

Pregnancy-related pelvic girdle pain is one of the most common, painful and debilitating conditions that you've never heard of

By Sarah Fishburn and Jen Campbell

PGP: an unresolved issue

Pregnancy-related pelvic girdle pain is a pelvic joint problem affecting up to half of all women and birthing people during and/or after pregnancy¹. It causes mild to severe pain in and around the pelvis, hips and lower back. Most women with PGP experience pain when getting in and out of bed, sitting or standing for long periods, getting dressed or turning over in bed. In other words, it can affect every aspect of women's lives, irrespective of ethnic background². This debilitating condition can also continue after the baby is born for months or even years without effective treatment.

The Pelvic Partnership was formed twenty years ago as a support group for women with PGP during and after pregnancy to offer support and signpost to the care and treatment they need to become pain-free. As a national charity we offer support and information about PGP to women with PGP, their families and carers, working collaboratively to raise awareness about PGP its treatment. We share information, tools and resources on our website and social media about PGP and its treatment. As experts by experience, we support women and their families by listening to their experiences and providing information, responding to their questions and concerns on our volunteer helpline, Facebook support group for women with PGP, monthly Q&As on our Instagram stories and 1:1 support on social media.

We frequently engage with many women with PGP across the UK who feel isolated and hopeless, wrongly believing that nothing can be done. These views are exacerbated by persistent myths around PGP, including that PGP is caused by "pregnancy hormones", that it is "a normal part of pregnancy", that "nothing can be done" and that "it will stop as soon as the baby is born". This is especially frustrating for women when this is not the case and symptoms persist postnatally, as they do for the majority of women. In fact, PGP is a pelvic joint problem not caused by hormone changes but by biomechanical joint changes. Consequently it can be treated safely and effectively during and after pregnancy with hands-on individualised treatment including manual therapy such as physiotherapy, osteopathy and chiropractic care³. Hands-on manual therapy will assess and treat the pelvic joint alignment and soft tissue issues around the pelvic joints. This can resolve the cause of the pain, or at a minimum reduce pain levels during pregnancy and facilitate a quicker recovery postnatally with continued treatment.

Medical gaslighting

By reducing PGP to a normal part of pregnancy, it enables healthcare practitioners to fob off, ignore and dismiss the pain women with PGP are experiencing and not give them the care, support and treatment they need.

¹ Cefrnja, D, Chipchase L. Fahey, P. Liamputtong P., Gupta A. (2021) Prevalence and factors associated with pelvic girdle pain during pregnancy in Australian Women. SPINE Volume 46, Number 14 (944-949)

² Cefrnja, D, Chipchase L. Fahey, P. Liamputtong P., Gupta A. (2021) Prevalence and factors associated with pelvic girdle pain during pregnancy in Australian Women. SPINE Volume 46, Number 14 (944-949)

³ Clinical Practice Guideline, Management of Pelvic Girdle Pain in Pregnancy and Postpartum, 2014, Chartered Physiotherapists Women's Health and Continence and Directorate of Strategy and Clinical Programmes Health Service Executive: <https://www.hse.ie/eng/about/who/acute-hospitals-division/woman-infants/clinical-guidelines/management-of-pelvic-girdle-pain-in-pregnancy-and-post-partum.pdf>

“My PGP was dismissed by the consultant and midwife who told me it was very common and I could just buy crutches if I wanted to... I was also repeatedly told I had to remain mobile to avoid blood clots. But no help was given for the PGP.”⁴

As a result of this medical gaslighting, women are not being listened to and supported during and after pregnancy. In a Pelvic Partnership survey in 2022 we collected data about women’s recent experiences of PGP; 82% of women surveyed did not feel supported or had mixed feelings about the support offered by their GP or midwife⁵.

“I was ignored and offered nothing, the midwife’s response to me saying I was in pain was “what do you expect, you’re pregnant”. Luckily I found this incredible charity, found an approved manual therapist and she treated me but at a cost.”⁶

As a result of this gaslighting, many women have not been able to access the care, support and treatment when they needed it. By delaying access to pain relief and treatment, PGP is worsened causing significant physical and mental health impacts to the woman during and after pregnancy and possibly leading to additional interventions during birth (induction or caesarean birth). There is also a broader health risk that given the response to their PGP, women may be disinclined to report other symptoms to healthcare professionals during and after pregnancy, for fear of being ignored, dismissed and “wasting time”.

Gaslighting is known to be a common issue in women’s health with 84% of respondents to the recent national Women’s Health Strategy’s call for evidence survey feeling that they had not been listened to, with most instances being related to gynaecological symptoms⁷. These impacts are avoidable or reduced if women are listened to and enabled to share health concerns with healthcare practitioners.

Impact on women’s lives

The symptoms of PGP can strike at any time during and after pregnancy, causing a significant impact on women’s lives:

Pain and physical mobility

Women experiencing pregnancy-related PGP will likely experience pain in and around their hips and pelvis when they try to get in and out of bed, walk, sit or stand for long periods, climb the stairs and get dressed. For some women the pain may remain mild-moderate and can be managed with a range of practical measures such as avoiding climbing stairs and getting dressed while sitting down. These women often do not seek treatment (due to being fobbed off when they ask) and continue to have symptoms postnatally.

For many other pregnant women, the pain can be severe, getting worse during the pregnancy, continuing postnatally and affecting their ability to get around and carry on with their normal activities.

⁴ Pelvic Partnership 2022 survey of 350 women with recent experience of pregnancy-related pelvic girdle pain: <https://pelvicpartnership.org.uk/wp-content/uploads/2022/06/Pelvic-Partnership-2022-Survey-Highlights.pdf>

⁵ Pelvic Partnership 2022 survey of 350 women with recent experience of pregnancy-related pelvic girdle pain: <https://pelvicpartnership.org.uk/wp-content/uploads/2022/06/Pelvic-Partnership-2022-Survey-Highlights.pdf>

⁶ Pelvic Partnership 2022 survey of 350 women with recent experience of pregnancy-related pelvic girdle pain: <https://pelvicpartnership.org.uk/wp-content/uploads/2022/06/Pelvic-Partnership-2022-Survey-Highlights.pdf>

⁷ Women’s Health Strategy for England, August 2022, <https://www.gov.uk/government/publications/womens-health-strategy-for-england#:~:text=The%20Women's%20Health%20Strategy%20is,and%20girls%20across%20their%20lives.>

“I had a baby in 2020. I was offered a physio appointment, they literally just offered advice of not using stairs and lifting properly. I was in immense pain!! I’m currently pregnant again and I am struggling to walk (I could cry) I will tell my midwife at my next appointment but I don’t feel confident I’ll get any relief or help. I’m sad because I’m struggling with my nearly two year old and just feel such a let down.”⁸

We asked women in the survey on how long they had been experiencing pain: 67.5% of respondents were experiencing PGP when completing the survey, and 50% of those had been in pain for more than six months⁹. It is worth noting the NHS defines chronic pain as “pain that carries on for longer than 12 weeks despite medication or treatment”¹⁰.

We also asked women the extent to which PGP affected their physical mobility: only 6% of respondents could walk normally without any pain, 80% could walk with some pain, 13% needed to use mobility aids such as crutches or a wheelchair and 2% of respondents reported being bedbound. When only 6% of women with PGP are able to walk without pain, this indicates how severe and debilitating this condition can be for women.

Many women with PGP need to use mobility aids such as crutches. As well as the physical benefit of reducing the pressure and strain on their pelvis, they can also enable them to carry on with their normal daily activities such as seeing family and friends, rather than having to stay at home alone, which can be very isolating and have a detrimental impact on their mental health. Using crutches or being in a wheelchair is also a very visible demonstration of the impact of PGP can have on women’s lives, drawing attention to this often invisible condition.

Mental health impacts

We hear from many women with PGP on our support services who are experiencing mental health problems associated with their pain and immobility, referred to by some researchers as “psychosocial distress”¹¹.

According to the Maternal Mental Health Alliance, one in five women are at risk of mental health issues during and after pregnancy, with the COVID-19 pandemic increasing “the mental health risks new and expectant mums face”¹². In our 2022 survey, 63% of women surveyed experienced a problem with their mental health during and after pregnancy, with 72% of those listing PGP as a factor in their mental health problems¹³. During the lifetime of the charity we are aware of three women who have taken their own lives as a consequence of their PGP and the lack of support from clinicians overseeing their care.

“I have never felt so lonely or lost.”¹⁴

The mental health impacts of PGP are considerable as a result of having to cope with pain, as well as having to live with the impact of that pain on your daily life. For example, it is unsurprising that there is an emotional cost to being in pain, but also the mental health cost of

⁸ Pelvic Partnership 2022 survey of 350 women with recent experience of pregnancy-related pelvic girdle pain: <https://pelvicpartnership.org.uk/wp-content/uploads/2022/06/Pelvic-Partnership-2022-Survey-Highlights.pdf>

⁹ Pelvic Partnership 2022 survey of 350 women with recent experience of pregnancy-related pelvic girdle pain: <https://pelvicpartnership.org.uk/wp-content/uploads/2022/06/Pelvic-Partnership-2022-Survey-Highlights.pdf>

¹⁰ NHS Scotland: <https://www.nhsinform.scot/illnesses-and-conditions/brain-nerves-and-spinal-cord/chronic-pain>

¹¹ Cepnija, D, Chipchase L, Fahey, P, Liamputtong P., Gupta A. (2021) Prevalence and factors associated with pelvic girdle pain during pregnancy in Australian Women. SPINE Volume 46, Number 14 (944-949)

¹² Maternal Mental Health Alliance: <https://maternalmentalhealthalliance.org/about/perinatal-mental-health/>

¹³ Pelvic Partnership 2022 survey of 350 women with recent experience of pregnancy-related pelvic girdle pain: <https://pelvicpartnership.org.uk/wp-content/uploads/2022/06/Pelvic-Partnership-2022-Survey-Highlights.pdf>

¹⁴ Pelvic Partnership 2022 survey of 350 women with recent experience of pregnancy-related pelvic girdle pain: <https://pelvicpartnership.org.uk/wp-content/uploads/2022/06/Pelvic-Partnership-2022-Survey-Highlights.pdf>

not being able to go to work, see family and friends, exercise and care for our families. As well as maternal mental health impacts, it is also worth noting the potential impact on infant mental health as a result of the ongoing physical and mental health challenges experienced by the parents.

Impact on wider economy

In some cases, women with PGP are unable to continue working for the full term of their pregnancy, and have difficulty returning to work postnatally as planned, especially in more mobile and active roles where they need to be on their feet all day. In many cases, employment that requires staff to be active and on their feet includes teaching, childcare, retail and hospitality, where the average income is much lower than more professional occupations where you are more likely to sit in an office or work from home. A recent study describes PGP as a major public health issue due to the “negative effects on activities of daily living” and because it causes long sick leave; indeed the study reports “PGP accounts for 37-72% of sick leave in pregnancy”, lasting 12-15 weeks on average¹⁵. For women who work in the home with family responsibilities, PGP can also impact on their capacity to look after their children and may require additional support from family, friends or financial support through government benefits.

Given the physical and mental health impacts for the woman and downstream economic impact and cost to NHS, all this underlines the importance of early intervention assessment and treatment for PGP¹⁶, which can reduce the risk of PGP being exacerbated, reducing the likelihood of severe pain and immobility, and in turn reducing the likelihood of lost work days and slower recovery and return to work.

Barriers to change

While we continue to work with women to give them the support, tools and information to access the individualised treatment they need, we continue to hit barriers that hinder our efforts to ensure women can get the care, support and treatment they need.

Awareness of PGP among healthcare professionals

Many women have reported to us that they find discussions with healthcare practitioners challenging because there is limited understanding and awareness of PGP, how much it can impact women’s lives, how what treatment options are available. As a result:

- women are not being referred to treatment as soon as they report symptoms of PGP meaning that if and when they are treated it will take longer to resolve the pelvic joint asymmetry,
- women are not supported along referral pathways for NHS physiotherapy and/or private manual therapy from physiotherapists, osteopaths or chiropractors and mental health supports, and

¹⁵ Malmqvist, S. et al (2015) The association between pelvic girdle pain and sick leave during pregnancy; a retrospective study of a Norwegian population. BMC Pregnancy Childbirth 15:237
<https://pubmed.ncbi.nlm.nih.gov/26437972/>

¹⁶ Clinical Practice Guideline, Management of Pelvic Girdle Pain in Pregnancy and Postpartum, 2014, Chartered Physiotherapists Women’s Health and Continence and Directorate of Strategy and Clinical Programmes Health Service Executive: <https://www.hse.ie/eng/about/who/acute-hospitals-division/woman-infants/clinical-guidelines/management-of-pelvic-girdle-pain-in-pregnancy-and-post-partum.pdf>

- women are not provided with pain relief and/or mobility aids when they need it.

Therefore, at the first hurdle, women are not being signposted to available support services, referred for treatment such as NHS physiotherapy at an early stage where it can make the most difference, and even being overlooked for pain relief options and mobility aids. Women are continuing to be in pain when it could be reduced or treated with appropriate referral and treatment pathways. Given that pre-conception, pregnancy and the postnatal periods are some of the most vulnerable of a woman's life, the physical and mental health impacts of this, as well as the downstream costs to the NHS, are significant.

Access and availability of experienced manual therapists

Women have shared with us that they find it hard to access experienced physiotherapists, osteopaths and chiropractors, especially referrals to NHS physiotherapists. For women with PGP who have a referral for NHS physiotherapy, only 19% were offered individualised treatment, including manual therapy¹⁷, while the vast majority were offered only group classes or generalised exercises and advice that is not individualised, not hands-on and doesn't treat the cause of the pain. It is worth noting that many more women were not even able to get a referral, so there is a significant proportion of women told to sit tight and put up with it, because of the long referrals.

“During pregnancy [my] midwife referred me on to [a] non-specialist physio at GP. We had a phone chat and she emailed some exercises which didn't help. During my pregnancy I got to the point where I was more or less housebound and we had to hire a wheelchair when we went out.”

“I was told the waiting list was too long and by the time I got an appointment I'd have had my baby.”¹⁸

This may also be a result of systemic barriers within the NHS, where women with mild to moderate PGP are treated and addressed separately to women severe PGP who in some cases are discharged while still in pain “because nothing can be done”. This approach needs careful revision to engage with the practitioners who have the skills but often are not connected to this group of women who could benefit from their skills in musculoskeletal manual therapy treatment.

For those women who can afford it, private physiotherapy, osteopathy and chiropractic care is a valid option, with many women using word of mouth or our list of recommended practitioners to connect with an experienced manual therapist. At an average of £50-80 per appointment, the cost of treatment is a significant barrier to treatment for many women. Many women reach out to us expressing frustration and worry that the only reliable treatment for their PGP is out of reach due to their finances. Indeed, 76% of the women in our survey¹⁹ who hadn't had private manual therapy cited affordability as the reason. As a charity we are very concerned about the long term impacts of living with PGP on women who are unable to pay for treatment privately and are not offered treatment on the NHS.

¹⁷ Pelvic Partnership 2022 survey of 350 women with recent experience of pregnancy-related pelvic girdle pain: <https://pelvicpartnership.org.uk/wp-content/uploads/2022/06/Pelvic-Partnership-2022-Survey-Highlights.pdf>

¹⁸ Pelvic Partnership 2022 survey of 350 women with recent experience of pregnancy-related pelvic girdle pain: <https://pelvicpartnership.org.uk/wp-content/uploads/2022/06/Pelvic-Partnership-2022-Survey-Highlights.pdf>

¹⁹ Pelvic Partnership 2022 survey of 350 women with recent experience of pregnancy-related pelvic girdle pain: <https://pelvicpartnership.org.uk/wp-content/uploads/2022/06/Pelvic-Partnership-2022-Survey-Highlights.pdf>

Proposal for a new approach

We started this essay by describing PGP as one of the most common, painful and debilitating conditions affecting women during and after pregnancy that you've never heard of.

We recognise broad changes to NHS policy are needed to reflect the prevalence and impact of PGP on women's lives. PGP can be safely and effectively treated during and after pregnancy and it is essential to raise awareness of this and facilitate access to treatment for all women, not just those who are able to pay for private treatment. In particular there should be focus on:

- improved education and awareness about PGP among healthcare practitioners, including the symptoms and the impact of PGP on women's lives, and the short, medium and long term consequences of women not receiving treatment
- upskilling of NHS physiotherapists to ensure they have the skills and confidence to give all women with PGP a hands-on assessment and individualised treatment, including manual therapy
- ensuring all NHS physiotherapy services take PGP and its physical and psychological impact seriously and offer appropriate treatment to all women at an early stage and regardless of ability to pay

Importantly, if there is not a broader cultural shift at the heart of the health and care system to place a higher value on the voices and experiences of women and birthing people, then these proposed solutions can only have a limited chance of success.

To conclude, we want to hand over to one of our service users, who shared their experience of how getting informed care, support and treatment has impacted them:

"My PGP started at 10 weeks pregnant. By 18 weeks, I couldn't walk on my left leg, and was in constant pain every time I moved. I've had 4 sessions of manual therapy with an osteopath and I can now walk on my left leg and the pain is a lot more bearable. Thank you! You change lives with the work you do."