

Submission
No 944

INQUIRY INTO BIRTH TRAUMA

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Partially
Confidential

Dear Committee

Thank you for the opportunity to provide a submission to this inquiry into birth trauma. This is something that impacts me greatly, every day of my life and in so many ways. It has been difficult to capture all the information I want to provide to the inquiry within a written submission, and therefore **my husband and I would greatly appreciate the opportunity to tell our story to the Committee, to increase the Committee's understanding of the extent of the impacts of birth trauma, and flow on impacts to an individual's ability to live a normal life and contribute to society and the economy.**

Introduction

I am a mum of two children (currently 5 and 6 years) living in the . I have physical birth trauma - bilateral avulsion of the levator ani muscle (full avulsion on the right, and partial avulsion on the left) and pelvic organ prolapse (3 compartment prolapse: cystocele, rectocele and uterine prolapse) – which has resulted in flow on mental and emotional trauma, and much more.

My submission provides:

- Background on my own birth trauma
- Some statistics on the prevalence of levator ani (LA) avulsion
- The impacts LA avulsion has had on my life, and the financial implications of ongoing treatment of my condition
- My future.

Background

I had my first child in April 2017 (I was 38yrs) and my second child in June 2018 (I was 39yrs). My first child was born vaginally via vacuum, forceps and episiotomy, and I had an epidural. This birth resulted in a lot of pain, bruising and incontinence. I had appointments with my obstetrician and pelvic floor physiotherapists during this time but was not advised on the nature of my injury. During the birth of my second child (also vaginally), I had an episiotomy only.

When my second child was 5wks old, to my horror, I discovered my prolapse. After seeing a new and very experienced women's health physio, and then a urogynecologist, I was diagnosed with bilateral avulsion of the levator ani muscle (LA avulsion). I then began my journey to learn about my injury and understand the immense impact it has on my life.

*(**Note: at this point I do not want to go into detail on the births as this is part of an ongoing legal claim. However, it is important to note I was not informed by any of my caregivers of the risks of an instrumental delivery, and the high rate of birth injuries resulting from (in particular) births using forceps).*

From my own experience, I recommend to the Committee the following: **ensure appropriate information is provided on all birthing methods so women can make informed choices. Knowledge and making informed choices are key to preventing birth trauma.**

Information on risks must be provided by caregivers. Without this, patients cannot make informed choices

The prevalence of LA avulsion - the horrific statistics!

In understanding the prevalence of LA avulsion, it is important to note that women may not necessarily be symptomatic in the postpartum period, and it may even take them until menopause or the years following to realise they have a problem (when they experience significant prolapse). So they may not even seek the assistance of a medical or allied health professional for diagnosis in the postpartum period. Therefore LA avulsion is likely under-reported in the general population.

In my particular situation, only 1 of 5 women's health physios I saw was able to diagnose that I had LA avulsion from an internal examination. This demonstrates the need for better and targeted training of women's health physios. Additionally, that one physio was the only one to refer me on for imaging which is so important in confirming the diagnosis of LA avulsion.

Most women's health physios need better training to diagnose LA avulsion

During my journey to learn about my own injury, I have been horrified to learn of the statistics; how common LA avulsion is in women who have had a vaginal birth, but also that prolapse surgery for women with LA avulsion has such a high failure rate. It is shocking to me that in this day and age, there is no long term or permanent solution to LA avulsion; and that women are left to manage their condition as best they can for as long as they can, but ultimately face an inevitable worsening of their condition as they go through menopause and beyond.

I have provided some of the key statistics below with links to the source articles:

- There is evidence that 36% of women with prolapse have an underlying levator ani muscle avulsion. This avulsion occurs in 13–36% of women mainly during the first vaginal delivery by stretching and tearing of the muscle from the insertion on the inferior pubic ramus.
(<https://obgyn.onlinelibrary.wiley.com/doi/pdf/10.1111/1471-0528.12676>)
- Twenty-one percent of women sustain LAM avulsion during their first vaginal delivery.
(<https://obgyn.onlinelibrary.wiley.com/doi/full/10.1111/1471-0528.12676>).
- Incidence rates of levator avulsion following caesarean, spontaneous, vacuum and forceps deliveries were 1, 15, 21 and 52%, respectively
(<https://obgyn.onlinelibrary.wiley.com/doi/10.1111/1471-0528.16837>)
- Levator ani muscle avulsion has been observed after 50–65% of forceps deliveries
(<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4418025/#R10>)
(note in some European countries, forceps have been banned).
- Globally up to half of all parous women have some degree of clinical prolapse, but only 10–20% are symptomatic. Short-term follow-up MRI studies have shown that levator ani muscle injury is found in 10% of women after spontaneous vaginal delivery, in 25% after vacuum extraction and in 66% of women after forceps delivery, but are not seen in nulliparous women. Opening of the genital hiatus and weakening of the pelvic plate have also been shown to occur more often in women with prolapse than in those with normal pelvic support <https://obgyn.onlinelibrary.wiley.com/doi/full/10.1111/1471->

Approx. 1 in 5 women sustain LA avulsion during their first delivery

LA avulsion has been found in up to 66% of women after forceps deliveries

[0528.12020#:~:text=Pelvic%20organ%20prolapse%20\(POP\)%20is,%25%20are%20symptomatic%20\(sPOP\)](https://pubmed.ncbi.nlm.nih.gov/305281202/#:~:text=Pelvic%20organ%20prolapse%20(POP)%20is,%25%20are%20symptomatic%20(sPOP))

Information regarding long-term treatment and surgical solutions include:

- LAM avulsion has only been studied in in the past 15–20 years, therefore the evidence regarding identification, repair and long term management is lacking (<https://www.sciencedirect.com/science/article/abs/pii/S0266613822002455?fbclid=IwAR39RiNF0ieLRTe1YvzD98iJKuNzEuYVQzCIJzs66WQcOmt6ISuppKh063I>)
- The lifetime risk of prolapse surgery for all women (not just those with LA avulsion) is reported to be 11–19% in welfare states ([https://obgyn.onlinelibrary.wiley.com/doi/full/10.1111/1471-0528.12020#:~:text=Pelvic%20organ%20prolapse%20\(POP\)%20is,%25%20are%20symptomatic%20\(sPOP\)](https://obgyn.onlinelibrary.wiley.com/doi/full/10.1111/1471-0528.12020#:~:text=Pelvic%20organ%20prolapse%20(POP)%20is,%25%20are%20symptomatic%20(sPOP))).
- In general, pelvic floor surgery has a high re-operation rate, reported to be between 19% and 29.2% (<https://pubmed.ncbi.nlm.nih.gov/9083302/>).
- But surgery for prolapse in women who also have avulsion of the levator ani muscle has a failure rate of 70-80% (I was advised of this statistic by my urogynecologist, Dr _____).

The impacts of LA avulsion on my life, and ongoing management

Research done to date has concluded that women with symptomatic disorders, suffer physical and emotional distress having a great negative impact on their social, physical, and psychological well-being (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4611001/>). This includes negative effects on sexuality, body image and quality of life.

([https://obgyn.onlinelibrary.wiley.com/doi/full/10.1111/1471-0528.12020#:~:text=Pelvic%20organ%20prolapse%20\(POP\)%20is,%25%20are%20symptomatic%20\(sPOP\)](https://obgyn.onlinelibrary.wiley.com/doi/full/10.1111/1471-0528.12020#:~:text=Pelvic%20organ%20prolapse%20(POP)%20is,%25%20are%20symptomatic%20(sPOP))), as well as workforce productivity, and cost to both the individual and the health care system as a whole (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4611001/> -secondary source).

In my own situation, it has been difficult to explain to my caregivers the extent of the impacts on my life; they are so far-reaching and caused me to be so overwhelmed that I contemplated suicide. The impacts are ongoing, and with the worsening of my prolapse over time, my anxiety about the future and the lack of treatment options is extreme.

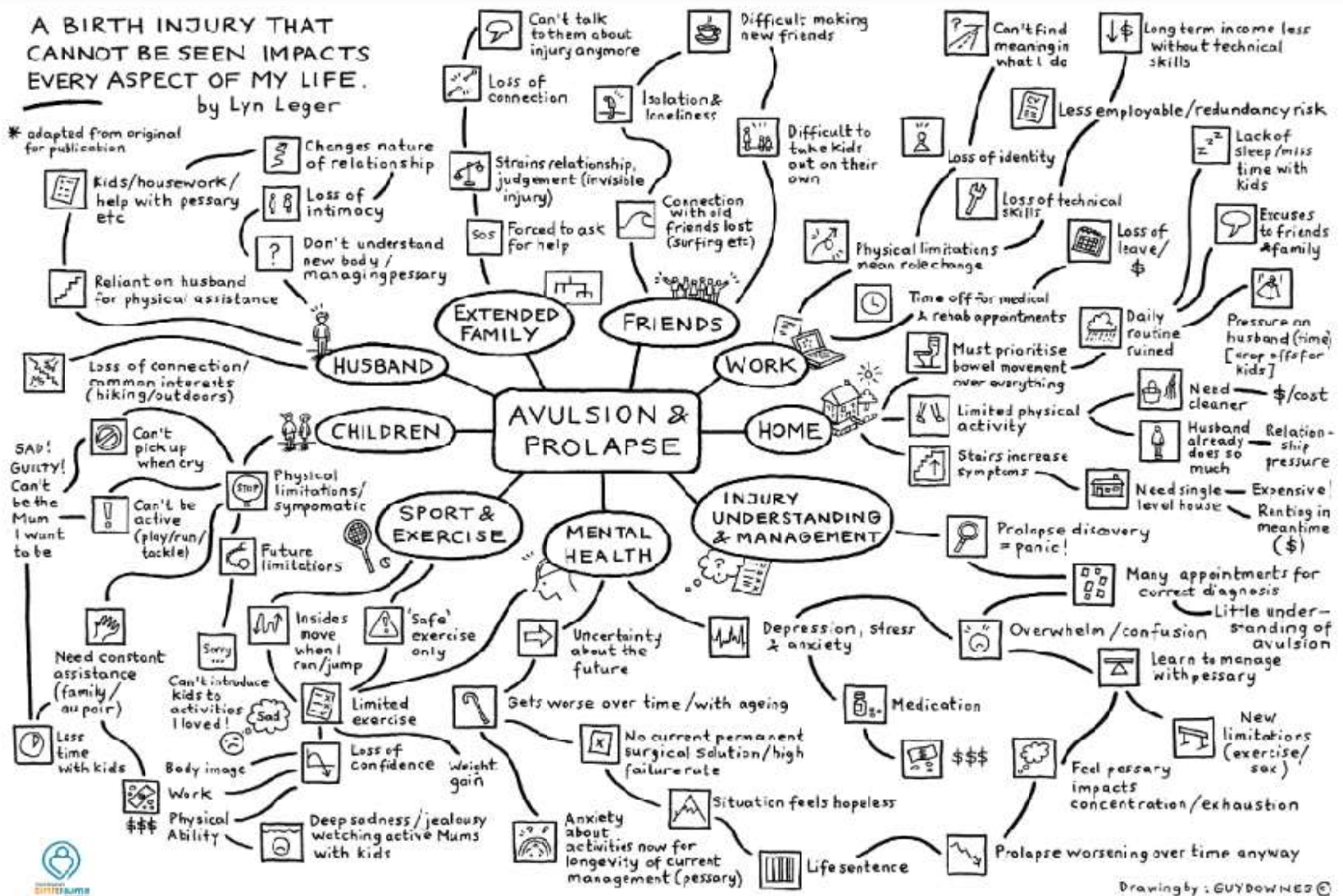
The best way I have found to explain the extent of the impacts to others is through the use of my mind map, on the next page (the professional cartoonist who drew it up for me was kindly funded by the Australasian Birth Trauma Association). **I would be grateful to be given the opportunity to present to the Committee to explain each impact in detail.**

The impacts on my life have been so far-reaching and so overwhelming that I contemplated suicide

My mind map will need to be updated as I age, as the only certainty with a LA avulsion is that my situation will worsen with time and my age. In the 5 years since I was diagnosed, I have already seen a worsening of my condition, which has had flow on impacts to how I manage it and therefore to my life in general.

A BIRTH INJURY THAT CANNOT BE SEEN IMPACTS EVERY ASPECT OF MY LIFE.
by Lyn Leger

* adapted from original for publication



Drawing by: GUYDOWNES ©

Financial implications of ongoing management of my condition

Apart from needing to change my role at work, key financial implications to me personally have been in regards to my ongoing management. With my GP we have developed an approach that works for me:

- 1 annual appointment with a women's health physio for check up and management/replacement of my pessary
- 1 annual appointment with a urogynecologist for vaginal wall erosion check up and general vaginal health/progression of the prolapses
- 2 weekly sessions with a pilates instructor with specialist training on pelvic floor but also focusing on building strength around the pelvic floor (because concentrating solely on pelvic floor exercises post-partum has conflicting evidence for efficacy - <https://www.sciencedirect.com/science/article/abs/pii/S0266613822002455?fbclid=IwAR39RiNF0ieLRTe1YvzD98iJKuNzEuYVQzCIJzs66WQcOmt6ISuppKh063I>)
- 1-2 weekly sessions with an accredited exercise physiologist for safe strength building and cardio sessions
- Sessions with an osteopath (as needed, approx. 10 per year) to ensure correct alignment is maintained, good breathing is maintained which ultimately ensures intra-abdominal pressure is reduced
- Sessions with a psychologist (as needed, approximately 6 per year).

It is important to note that I live in a regional town in the NSW , and women's health physios knowledgeable about my injury are not easily accessible and do not run appropriate classes to be able to access similar treatment to what my pilates instructor can provide.

The cost of the above approach is \$10,000+ per year. I have had to bear this cost as maintaining my conditioning is important so that I am able to continue to do my job, and be a functioning member of society.

However, **I have been unable to continue all my weekly appointments due to the upfront costs.** I am fortunate to be able to afford private health, however pilates is no longer covered and I pay the full cost for these sessions. This cost ranges \$110-\$250/week (\$250/wk if I do the 1-on-1 sessions, which give me the best targeted result for my condition).

My current chronic disease GP management plan provides only 5 subsidised allied health sessions, as well as additional mental health sessions. Pilates sessions are not covered.

As an immediate step, I recommend that cases of birth trauma be treated similar to eating disorders. In Australia, patients with an eating disorders treatment and management plan (from a GP) are eligible for comprehensive treatment and management services. This includes up to 20 dietetic services, up to 40 eating disorder psychological treatment services, and review and ongoing management services to ensure that the patient accesses the appropriate level of intervention. A similar

In regional areas, women's health physio programs appropriate to the level of ongoing treatment required is not available. Other alternatives such as pilates MUST be funded

Birth trauma treatment and management plans should be implemented, similar to those available for eating disorders, providing for an increased number of subsidised sessions with care providers

approach in my situation would be to have a birth trauma treatment and management plan which in a 12 month period would provide:

- 20-40 sessions which could be used on specialist pilates sessions and sessions with an accredited exercise physiologist
- 20 psychology sessions.

My future

There is only one certainty about my future, and that is **my condition will worsen over time**. I will likely need surgery. Currently surgery for prolapse with underlying LA avulsion has a 70-80% failure rate (statistics provided by my urogynecologist), and surgery for the actual LA avulsion injury is (at best) experimental. See the statistics section above for more information.

This situation causes me great distress and anxiety and is one of the focus areas of my ongoing appointments with my psychologist.

To my knowledge, there is no research focused on a surgical solution to LA avulsion. This needs to change. With 1 in 5 women with a LAM injury we need immediate research on:

- The economic costs of LA avulsion injury (using cost benefit quantitative evidence). This study would need to cover the impacts of this injury to a woman's psychological and physical health and well-being, i.e. how it impacts all facets of our lives, but also the limitations it creates for us in terms of participation in society (as a functioning family member, work, relationships, etc). This study could then be used as justification for funding the following research.
- Long term surgical solutions. Institutions such as the Hudson Institute are conducting research on prolapse surgery, and should be funded to conduct targeted research into surgical solutions for LA avulsion that are long lasting with a very low failure rate, and that give some hope to women like me for our long term future and quality of life.

Additionally, I will need ongoing assistance in the house with cleaners, home and yard maintenance etc. This will have a huge ongoing cost. I will be a burden to my family (and society) far earlier than I would have been without this injury. As an invisible disability, it should be treated as such, and home help provided as part of a broader care package.

Thank you again for the opportunity to submit to this inquiry on birth trauma.

Lyn Leger

We can send spacecrafts to and fly drones on Mars and we are planning to establish a community on the moon in the next decade, but we can't fix a woman's vagina after giving birth!!

We need to change our priorities, and invest in research to provide surgical solutions to LA avulsion

On a case by case basis, it should be considered whether LA avulsion and prolapse should be considered an invisible disability. Assistance should be provided as per other disabilities e.g. funding, access to parking permits