SUMMARY OF

Birth injuries: the hidden epidemic







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Please note, the following summary includes distressing content that may be triggering for some readers.

Please take care of yourself and others when reading or discussing this content. If this raises any concerns for you, please remember that help is available.

Australia

Lifeline: 13 11 14

Beyond Blue Support Service: 1300 659 467

Gidget Foundation Australia: www.gidgetfoundation.org.au

National Perinatal Mental Health Helpline: 1300 726 306

Australasian Birth Trauma Association (ABTA): https://www.birthtrauma.org.au/

United Kingdom

If you need urgent help you visit your local GP, A&E or call NHS 111.

Call Samaritans on 116 123

MASIC Foundation (supporting people injured in childbirth): www.masic.org.uk

Birth Trauma Association: www.birthtraumaassociation.org.uk/

Make Birth Better: www.makebirthbetter

PANDAS (Support for perinatal illness): www.pandasfoundation.org.uk

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1. Foreword

This is a summary to the full report *Birth Injuries: a hidden epidemic* which you can access <u>here</u>. The full report discusses our findings in further detail (including graphs and data tables), and includes more information on recruitment of participants, data collection, study limitations, a full appendix to all survey results, conclusions and recommendations for further research.

This summary, like the full report *Birth Injuries: a hidden epidemic*, shares key insights from the international survey *Birth injuries: improving diagnosis and treatment* conducted jointly by the Australasian Birth Trauma Association (ABTA), Birth Trauma Association (BTA), & Make Birth Better (MBB) in May 2022.

Birth Trauma Association (BTA), Australasian Birth Trauma Association (ABTA) and Make Birth Better (MBB) provide support and education to women, birthing people and families impacted by birth-related trauma. The BTA and MBB operate in the United Kingdom, and ABTA provides services to women, birthing people and families in Australia and New Zealand.

The Birth injuries: improving diagnosis and treatment survey was conducted in May 2022 with the view to release findings during Birth Trauma Awareness Week 2022 (18-23 July). The aim of the survey was to:

- understand how birth injuries affect the women and birthing people who experience them, as well others in their families and communities;
- and how long it took to have injuries diagnosed and to obtain treatment.

Our participants' responses quoted in this report show the major impacts birth injuries can have on daily life, mental and physical well-being, relationships and intimacy.

2. What are physical birth injuries?

Birth injuries are physical injuries experienced during childbirth. They can include but are not limited to: vaginal/perineal tears (of any degree), pelvic floor muscle damage, infected stitches, infection of the womb lining (uterus), fistula (formulation), wound dehiscence, hysterectomy, bladder damage, blood clot/s, prolapse, pudendal neuralgia, coccydynia (refers to any type of persistent tailbone pain), bone injuries (such as fractured coccyx) and other injuries not otherwise categorised that may have been experienced.

We recognise that birth injuries can impact the birthing person or the baby, however, for the purpose of this survey we focus only on which injuries affect the person who gave birth.

3. Key insights

Our survey results show there is still a lot of stigma around physical birth injuries, with people who have a birth-related injury often feeling a lot of shame in talking about it. Our results clearly show the incredible impact these injuries have on people's daily life (see key statistics under 'Impact on daily life'), which is undoubtedly something that needs more awareness.

But what's more perhaps, is that our results show a huge issue around delayed diagnosis and inadequate treatment. We feel this illustrates just how much women's health problems around birth are neglected, and with the <u>Women's Health Strategy</u> - which specifically addresses stigmas and poor diagnosis around women's health - expected to launch during Birth Trauma

Awareness Week 2022 (likely before summer recess 22 July), we believe these are key findings that cannot be overlooked.

Last, but by no means least, we feel it is important to stress that there is treatment for the most symptoms and injuries women and birthing people are experiencing. We feel in many cases they are suffering unnecessarily - with an early diagnosis and a referral to a specialist, these injuries can be successfully treated.

3.1 Diagnosis and treatment

Results from the survey suggest that obtaining a diagnosis was not necessarily straightforward as a range of health professionals were involved from whom respondents obtained their diagnosis.

- Nearly **1 in 5 respondents (17%)*** said they **had to wait at least 6 months to a year** to receive diagnosis
- Nearly **1** in **4** respondents (23%) mentioned their injury was diagnosed at different times, indicating possible **misdiagnosis**, or possibly **symptoms being dismissed or not taken seriously** (misdiagnosis and not being listened to are themes reflected by our survey)
- 3 in 4 respondents (73%) said they received treatment for their condition, yet 6 out of 10 (60%) mentioned treatment has only partially been effective; and 1 in 4 (24%) said they still have a problem
- Only 16% said treatment had been completely effective so 84% are living with the problem without a solution

*We had 801 people participating in our survey which we ran from 5 May-1 June 2022 (UK=325/AUS=416/NZ=7/Other=53).

3.2 Impact on daily life

When you consider the substantial impact birth-related injuries have on people's daily lives, their mental and physical well-being, relationships and intimacy, it's a disgrace that they receive so little attention. With the incredible stigma clinging to it, we are left wondering how many are suffering in silence.

- 84% said their injury has impacted their body confidence and self-esteem
- 83% said their injury has impacted their sex life
- **74%** said their injury has impacted their **ability to exercise**
- 73% said their injury has impacted their decision to have another baby
- 65% said their injury has impacted the relationship with their partner

3.3 Type of birth

By far the most common type of birth our respondents experienced was a vaginal birth, with 84% of people giving birth this way when they suffered their injuries. This category includes all types of vaginal births being those assisted with forceps, ventouse, or a combination of these. Thirteen participants gave birth via caesarean this includes emergency and elective. Three of the respondents gave birth via caesarean section after failed ventouse and/or forceps.

3.4 Most common injuries

The top three most common injuries reported by our 801 respondents are:

1. 291: 3rd or 4th degree tears

2. 278: prolapse

3. 199: infected stitches

Perineal or vaginal tears and/or prolapse were the most commonly reported type of injury post birth: 537 respondents reported a tear of any type - so 67% of the 801 respondents reported some type of tear as a birth injury. Of this 537, prolapse was reported by 278 – meaning that half of those that had a tear, went on to experience prolapse.

3.5 Symptoms

Two themes emerge from the responses specific to symptoms, both of which show the impact birth injuries have on a woman's quality of life.

The first is **living with pain**. Our results very clearly show the common presence of pain, with almost half of respondents (47%) experiencing vagina or vulva pain, the same amount suffering pain during sexual intercourse, over a third (35%) suffering from back pain and more than one in four (27%) experiencing abdominal pain.

The second is **living with shame**, illustrated well by urinary and faecal incontinence or urgency. More than four in ten respondents (44%) suffer from urinary incontinence and almost one in five (18%) experience faecal incontinence. These symptoms have a significant impact on quality of life.

4. Key themes

Of the 801 respondents, there were 794 usable narrative responses to the free text question: 'Can you tell us a little more about how the physical birth injuries might have affected your life?'

Eight key themes emerged from the responses provided, these are:

- Impact on self-esteem and mental health
- Misdiagnosis/delayed diagnosis
- Fear and isolation
- Ability to be physically active
- Impact on relationships and work
- Medical gaslighting
- Sex life and intimacy
- Future births and growing families

With each theme we have pulled some quotes from the narrative responses.

^{*}Please note that many respondents identified as having more than one condition

Impact on self-esteem and mental health

There were high levels of mental health diagnoses among respondents, with postnatal depression or anxiety (PNDA) being particularly prevalent.

"The physical injuries have resulted in me developing significant PPD and PTSD and quite significant anxiety. Especially health related anxiety and I have a complete loss of confidence in the medical profession. I feel I was lied to..."

"It has affected every part ofmy life. I used to be an active, independent, happy, confident person. I feel like a shell of my former self. I have lost my hope, my self esteem is so low now."

Misdiagnosis/delayed diagnosis

Almost a third (210, 29%) of respondents waited more than two months for a diagnosis, with one in ten waiting over a year before receiving a diagnosis. Respondents were often given conflicting advice, and repeatedly reported being told that persistent symptoms were 'normal'. A striking feature of our respondents narratives was how common it was for respondents to be dismissed or not believed when they reached out for help - a phenomenon sometimes described as 'medical gaslighting'. Some respondents felt delays worsened the harm or reduced their chances of making a full recovery.

"The hospital that diagnosed my sphincter tear said that it can't be fixed now, but it could have been fixed if it was picked up at time of delivery... [and] I would not be incontinent."

"None of them listened to me. I was told several variations of 'that's normal" and "it'll pass with time, all women hurt after birth".

Fear and isolation

Many respondents reported living in a persistent state of fear and anxiety, which contributed to feelings of isolation. The theme of fear reverberates through the responses. Respondents reported fear of birth; the medical system; not being able to find a toilet; being in public; complications with menopause; and the future.

"I used to be outgoing now I prefer to stay home. It's really isolating but I'd rather have a accident at home than [risk] having an accident in public"

"[I have...] lots of fear. Fear around damage to my baby by missing me for the first few hours of his life, fear ofof bladder leakage, fear of sex... fear of the same thing happening if we have a second baby."

Ability to be physically active

Three quarters of respondents (596) indicated that they were unable to be physically active or to do the activities they would like to do due to injuries from their birth.

"[I'm]still unable to return to previous sporting activities 3 years on."

"I was an elite age group athlete. Not anymore... My whole way of life has changed".

"I can't run, dance, jump... It is very life limiting"

Impact on relationships and work

Over half of respondents (421) indicated that their birth injuries affected bonding with their baby. Around 65% of respondents (520) said their injuries had impacted their partner relationship. One in five (173, 22%) of the respondents indicated that it had affected their ability to work. Respondents also reported no longer feeling social due to the physical and mental impact of injuries.

"I was extremely traumatised by my birth and could not bond with my baby for a very long time. It was weeks before I felt anything but resent for her because I was blaming her."

"[Birth injuries have] had massive impact on self esteem and confidence both when out in public and when naked with partner"

"It has been awful. I haven't been able to work full time- I am disabled because of my pregnancy."

Medical gaslighting

There are common reports from respondents that they were not believed, or were told their symptoms are normal.

"I felt like I was just crazy because they made it seem normal to be in pain."

Many felt dismissed when they sought help, with medical professionals telling them symptoms "will pass with time, all women hurt after birth".

Respondents also report having their feelings of trauma dismissed as they "have a healthy baby". They report feeling confused, dismissed, anxiety, neglected, disappointed, unimportant, in limbo, and let down by multiple failures to be referred.

Sex life and intimacy

84% indicated that birth injuries have impacted their sex lives due to factor such as painful sex, fear of making their symptoms worse, fear of incontinence, self-loathing and disgust, and loss of sensation. Sexual problems were also reported as a contributor to relationship breakdowns.

"I still struggle to have intercourse which has been a source of relationship with my partner breaking down"

"It's affected my relationship of 7 years. Not only can we NOT be intimate, I won't even let him look at it. I'm so ashamed of how I've been left to feel and look."

Future births and growing families

Three quarters of respondents indicate their birth injuries have affected their decision whether to have another baby. Many respondents described fear of another labour and feeling that the potential risks were too great to try again.

"My injuries, in combination with my poor mental health after birth, led me to decide against having other children."

Conclusion and recommendations

The experience of giving birth is leaving behind long-term damage to many women and birthing people's physical and mental health. Respondents to the *Birth injuries: improving diagnosis and treatment* survey have reported debilitating physical injuries causing chronic pain, urinary and faecal incontinence, and the destruction of self-confidence, relationships, and hopes for the future.

Our findings point to systemic failures in maternal health systems. These systems often fail to adequately prepare parents for birth; routinely ignore, dismiss, or misdiagnose injury and dysfunction; and leave women and birthing people feeling isolated and abandoned. Yet, these are the same people expected to shoulder the burden of caring for their newborn children and families.

The ABTA, BTA and MBB are advocating for changes to increase community and health professional awareness to reduce the prevalence and impacts of birth-related trauma. While the UK, Australia and New Zealand have some differences in their health systems and therefore impacts on women and birthing people may vary slightly, the results of our joint survey demonstrate that change is needed in all contexts.