Submission to the
Australian Commission on Safety and Quality in Health Care
Severe (third and fourth degree) Perineal Tears Clinical Care Standard

Rowan Cockerell, CEO, Continence Foundation of Australia, r.cockerell@continence.org.au

The Continence Foundation of Australia

The Continence Foundation of Australia (the Foundation) is the national peak organisation whose mission is to represent Australians with, or at risk of, incontinence, their carers and health professionals who treat and assist people with incontinence.

The Foundation develops and delivers a range of initiatives in partnership with the Australian government as part of the Bladder Bowel Collaborative and broader National Continence Program. The Bladder Bowel Collaborative initiatives and projects focus on increasing education and awareness of bladder and bowel health in Australia, supported by the upskilling of specialist and non-specialist continence health professionals. This, in combination with the National Continence Helpline, Continence Foundation of Australia website (continence.org.au) and National Continence Program website (bladderbowel.gov.au) ensures that the general public are able to access information and support related to bladder and bowel health via a number of channels.

The Foundation's membership broadly represents the continence sector and workforce who both provide care and services for, and raise awareness and advocate, on behalf of Australians with, bladder and bowel control problems.

The Continence Foundation of Australia welcomes the development of the *Severe (third and fourth degree) Perineal Tears Clinical Care Standard* by the Australian Commission on Safety and Quality in Health Care (ACSQHC). The Foundation commends the ACSQHC for requiring:

In *Quality statement 6 – Postoperative care*, that before discharge:

- women should be informed about the type of information and care they should expect to receive while recovering,
- clinicians are expected to make referrals for follow-up care, and
- health services should ensure that mechanisms for appropriate referral and follow-up are in place.

In *Quality statement 7- Follow-up care*, that after discharge:

- women should receive follow-up care to ensure the best possible recovery,
- clinicians should individualise follow-up care and ensure a follow-up appointment 'in the weeks after discharge', and
- health services should ensure that support or referral pathways for a multidisciplinary team-based approach or a specialist clinic are available.

The Foundation is concerned however that, given that many women with 3rd and 4th degree perineal tears will suffer faecal or anal incontinence, follow-up care is inadequate for many. Women with 3rd and 4th degree perineal tears need (1) access and timely referral to a multidisciplinary service or team, which include clinicians trained and skilled to deliver care to women with 3rd and 4th degree tears; (2) to understand who to contact and how and when to access the care they need; and (3) to be proactively supported by primary care practitioners once discharged from hospital.

The Foundation contends that the Clinical Care Standard should be strengthened by providing more specific reference to the specialist workforce available to support women with 3rd and 4th degree perineal tears. The Clinical Care Standard would reinforce this with the following statements:

- Health service organisations acknowledge the importance of referral to clinicians trained and skilled to deliver care to women with 3rd and 4th degree tears, including continence specialists (continence nurse advisors, continence physiotherapists and midwives with continence training).

- Health service organisations are expected to provide best practice care and locate a multidisciplinary service or team, which include clinicians trained and skilled to deliver care to women with 3rd and 4th degree tears, at the health service where women birth.

- Clinicians should refer women, before discharge, to the multidisciplinary service or team, which includes clinicians trained and skilled to deliver care to women with 3rd and 4th degree tears, including continence specialists (continence nurse advisors, continence physiotherapists and midwives with continence training), located within the health service where they birthed.

- Women with 3rd and 4th degree perineal tears need to understand who to contact and how and when to access the care they need, particularly in regard to incontinence, when discharged from hospital.

- Primary care practitioners proactively identify whether women, with 3rd and 4th degree perineal tears, are incontinent and refer them to clinicians trained and skilled to deliver care to women with 3rd and 4th degree tears, including continence specialists (continence nurse advisors, continence physiotherapists and midwives with continence training).

Throughout this submission, 3rd and 4th degree perineal tears are used to describe higher degree obstetric and anal sphincter injuries instead of severe perineal tears. The Foundation considers words such as 'severe' and 'major' as emotive and unhelpful. The use of terminology and information needs to remain objective to assist in de-escalating emotions during this potentially difficult time for women. Since 2011, Diabetes Australia has had a position statement which describes best practice around the use of language when speaking about conditions and people living with those conditions.

People are sensitive to the implications of the words and phrases used to describe, categorise and label aspects of their identity; language can define them and their health. Language, and the attitudes it reflects, can affect self-confidence and motivation, and influence health and well-being directly or indirectly. Certain words and phrases can be de-motivating, inaccurate or even harmful. (Diabetes Australia, 2016)

The supporting evidence

1. Prevalence of faecal or anal incontinence after 3rd and 4th degree perineal tears

Incontinence is a common consequence of 3rd and 4th degree perineal tears. Third and 4th degree tears, at the time of birth, are well-recognised risk factors for the early development of faecal incontinence, anal incontinence, flatulence and faecal urgency.

A recent prospective cohort study of 603 Danish women was undertaken between July 2015 to January 2018 to determine the prevalence of anal incontinence (St Marks' score of >4*) in primiparous women 12 months after obstetric anal sphincter injury (Gommessen et al., 2019). The results of the study showed a 2- to 4-fold increase in the relative risk of developing anal incontinence in women with 3rd and 4th degree tears compared with women with no/labial/1st degree tears (see Table 1.)

Table 1. Relative risks of anal incontinence according to the degree of perineal tears.

Condition	**Prevalence of anal incontinence**	**Increased relative risk of anal incontinence (95% confidence interval)**
No/labia/1st degree tears	7%	1
2nd degree tears	9%	2.46 (1.28–4.71)
3a degree	14%	-
3b degree	15%	-
3c degree	35%	4.74 (1.98–11.3)
4th degree tears	33%	2.23 (1.59–11.3)

Source: Gommesen D, Nohr EA, Qvist N, Rasch V. Obstetric perineal ruptures—risk of anal incontinence among primiparous women 12 months postpartum: a prospective cohort study. American Journal of Obstetrics and Gynecology. 2019 Aug 23. DOI: https://doi.org/10.1016/j.ajog.2019.08.026

* The St Marks incontinence score questionnaire assesses incontinence for solid and liquid stools and gas, alteration in lifestyle, the need to wear a pad or plug, the use of constipating medicines and faecal urgency.

There is ample research to show that faecal or anal incontinence are longer term consequences of 3rd and 4th degree perineal tears, but there is much less research regarding the prevalence of these often-debilitating conditions in the early weeks and months following birth.

To address this gap in knowledge, a US study sought to determine the prevalence of faecal incontinence, anal incontinence, flatulence and faecal urgency in women with 3rd and 4th degree perineal tears (Richter et al., 2015). A prospective cohort study of 343 primiparous American women, undertaken between July 2010 and June 2011, determined the prevalence of faecal incontinence at 6, 12 and 24 weeks, and anal incontinence, flatulence and faecal urgency at 24 weeks#.

Table 2. Incontinence rates in women following 3rd and 4th degree perineal tears.

Condition	Time after perineal tear	Prevalence
Faecal incontinence	6 weeks	7%
Faecal incontinence	12 weeks	4%
Faecal incontinence	24 weeks	9%
Anal incontinence	24 weeks	24%
Flatulence	24 weeks	19%
Faecal urgency	24 weeks	21%

Source: Richter HE, Nager CW, Burgio KL, Whitworth R, Weidner AC, Schaffer J, Zyczynski HM, Norton P, Jelovsek JE, Meikle SF, Spino C. Incidence and predictors of anal incontinence after obstetric anal sphincter injury in primiparous women. Female pelvic medicine & reconstructive surgery. 2015 Jul;21(4):182.

Faecal incontinence was defined as any involuntary leakage of mucus, liquid stool, or solid stool. Anal incontinence defined as leakage of mucus, liquid stool, solid stool, and/or gas. Flatulence was defined as any gas leakage. Faecal urgency was determined by asking the question: 'How often do you have a strong desire to move your bowels, which makes you rush to the toilet.'

It is clear that women with 3rd and 4th degree perineal tears are already experiencing faecal incontinence at 6 weeks or earlier. It is highly likely that these women will have been discharged from hospital with incontinence and they will need support and information from continence specialists to effectively manage their incontinence. Faecal incontinence is highly stigmatised and day-to-day management is difficult, confronting and debilitating. Being left to manage faecal or anal incontinence alone is not an option and these women need to be proactively supported.

2. Damaging outcomes of ongoing faecal or anal incontinence

Faecal and anal incontinence are life-altering conditions which can greatly and detrimentally impact quality of life. Identification and effective treatment are important to prevent psychological, emotional and physical impacts on women's lives.

The language that Australian women use to describe their experience of 3rd and 4th degree perineal tears vividly describes their trauma (Priddis et al., 2014a). In regard to faecal incontinence, their contaminated and uncontrolled body makes them feel 'dirty' and 'like a baby with a dirty nappy'.

Like when you're a kid if you pooh your pants, there's this kind of stigma that you're dirty and lazy. And even when you're an adult every time it happened I was just like–oh this is filthy, I'm in my twenties and I can't control myself. I didn't want to talk to anybody about it, I didn't even want to talk to the doctor about it. [Matilda] (p6, Priddis et al., 2014a)

Australian women described feeling shocked (Priddis et al., 2014a) at how basic bodily functions were no longer in their control, such as unexpected episodes of incontinence. This was further compounded by the lack of information and education that they had received and the way it 'collided with their expectation of what would happen following birth' (Priddis et al., 2014a).

When Tucker and her colleagues (2014) interviewed Australian women, they found that they had an 'overwhelming negative psychological response' to their anal incontinence. They grieved for their many losses: of their self-identity, self-worth or control; the loss of young adulthood – loss of independence and sexual attraction; the loss of middle adulthood – loss of control as an adult.

An Australian study investigated the extent to which primary-care practitioners (GPs and MCHNs) routinely enquire about postpartum urinary and faecal incontinence and determined how many women disclosed their symptoms at 3, 6, 9 and 12 months postpartum (Brown et al., 2015). At 3 months, 23% were asked about urinary incontinence and only 17% of women were asked about faecal incontinence. Discussion of symptoms with health professionals was most likely to occur in the first 3 months postpartum, and rarely occurred during the first 12 months postpartum. Over 70% of women reporting severe urinary incontinence or faecal incontinence had <u>not</u> discussed symptoms with a health professional. Although this cohort of women were less likely to have had severe perineal tears, it does reflect their reluctance to report even severe faecal incontinence to a health professional. A lack of focus on maternal health, as opposed to infant health, and women considering incontinence as a 'minor' problem, were suggested as reasons for the lack of reporting (Brown et al., 2015). This work also highlights the fact that health professionals must be proactive and ask whether women are experiencing such symptoms.

When women don't report that they have faecal or anal incontinence they develop coping mechanisms which, although they may work for them at some level, may not be the best strategies to use (Elden & Lindgren, 2014; Priddis et al., 2014a). Women who are not sufficiently supported and informed mainly rely on the use of pads, which may or may not be designed for incontinence (Elden & Lindgren, 2014) or, more worryingly, may withdraw from or severely limit their daily activities (Tucker et al., 2014; Lindqvist et al., 2018).

Quality of life is also significantly negatively affected when faecal or anal incontinence is experienced, and this has been quantified as part of the *Fecal Incontinence Postpartum Research Initiative* in the US. At 6 months postpartum, 53% of women with anal incontinence reported feeling frustrated, 26%

reported it affected their emotional health, 18% reported it affected their child-caring abilities and 16% reported a negative effect on social activities (Lo et al., 2010). Disturbingly, two years later these quality of life measures had not improved and this cohort of women were very unlikely to report their symptoms to a medical provider, even after 2 years.

A very recent study by Lindqvist and her colleagues (2019) found that women with 3rd and 4th degree perineal tears with incontinence (urinary/faecal and gas) managed their situations by withdrawing from situations which may cause 'embarrassment and shame'. Importantly, this work revealed that getting adequate and necessary help and support from health professionals was described as 'vital to helping women heal and move on'.

3. Support from health care professionals is vital for recovery

Because the condition is so stigmatised, women are unlikely to report that they have faecal or anal incontinence. An essential theme of Tucker's work was *Silence*: keeping silent; professional silence and breaking the silence. Women kept silent about their condition as a means of self-preservation and 'waited for health professionals to provide information and support'. The professional silence around anal incontinence left women feeling angry and frustrated:

Women described anger and frustration with professional silences that avoided initiating discussion, providing information regarding the immediate and long-term impact of OASIS and AI, and effectively linking women to appropriate services. Inattentiveness was often seen as limited knowledge and fear of client dissatisfaction. (Tucker et al., 2014)

Very recent research has identified that, for women with 3rd and 4th degree perineal tears, encountering a supportive and helpful health care professional was vital for their recovery. Some of the recovered women described how finally encountering the person who gave them ample time, listened, understood and helped them to get the correct treatment and support, started the process of physical and mental recovery for them (Lindqvist et al., 2019).

Finally, I got hold of this fantastic midwife who not only understood my situation, but could give adapted advice on how to feel better. At last, I felt that someone did believe in me.

This doctor really put some effort into supporting me and thoroughly told me where my injury was located and what was applicable for the future.

4. Australian women's experiences of follow-up care after 3rd and 4th degree perineal tears

Despite the acknowledged need for Australian women with 3rd and 4th degree perineal tears to be referred to a multidisciplinary team or a specialist clinic based in a health service, the reality of their experience is very different. Research into health services in New South Wales, published in 2014, exposed the actual experience of women and found the services were wanting. A 'patchwork of services' was used to describe the way health services operated, with a lack of consistency in both practice and standardisation of care (Priddis, et al., 2014b). Ideally, women would be referred to a multidisciplinary service or team, which included clinicians trained and skilled to deliver care to women with 3rd and 4th degree tears, including continence specialists (continence nurse advisors, continence physiotherapists and midwives with continence training) based at the health service where they gave birth, but this was not and will not be a reality for many.

In preparation for discharge from hospital in New South Wales, the level of support and information provided to each woman appeared to vary based upon the individual care provider, model of care, and health service. At discharge, while some participants described receiving referrals for an endoanal ultrasound and receiving community midwifery support, other women reported that they received no support. For many women the level of support they received was inadequate for their needs.

Women described feeling confused and unsure as to when and where to seek support, particularly for women experiencing symptoms such as urinary incontinence, perineal pain and urinary retention. (p8, Priddis et al., 2014b).

Women who participated in the study felt that, following the birth, the attention of health professionals moved from the woman to the baby and focused on the care and wellbeing of the baby, with little concern as to the wellbeing of the new mother. They felt that receiving honest and accurate information was important, particularly during the suturing process and the immediate postpartum period (Priddis et al., 2014b).

It would be good to have something if you did have questions to look through. You know they teach you how to wash the baby, and there's all sorts of diagrams –but there's nothing about aftercare for the mother except keep it clean, and make sure you can go to the toilet. (Ava) (p9, Priddis et al., 2014b)

The Clinical Midwifery Consultants who were interviewed for the study identified that postnatal services varied depending on the Local Health District and the practices of individual health practitioners. Support for women living rurally was even more underfunded and poorly structured which resulted in inconsistent follow up with little consideration of the distances women needed to travel to access care (Priddis et al., 2014b).

References

Brown S, Gartland D, Perlen S, McDonald E, MacArthur C. Consultation about urinary and faecal incontinence in the year after childbirth: a cohort study. BJOG: An International Journal of Obstetrics & Gynaecology. 2015 Jun;122(7):954-62.

Diabetes Australia. *Position statement. A new language for diabetes: improving communications with and about people with diabetes*. [internet] 2019 [cited 2019 December 3] Available from: https://www.diabetesaustralia.com.au/position-statements

Elden H, Olesen A, Svahn L, Lindgren H. Feeling old in a young body: Women's experiences of living with severe consequences of an obstetric anal sphincter rupture: An interview study. Clinical Nursing Studies. 2015;3(1):17-29.

Gommesen D, Nohr EA, Qvist N, Rasch V. Obstetric perineal ruptures—risk of anal incontinence among primiparous women 12 months postpartum: a prospective cohort study. American Journal of Obstetrics and Gynecology. 2019 Aug 23. DOI: https://doi.org/10.1016/j.ajog.2019.08.026

Lindqvist M, Lindberg I, Nilsson M, Uustal E, Persson M. "Struggling to settle with a damaged body"–A Swedish qualitative study of women's experiences one year after obstetric anal sphincter muscle injury (OASIS) at childbirth. Sexual & Reproductive Healthcare. 2019 Mar 1;19:36-41.

Lo J, Osterweil P, Li H, Mori T, Eden KB, Guise JM. Quality of life in women with postpartum anal incontinence. Obstetrics & Gynecology. 2010 Apr 1;115(4):809-14.

Priddis H, Schmied V, Dahlen H. Women's experiences following severe perineal trauma: a qualitative study. BMC women's health. 2014a Dec;14(1):32.

Priddis HS, Schmied V, Kettle C, Sneddon A, Dahlen HG. “A patchwork of services”–caring for women who sustain severe perineal trauma in New South Wales–from the perspective of women and midwives. BMC pregnancy and childbirth. 2014b Dec;14(1):236.

Richter HE, Nager CW, Burgio KL, Whitworth R, Weidner AC, Schaffer J, Zyczynski HM, Norton P, Jelovsek JE, Meikle SF, Spino C. Incidence and predictors of anal incontinence after obstetric anal sphincter injury in primiparous women. Female pelvic medicine & reconstructive surgery. 2015 Jul;21(4):182.

Tucker J, Clifton V, Wilson A. Teetering near the edge; women's experiences of anal incontinence following obstetric anal sphincter injury: an interpretive phenomenological research study. Australian and New Zealand Journal of Obstetrics and Gynaecology. 2014 Aug;54(4):377-81.