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Birth injuries: the hidden epidemic

A summary of insights from an international survey conducted by the the Australasian Birth Trauma Association (ABTA), Birth Trauma Association (BTA) & Make Birth Better (MBB).

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This document provides a summary of results from the Physical Birth Injuries survey undertaken by the Australasian Birth Trauma Association (ABTA), Birth Trauma Association (BTA) and Make Birth Better (MBB) in May 2022.

These organisations 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 and families in Australia and New Zealand. Together, these organisations have undertaken this survey, entitled 'Birth injuries: improving diagnosis and treatment'.



Trigger warning

Please note that the following report includes distressing content that may be triggering for some readers. It includes descriptions of physical birth injuries, trauma, post-natal depression and anxiety, post-traumatic stress disorder, suicide ideation, and other mental health challenges.

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. A selection of contacts are listed below.

Australia

New Zealand

United Kingdom

If you need urgent help please visit your local GP or A&E department

Lifeline

13 11 14

Beyond Blue Support Service 1300 659 467

Gidget Foundation Australia:

https://www.gidgetfoundation.org.au/

National Perinatal Mental Health Helpline: 1300 726 306

Australasian Birth Trauma Association birthtrauma.org.au

Lifeline

0800 543 354 for counselling and support. Text 'Help' to 4357

The Depression Helpline 0800 111 757 or free text 4202

Perinatal Anxiety and Depression 04 461 6318 021 024 82123

Australasian Birth Trauma Association birthtrauma.org.au

Australasian Birth Trauma
Aotearoa coming soon

Samaritans

116 123

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

Birth Trauma Association

 $\underline{www.birthtraumaassociation.org.uk}$

Make Birth Better: www.makebirthbetter

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

1. Executive summary

This report details findings from the survey 'Birth injuries: improving diagnosis and treatment', undertaken by the Australasian Birth Trauma Association (ABTA), the Birth Trauma Association (BTA) and Make Birth Better (MBB) in May 2022.

The survey captures responses from 801 women from Australia, the UK and New Zealand who self-identified as having experienced birth injuries (with or without ongoing effects), mostly between 2016-2022. The majority of respondents gave birth in Australia (416) or the UK (325), with the remaining 60 in New Zealand or elsewhere.

This report uses the term 'woman' throughout. This should be taken to include people who do not identify as women but have experienced injuries associated with child birth.

The survey included multiple choice survey questions and free text questions which allowed women the opportunity to describe the impact of birth trauma in their own words. The results highlighted in this report include quantitative data and a summary of the themes which emerged from our respondents' own stories.

Key themes summary



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 of my 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. Women 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 women 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 women reported living in a persistent state of fear and anxiety, which contributed to feelings of isolation. The theme of fear reverberates through the responses. Women 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."



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 & 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. Women 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". Women also report having their feelings of trauma dismissed as they "have a healthy baby". Women 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 women 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."

Key details

Type of birth

Almost all respondents gave birth in hospital settings, with 84% (674) birthing in private or public hospitals. This is consistent with national Australian, UK and NZ data showing that most women in all countries give birth in hospital.

401 repondents reported giving birth vaginally, 144 unassisted and 257 with instruments (forceps, ventouse/suction, or both). 56 respondents had caesareans.

Birth injuries

Respondents reported a range of birth injuries, including vaginal tears, prolapse, episiotomy problems, bladder damage, neuralgia, and bone injuries. The most common were vaginal tears, with 537 women (67%) reporting either first, second, third or fourth degree tears.

Diagnosis and treatment

Of 714 respondents, less than half had their injuries diagnosed within the first two months of giving birth, despite most women in Australia and the UK, having a six week post-partum health check.

Diagnosis was most often provided by an obstetrician (27%); but almost one in five (18%) had their condition diagnosed by a women's health physiotherapist, highlighting the importance of this care. It was apparent that obtaining an accurate diagnosis could be a complicated process involving multiple services. As one respondent put it, "Different healthcare professionals for different injuries; Obstetrician, GP, Women's Health Physiotherapist, Colorectal Surgeon". This complexity could be expected to put accurate diagnosis and treatment out of reach for many women, particularly those in less well-resourced areas.

Over a quarter of respondents (216) had not received any treatment for their injury at the time of the survey.

Of the 585 women who had received treatment, the most common avenue for support is specialist women's health physiotherapy, with 453 women (77%) accessing women's health physiotherapy. One in five respondents (176) had had surgery. While some women (94), had completely healed, the majority (349, 60%) reported that treatment treatment had been "partially" effective. Of those who sought treatment, 84% (491) continue to live with symptoms from their birth injuries.

Ongoing symptoms

The survey data tells an alarming story about the damage that some birthing women endure, and the range of symptoms women can experience long after birth that affect their quality of life. Particularly striking was common presence of pain, and urinary and fecal incontinence or urgency, both of which are well known to impact quality of life.

Almost half of respondents (47%) reported experiencing vagina or vulva pain - the same amount suffering pain during sexual intercourse. Over a third (35%) reported back pain and more than one in four (27%) experienced abdominal pain.

More than four in ten respondents (44%) suffer from urinary incontinence and almost one in five (18%) experience faecal incontinence. Dealing with the physical, social and emotional impacts of incontinence in particular, was frequently reported as having had a major disabling effect on every day life.

Birth injuries broad ranging impact on wellbeing can present ongoing mental health challenges. Injuries leading to pain and incontinence significantly impacted our respondents' ability to work, exercise and maintain normal social life. Respondents reported reduced body confidence and self-esteem, and problems in family relationships including with children. Significantly, 85% of respondents reported that their mental health had been affected by their physical injuries.

Of the women who had received a formal mental health diagnosis, the most commonly reported condition was post-natal depression or anxiety (PNDA). Importantly, one third of respondents (279) have been diagnosed with post-traumatic stress disorder (PTSD), with some cross-over between respondents who also selected other conditions.

Almost half of respondents (201, or 47%) have not had a formal diagnosis; and for those that are diagnosed, almost one third (67, or 30%) are not receiving treatment.

Conclusion and recommendations

The experience of giving birth is leaving behind long-term damage to many women's physical and mental health. Respondents to this 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.

The 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 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 may vary slightly, the results of this survey demonstrate that change is needed in all contexts.

2. Survey details

About the survey

The Physical Birth Injuries (PBI) survey was undertaken by the Australasian Birth Trauma Association (ABTA), Birth Trauma Association (BTA) and Make Birth Better (MBB) in May 2022, ahead of Birth Trauma Awareness Week 2022.

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 for women to have injuries diagnosed and to obtain treatment.

This report highlights the key insights from this survey. 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.



What are physical birth injuries?

Birth injuries are physical injuries experienced during childbirth. They can include 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.

Recruitment of respondents, survey and data collection

The survey questions were developed collaboratively by ABTA, BTA and MBB and hosted on Survey Planet. A callout was posted on the organisations' social media channels when the survey opened on 5 May 2022. The survey closed on 1 June 2022.









A total of 801 responses were obtained overall, with varying response levels to individual questions. Consent was obtained from all respondents for inclusion of de-identified data and quotes in this report.

Limitations

Respondents had given birth in Australia (416), the UK (325), New Zealand (7) and other locations (53). The data in this report <u>does not</u> disaggregate the experiences of women in different locations. The answers given by the respondents, including in narrative form, provide profound insights into women's experiences; however, the data does not provide information about practices in particular health services or areas.

Respondents were sourced through social media platforms associated with the ABTA, BTA and MBB organisations and all self-selected as having experienced birth injuries. People completing this survey were likely to already identify as having experienced birth trauma due to their existing connection with these organisations.

The survey responses describe some harrowing experiences associated with fear of not being taken seriously by medical professionals, and delays in having life affecting injuries properly diagnosed. However, we do not know why so many diagnoses took arguably too long, increasing the distress and physical suffering of those with injuries. Further research is needed to understand the process of diagnosis of birth injuries and to determine what might be done to improve diagnostics, and access to treatment.

There are also more insights that could be gained from the data from this survey, through a cross analysis of the responses to separate questions. This additional analysis was not undertaken for this report due to resource constraints, but there remains an opportunity for that work to be done in the future.

Finally, we note that 91.8% of respondents to the survey identified as 'white' - which was defined in the survey as: English / Welsh / Scottish / Northern Irish / British, Australian / New Zealander, Irish, Gypsy or Irish Traveller, Any other European, African or Middle Eastern white background. Further research is needed to better understand the experiences within under-represented and marginalised communities and culturally and linguistically diverse communities that fall outside this group.

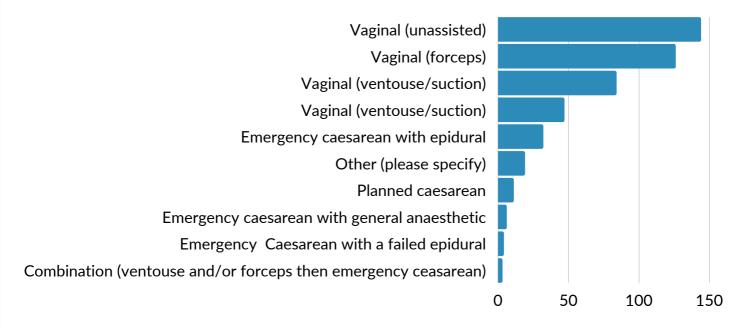
3. Research insights

Type of birth

The Australian Institute of Health and Welfare reports that in 2019, almost 2 in 3 women (64%) had vaginal births, while the remainder (36%) had a caesarean section birth. More than 85% of those who give birth vaginally will suffer from some degree of perineal tear[1].

These health statistics, and the commonplace nature of tears in vaginal birth, is reflected in the responses to this survey.

The vast majority (84%) of respondents to this survey had given birth vaginally when they suffered their injuries - including unassisted vaginal births, as well as those assisted with forceps, ventouse, or a combination of these. Thirteen respondents gave birth via caesarean, including emergency and elective caesarean section. Three of the respondents gave birth via caesarean section after failed ventouse and/or forceps.





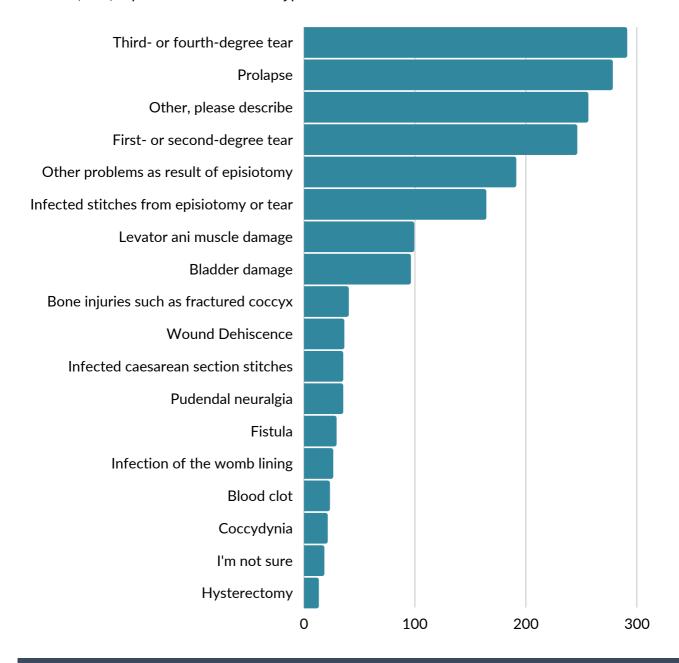
Please note that many women identified as having more than one condition.

Most common injuries

Respondents could select from a list of 18 injury types including an open category ("other") - in which they could specify injuries not otherwise described. More than one selection could be made. The three most common selections were:

- 1.3rd or 4th-degree tears (291)
- 2. Prolapse (278)
- 3. Infected stitches (199)

Perineal or vaginal tears and/or prolapse were the most commonly reported type of injury post birth. 537 women (67%) reported a tear of some type.

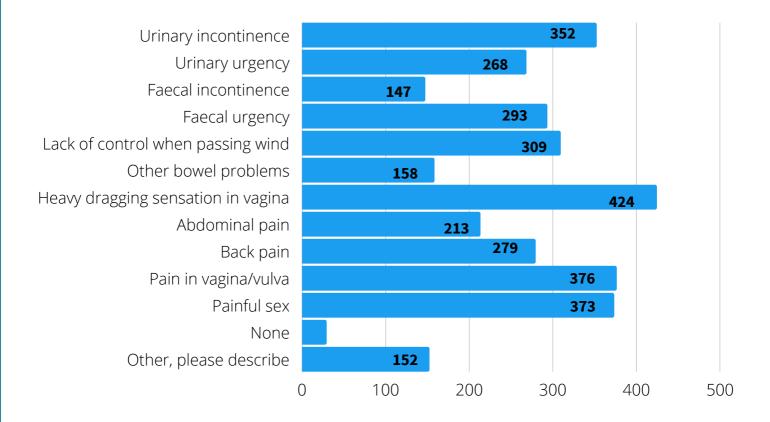


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Please note that many women selected more than one condition.

Symptoms

Respondents reported a variety of symptoms that are known to negatively impact quality of life. These are represented in the graph below. Note that more than one selection could be made.



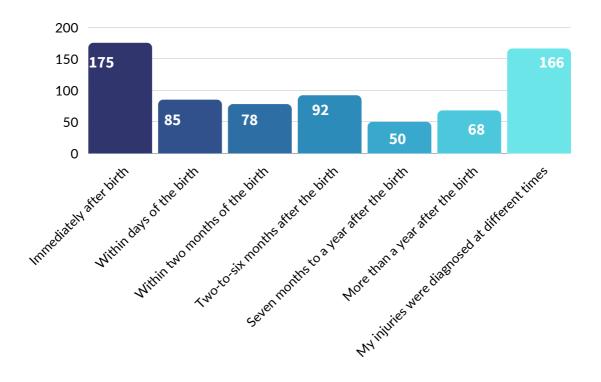
Note that respondents could select more than one category so responses are not cumulative. The most commonly reported symptom was pain. Almost half of the respondents reported experiencing ongoing pain in the vagina or vulva (376, 47%); or painful sex (373, 47%). Over a third reported back pain (279, 35%), and more than one in four (213, 27%) experienced abdominal pain.

In addition to pain, many women reported faecal/urinary incontinence, urinary urgency and flatulence that could not be controlled. Incontinence is well known to impact quality of life, and the narrative accounts of survey respondents emphasised the profound and wide ranging effects of incontinence on their ability to exercise, socialise, and to work, and well as on self-esteem and sexual intimacy.

These data tell an alarming story about the damage that some birthing women endure, and previous ABTA research has indicated this is inadequately described in pre-birth classes and other education that women receive prior to delivery.

Diagnosis and treatment

We asked respondents to tell us when they had received a diagnosis regarding their birth injury and how long post birth this diagnosis was given. This has been tabulated below.





Respondent quotes...

"It was devastating for me to having to use adult nappies after the birth of my daughter and to have the long wait time to see someone who might be able to help... was heartbreaking. My women's health physio ended up referring me to a mental health service as I was crying every day and couldn't cope with wearing incontinence aids 24/7"

"On one hand it was probably good the first month to not be overly scared right away but starting with 6 month after birth when the gyn said everything was fine, which didn't feel like it at all, it started to affect my mental well-being enormously. I started to be scared and felt horribly alone, broke and sick."

"I felt I couldn't escape the trauma because the wound wasn't healing. Physically I couldn't sit, walk, shower or go to the toilet properly. So that also affected my mental state, as I was so disconnected from my baby because of the pain."

"I was mentally and emotionally exhausted. By the time I was diagnosed I was having attacks of anxiety overnight about what could have been done differently to prevent everything that had happened."

"Physically I could not have sex due to the pain from my episiotomy scar, the delay in having to wait 10 months for an appointment affected my ability to be intimate with my husband but also my mental health because I felt like I would never heal or be able to enjoy sex again.

Obtaining a diagnosis was often complicated and a number of different types of health professional might be involved in a person obtaining a diagnosis.

Who diagnosed your injury?

Health Professional	Responses (n = 714)	Percentage
Obstetrician	190	27%
Women's health physiotherapist	128	18%
Other (please specify)	120	17%
Gynaecologist	70	10%
GP	69	10%
Midwife	60	8%
Urogynaecologist	47	7%
Colorectal surgeon	30	4%

'Other' responses, which are not included in the table above, tended to describe multiple diagnoses received from different clinicians including specialist doctors and generalist physicians/surgeons/medical practitioners working in emergency departments. In one fairly typical response, a respondent noted that she had 'different healthcare professionals for different injuries; Obstetrician, GP, Women's Health Physiotherapist, Colorectal Surgeon'. These narratives highlight the often complex path of the diagnostic journey for women with birth injuries.

This complexity may provide a reason why only 50% of respondents had their injuries diagnosed within the first two months post-delivery, despite most women having a post-natal appointment at around six weeks after birth. Alarmingly, 68 respondents reported not being diagnosed until more than a year after giving birth.

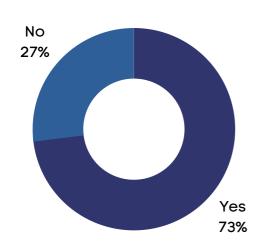
It was most common for women to be diagnosed by an obstetrician (27%); but almost one in five (18%) received a diagnosis from a women's health physiotherapist. In narrative responses, women repeatedly described being finally listened to when they got to a women's health physio. The role of these professionals in supporting women with birth injuries was profound, and highlights the importance of access to women's health physiotherapy to identify injuries and to provide treatment for symptoms such as pain and incontinence.

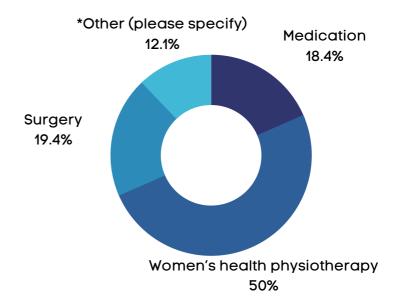
In terms of treatment, 73% (585) of respondents had received at least some treatment, and 216 had not had any at all. Some of those may not have needed treatment.

Have you had treatment for your condition?

Type of treatment n=585

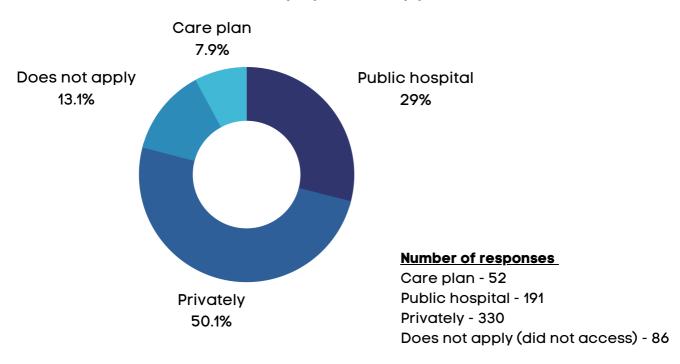






Please note that many women identified as having more than one form of treatment. Other included women using specific aids including pessaries, cortisone injections, electrical pelvic floor stimulators.

Access to women's health physiotherapy n=585



Of particular note is that women's health physiotherapy is the main form of treatment for women experiencing symptoms from a birth injury. This highlights the important role of this group of specialists in the diagnosis and care of women postpartum.

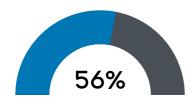
Of those receiving treatment, more than three quarters (77%) of respondents were accessing specialist (women's health) physiotherapy.



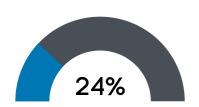
Respondent quotes...

"I saw four health professionals, but it wasn't until the 5th (very experienced women's health physio) that I got the full picture of the problem."

"The impact wasn't acknowledged by any professionals except women's health physio. It was a very isolating and shameful experience."



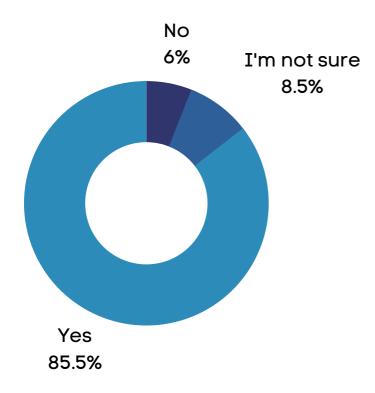
Of those who were able to receive treatment from a women's health physiotherapist more than half (56%) accessed that treatment privately, highlighting that the cost of birth injuries is expected to be covered by women who are suffering considerable health problems, and their families who may both rely on them, but also seek to support them. The structural assumption contained in the payment models relies on women having adequate private health insurance or disposable incomes to access health care services outside of the public system. This is a privileged position and it is likely that many individuals are unable to access these services because they do not hold private health cover. Further, health workforce issues mean that access to these services can mean waiting several weeks and months, which given the nature of some of these injuries, is distressing for these women.



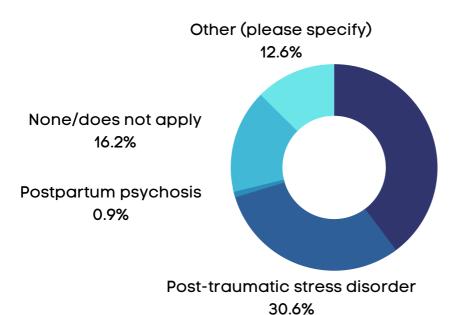
A quarter of respondents (24%) said the treatment they received had not been effective. Whatever confidence may be had in women's bodies being 'designed' for labour, modern complications associated with higher-weight babies, longer gestations, and older first time mothers, particular in countries like Australia, Canada New Zealand and the UK, continue to be associated with physical injury and ongoing symptoms for which more recognition and support is required. Less than one in five (just 16%) respondents reported that their treatment had been completely effective, meaning the vast majority of respondents continue to live with the daily impacts of birth injuries on all aspects of life.

Impacts of injury

Mental health affected (n=801)

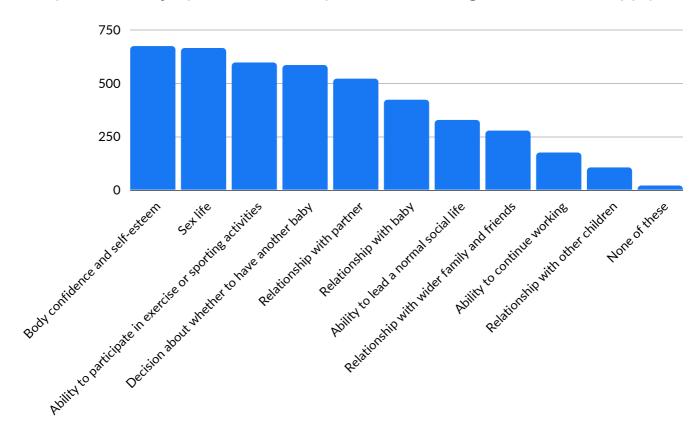


Mental health diagnosis (n=685)

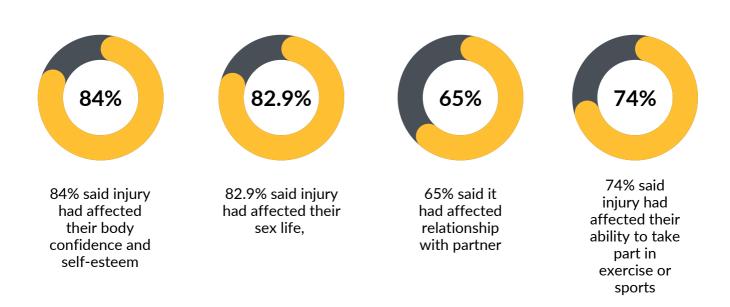


Postnatal depression or anxiety 39.8%

Did your birth injury ever affect any of the following (select all that apply):



There is a clear and significant impact that birth injuries impart on daily life. These impacts were felt in women's ability to enjoy family life, to socialise, to exercise and to work, as well as to have healthy sex lives and intimate relationships.



4. How birth injuries affect lives

We also asked women to tell us in their own words, how physical birth injuries affected their lives. An analysis of 794 responses to the this question revealed eight key themes.

Eight key impacts identified by women in their own words









Impact on mental health

Misdiagnosis / delayed diagnosis Fear or isolation

Ability to be physically active









Impact on relationships & work

Medical gaslighting

Sex life and intimacy

Future births and growing families



4.1 Impact on mental health

Many women reported depression and PTSD following birth injuries, and described feeling a sense of shame and disability in their bodies.

RESPONDENT QUOTES



"Depression, anxiety & major impact on my self esteem. A sense of shame.."

"[My injuries] have affected almost every area of my life. Very few people know about them. It is something I am embarrassed about and keep hidden from others. After the birth of my baby I thought I would never get better, I was very down and felt hopeless. Now things have definitely improved but I will never have another baby as I could not go through it again."

"I am a completely different person. I have PPTSD and GAD, I can't sleep well and after returning to work I cannot operate at the same capacity as before."

"Low self esteem due to birth injuries and trauma."

"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 and was not given the opportunity to make informed decisions about my care."

"Birth trauma led to immediate severe Postnatal Anxiety & Depression with PTSD. I was admitted to a Mother Baby Unit 3 weeks postpartum."

"Severe post natal depression with suicidal thoughts."

"I'm permanently disabled now something I never thought would
happen from giving birth. Not a day has
gone past where I haven't been in pain
and I don't feel I have my
independence anymore. I've been
robbed of my livelihood, motherhood
that I envisioned for my son and
intimacy with my husband. I can't do
simple things people take for granted
like running, jumping, having a good
nights sleep...I don't hold excitement
for myself anymore I'm scared of my
future and what it holds for me"

".... once some of the shock had passed and day to day life went on, I realised how very different my life was going to be going forward. I'm fearful of everything, from sex to exercise. There is a constant worry that I'm going to get a hernia, or my bag will need changing or even worse, leak, in a meeting at work or on a busy train. My life will never be the same, it has impacted my relationship to the point of counselling and now considering not having another child."

4.2 Ability to be physically active

74% of respondents indicated that they were unable to be physically active as a result of birth injuries. The impact of this on every day life is reflected in many of the comments.

RESPONDENT QUOTES



"It was and is impossible to live a normal life with these injuries. You can arrange and survive, obviously but if standing and walking already gives you pain and a horrible sensation, how should you get along?"

"I couldn't do normal activities like gardening or bushwalking, which were my favourite things. I couldn't carry my baby for long. I can't run, dance, jump etc. It is very life limiting."

"I used to be very active, in particular I was a keen weightlifter but as I live with some degree of pain and fear of further injury I have not been able to exercise like I used to. This has affected my physical and mental wellbeing. My injuries made me feel disgusting, destroyed, undesirable. I also had PTSD from the birth, which the injuries made worse too."

"I have withdrawn from exercise and social outings".

"Unable to have freedom to do activities I would like to do, and still unable to return to previous sporting activities 3 years on."

"I was an elite age group athlete. Not anymore. I can't run after my kids when they ride their bikes. (I own a bike shop) I am a triathlon coach and can't warm up with my run groups. Sex isn't what it should be. My whole way of life has changed"

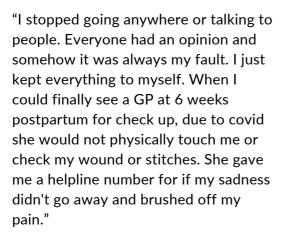
"I have been suffering from constant pressure and pain, fear of movement, I have given up exercise, I fell into depression and had to go on medication for that, and lost the desire and hope to get better as the current treatment options and costs were dismal."



Medical gaslighting

A striking feature of respondents' narrative accounts was how often symptoms were dismissed as "normal", and complaints about pain, pressure in the vagina, and incontinence were frequently minimised or not believed at initial consultations. This not only contributed to feelings of isolation and abandonment, but it also prolonged daily suffering without access to medical help.

RESPONDENT QUOTES



"The GP advised I didn't have a prolapse at 6 week check but I could feel that it wasn't right, and I couldn't understand what I was looking at when I checked. I felt confused and dismissed. Felt disappointed, unimportant, let down by multiple failures to refer to PT. Worried by the time it had taken, concerned I might have missed out on early care and maybe led to worse outcome."

"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'. Despite being able to feel a bulge in my vagina, and having done my own research to determine it was a prolapse, I was dismissed and gaslighted for 3 years with medical professionals trying to make me believe I was imagining problems that weren't there."

"My partner and I both describe that time as traumatic, and I believe the neglect contributed to my physical issues become worse due to lack of support." "Greatly impacted both myself and my partner, due to the anxiety and medical gaslighting. Felt I was in limbo, afraid to move not knowing what was wrong. I missed out on time with my newborn because of the severe anxiety and trying to solve the problem on my own as medical professionals (midwife, 2x gyno, 3 physio) kept telling me nothing is wrong. My partner and I both describe that time as traumatic, and I believe the neglect contributed to my physical issues become worse due to lack of support."

"It affected me as every doctor thought I was crazy and it would fix itself. It impacted me as I had to time toilet to make sure I didn't wet myself. There may have been something that could have been done if picked up and believed by Drs in the beginning."

"I wasn't believed for weeks that I was unwell as lockdown meant telehealth only care, I felt like I was just crazy because they made it seem normal to be in pain."

"I tried to seek help and was told nothing was wrong."

"I doubted myself and whether it was in my head"

"The impact wasn't acknowledged by any professionals except women's health physio. It was a very isolating and shameful experience."

"They wouldn't believe me"



4.3 Misdiagnosis or delayed diagnosis

While 25% of respondents had their injuries diagnosed immediately after birth, a quarter of women had them diagnosed at different times and 10% of respondents had to wait over a year before receiving a diagnosis. A number had conflicting diagnoses and varying advice. It may be the case that many types of birth injuries require specialist assessment, but more research is required to understand the reasons for delays in different areas and contexts. In our respondents' narrative accounts, mis- or delayed diagnoses seemed to be strongly associated with medical practitioners initially dismissing women's symptoms as "normal". This experience was so prevalent in these women's stories, it is described further under 'medical gaslighting' below.

RESPONDENT QUOTES



"As I felt so different after my first birth I kept questioning why everyone kept saying my symptoms were normal. Once I finally got my diagnosis I was really upset and wondered if I'd made it all worse by carrying baby and toddler around at the same time every day as after my six-week check and again at nine weeks post-birth they had said everything was normal."

"Delay to diagnosis was simply because I was ashamed to go to a professional. GP misdiagnosed as normal, women's health physio diagnosed as stage 2. Gyno as stage 1."

"I do not know if I will have another surgery... I feel I am missing out a window of opportunity"

"Male Obstetrician told me my injuries 'were normal for what you'd expect to see in a woman who'd given birth.' Felt like I was expected to just live with it... I had a triple prolapse after episiotomy with forceps... The women's health physio was amazing"

"The wound at my perenium wasn't healing so my gp sent me to a specialist who wasn't entirely sure what had happened. She luckily went to a talk by [a urogynaecologist] who I then saw and [diagnosed me] with a near complete avulsion of both levators. This process took 6 months"

"I felt inadequate, silly and totally dismissed. I felt like the doctors wanted me to go away and not cause a fuss and were trying to convince me that what happened to me was normal. In my GP's exact words "it happens" with a shoulder shrug."

"My pain level increased by the day and the waiting and not knowing, accompanied by the... psychological distress I was experiencing following a traumatic birth led me to being put on a mental health care plan, referred to a Perinatal Psychologist and diagnosed with Postnatal depression, anxiety and PTSD from birth trauma."

The midwife who diagnosed my tear said it was 2nd degree and treated it as such. At 6 weeks postpartum I knew something was wrong, and saw my OB who said I would need surgery that it was a 3rd degree tear and referred me to a Urogynecologist who said it was a 4th degree tear"

"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. If it was fixed in a timely manner or even prevented I would not be incontinent."





4.5 Fear and isolation

Many women report living in a persistent state of fear or shame, fear of birth, fear of the medical system, fear of not being able to find a toilet, fear of the future.

RESPONDENT QUOTES



"I am unable to get out of the house by myself because of the anxiety I suffer with. I am unable to lift anything heavy. I have PTSD and severe anxiety which effects my day to day life. I leak urine constantly. I hate myself and my body, I feel disgusting with what has happened to me. I'm scared to have anymore children as I don't want to be injured again. I push family and my husband away. I feel miserable constantly."

"It has brought up feelings of disgust and shame about my own body which are very hard to ignore."

"Although the injury was physical, the psychological impact has been significant. I felt broken and out of control. I feared going to the toilet, going out in public (in case of an accident) and was anxious that having a baby had changed me forever (not in the way I expected). I was so worried that I would never be able to hold my bowel or return to work or walk normally."

"Over the 3 years, although the flashbacks had lessened, the anxiety that caused had become entrenched. I became scared of everything. My prolapse was a constant reminder of the trauma and pain I experienced, so I couldn't get it out of my mind. I became terrified of feeling that again so was scared of anything where I could get hurt, almost to the point of not wanting to leave the house."

"Lots of fear. Fear around damage to my baby by missing me for the first few hours of his life, fear of getting back into fitness because of bladder leakage, fear of sex as I was so worried it would hurt, fear of the same thing happening if we have a second baby."

"Huge impact on my confidence and return to regular exercise and activities of daily living. Huge fear of complications with menopause, Huge fear of having another baby, Guilt about why i didn't elect to have a c-section given my age, Financially very costly having regular women's health physio appointments, musculoskeletal physio appointments, urogynaecologist, and GP"

"Anxiety and fear of the future. What if I never get better. Worried about the constant pain or my partner leaving. Feeling helpless as it seems no doctors understand."





4.6 Impact on relationships & work

Over half of respondents (421) indicated that their birth injuries prevented them from bonding with their baby. 65% (520 people) said their injuries had impacted their partner relationship. 34% said their relationships with family and friends had been affected, with 22% of the respondents indicating that they were unable to return to work.

RESPONDENT QUOTES



"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 resentment for her because I was blaming her."

"Very painful to sit- difficulty going out with friends / family and sitting to have a coffee/meal. Painful when driving to and from social interactions/or everyday activities/jobs. Avoided these things more than I would have liked due to trying to get my injury to heal."

"I can't work, I used to work in retail, I still can't hold wind. My son was not given the proper care because of my injuries, pain, surgeries, medication and the issues that arose in my relationships with my husband and his family."

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

"I am constantly planning and preparing when going to work or out on social activities to ensure I can make it to a toilet. I feel extreme embarrassment about being young and incontinent." "Prolapse and 3rd degree leading to fecal incontinence. I always need to know where the toilet is. I can't go for long walks as I will usually have an accident. I can't run or jump. It lead to PTSD and severe anxiety which affected my performance at work. It is also painful after sex, 5 years later"

"I have been diagnosed with PTSD from the traumatic birth and postpartum period. I had to extend my leave from work (unpaid) which has put so much extra stress on my family. Physically, I have not had a day without pain since the birth and my daughter is now 16 months old."



4.7 Sex life and intimacy

84 % (664) of respondents indicated that birth injuries have impacted their sex lives, 84% (673) said their injuries had impacted their body confidence and self-esteem. The following factors were indicated as contributors:

- Painful sex
- Fear of making their symptoms worse
- Fear of incontinence
- Feeling broken and disgusted
- Complete loss of sensation

RESPONDENT QUOTES



"Scar tissue makes sex painful causing lack of want to be intimate with my husband which has led to decreased intimacy and connection"

"I wanted another baby but now I can't even stand the thought of being intimate with my husband. This has ruined our marriage and my life. I have wanted to kill myself just to end the pain."

"No longer a social person.

Relationship breakdown as unable to be intimate with partner. Reluctant to enter into a relationship for same reason. Depressed and isolated as feel no one understands"

"The prolapse means I need to urinate more often so that also affected me leaving the house. It's embarrassing. It's affected my sex life and relationship too. My whole life has been impacted." "I felt like I failed as a woman as I wasn't able to give birth naturally. I suffered with PTSD and required therapy when pregnant with my second. Friends took away my right to feel traumatised by saying "at least you've got a healthy baby". It has greatly affected my sex life as I don't have lot of sensation due to the severity of tearing."

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



4.8 Future births and growing families

73% of respondents indicated that their birth injuries had affected their decision on whether to have another baby with an additional 103 respondents stating that their injuries had affected their relationship with their children.

RESPONDENT QUOTES



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

"My birthing injuries have impacted my life in many ways from ability to participate in sport, sex life and general day to day pain and discomfort. But the biggest impact was after discovering I was unexpectedly pregnant, I decided to terminate the pregnancy. I simply could not put my body through the horror of labor again and the potential risks were just too great for me to even consider going through it all again."

"Severe anxiety & pain, stress & tension in family relationships/marriage etc. lack of self confidence & ongoing fear of ever birthing again"

"It has had a huge affect on whether I want to go ahead and have another baby, and if I do, do I try for a vaginal birth or not because of the 3rd degree tear. When I think back to what happened it makes me anxious. I feel that it affected me and my daughter bonding initially as I had to go to theater to have the tear repaired."

5. Conclusion

Each year in Australia, almost 300,000 women give birth, with research suggesting that as many as one in three women experience birth-related trauma [2,3]. Research suggests that around one in four first-time mothers, between 15,000 and 30,000 women in Australia per year, may suffer major irreversible physical birth trauma in the form of pelvic floor muscle or anal sphincter tears [4]. We also know that up to 20% of all women who deliver a baby vaginally will end up with surgery for pelvic organ prolapse, anal or urinary incontinence [5].

In the UK 614,000 women give birth each year and at least 1 in 3 find their birth in some way traumatic {6}. A third- or fourth-degree tear occurs in about 3 in 100 women having a vaginal birth. It is more common with a first vaginal birth, occurring in 6 in 100 women {7}. As echoed in this report, we already knew that 85% of women with severe birth injury say it impacted on their relationship with their child and 45% suffer postnatal depression as a result of their injury {8}.

Drawing out the themes from the survey, it is evident that for a significant number of women, the experience of giving birth is leaving behind long-term mental health impacts; debilitating physical injuries that cause chronic pain, urinary and faecal incontinence; and the destruction of women's self-confidence, relationships, and hopes for the future.

The findings also point to systemic failures in maternal health systems. Systems that do not adequately prepare parents for the risks associated with birth and to facilitate informed birth choices; minimise the process of recovery; routinely ignore, dismiss, or misdiagnose injury or dysfunction; and leave women feeling isolated and abandoned. Yet these women who experience birth trauma are expected to shoulder the burden of caring for their newborn infants and families.



6. Recommendations

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

Antenatal

- A collaborative, multidisciplinary approach to care is the key to early recognition of factors that may impact birth. This information can then be used to tailor birth preparation individually for each woman and birthing person.
- There are benefits to families forming positive relationships with known carers
 who will support them through pregnancy, birth and postnatally (continuity of
 carer). However, it is important to note that there is no one model of care that
 should be given priority over another and whether it is midwifery-led care or
 obstetric-led care is up to the woman and her family.

Supporting informed choice

- Birthing families need access to evidence-based, unbiased information on a
 comprehensive range of birthing practices and potential birth complications to
 enable informed choice. Health systems must be designed to ensure those
 options are presented to women and families in a timely and appropriate way so
 they can be considered in decision-making.
- We recommend development of national standards around consumer antenatal education content and curriculum, which includes trauma-informed care.
- We encourage collaboration between healthcare professionals versus a single model of care (meaning one-size-fits-all), with a maternal health system moving towards team-based, family-led care.
- We recommend a multi-disciplinary approach to providing birth preparation
 information for mothers, birthing people and their partners. We would like to see
 collaboration among health professionals so birthing families are able to access
 unbiased advice and undertake screening for factors that may impact birth in
 order to best prepare them for the birth process. Positive and respectful
 collaboration is essential to the success of a multi-disciplinary approach.

Improved birth trauma education for healthcare providers

• We recommend birth-related trauma training for healthcare providers to enable greater empathy and better health outcomes for the women and families. This must also include support for healthcare professionals themselves as many practitioners experience burnout and vicarious trauma which impacts their service provision[9].

Consumer engagement

We advocate for consumers to be involved in the design, implementation and
evaluation of all maternity services. Those who have experienced trauma as a result of
childbirth are in a unique position to provide valuable feedback on minimising trauma
and advising on issues relevant to recovery.

Postnatal

Improved diagnosis and pathways to care

- We recommend investment in appropriate postnatal services that are able to diagnose maternal trauma in an accurate and timely manner and provide pathways to care. It is envisaged that these postnatal services would assess birth trauma in the early postnatal setting (as opposed to months or years later) and would include the following:
 - Access to birth debriefing as a standard
 - Support for clinical audits to improve health outcomes for affected women and their partners, and facilitate staff teaching, training
 - Multidisciplinary treatment provided to women and birthing people impacted with physical trauma
 - Access to imaging services capable of diagnosing somatic birth trauma
 - Free, or heavily subsidised access to postnatal specialist (women's health)
 physiotherapy
 - Prompt referrals for mental health support.
- All maternal health care service providers involved in the postnatal care of birthing
 families receive more comprehensive training on both physical and psychological birth
 trauma, how it impacts people's lives and how they can play a role in limiting the
 severity of this trauma, with a view to improving empathy and clinical diagnosis and
 treatment. This requires the provision of ongoing support and training in self-care for
 all staff involved. [9)
- A system of collaborative care where birthing families are empowered to make the choice that works best for their individual needs, wants and circumstances

Research and Data Collection

- Improve data collection in postnatal period to capture maternal health and wellbeing outcomes, including birth injuries.
- Investment in population-level research into birth-related injuries to better understand the prevalence, impacts, and treatment options.
- Patient-Reported Outcome Measurement Study developed to identify a woman/birthing person's mental wellbeing in conjunction with physical wellbeing beyond six weeks.
- Further research into CALD and minority groups to further understand the intersectionality and complexities of diverse community access and equity to women's health care outcomes.

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All of the recommendations made should be carried out while keeping in mind women for whom financial, geographical, cultural or language barriers may impede access to care.