comes to arranging access to their child's health care service they are given further grief and difficulties from a service that provides a travel scheme to those who are required to travel for medical reasons it really is one place that should be providing understanding and empathy, not be the cause for further stress. And then on top of the issues they are having with travelling to Brisbane they are then faced with the problems at LCCH.

In closing I would like to thank you Mr Dick for your time today, I hope you better understand the importance of changes needing to be implemented specifically at Lady Cilento, 11 months since the opening of the hospital and on the surface it appears only minor changes have occurred and this is largely due to the actions and response of both the Board and Executives and the Govt, it's ironic that today I am here in the very town that is know for "Dr Death" another great example of outcomes when big decision makers are allowed to spend more time covering up the issue than preventing further incidences.

Yours Faithfully

Justine Christerson
Founder Breaking Down the Barriers for Rural Patients in City Hospitals - Brisbane
Advocate for rural patients
Australian of the Year Local Hero Qld Finalist




hard copies provided of Australian Charter of Health care rights, PTSS, heat maps from clinical review, Minister statement 30/3/15 Cameron Dick, clinical readiness assessment form