

Dear Secretary of State,

On behalf of the Trustees of the Pelvic Partnership, I would like to congratulate you on your new position as Secretary of State for Health and Social Care and commend you to consider the challenges outlined below, facing the 1 in 2 women and birthing people who experience pregnancy-related pelvic girdle pain (PGP).

While writing this letter, we asked our service users what they consider the main challenges and we include some of their comments in italics below.

What is pelvic girdle pain (PGP)?

PGP is a severe condition affecting the pelvic joints during and/or after pregnancy. It can cause pain, physical immobility and lead to associated mental health impacts during and/or after pregnancy. Left untreated, it can continue for months or even years postnatally.

As a result of challenges outlined below, too many women in the UK are left to manage this pain themselves, affecting their ability to walk, sit or stand for long periods, get dressed, climb the stairs, work and care for their families. As a result, the impact on a woman's health and wellbeing is significant and we hear from hundreds of women across the UK each year, who are unable to access the care, support and treatment they need.

Challenges and their impact

1. Limited knowledge and understanding of PGP among healthcare practitioners

On our support services, we hear from too many women who feel ignored, dismissed and disbelieved by their healthcare practitioners when they report symptoms of pain during and/or after pregnancy. In the main, we consider this is due to a lack of appropriate knowledge and understanding of PGP and the extent to which it can affect your physical and mental health during and/or after pregnancy, as reinforced by feedback from our service users:

"I feel it would be really helpful if midwives spoke to you in your booking appointment about PGP symptoms, preventative/reductive actions (e.g. how to get in and out of bed, not opening legs wide), to take the pain seriously to avoid deterioration, and when and where to seek help. I really don't think my PGP would have got as bad as it did if I hadn't have thought it was just general pregnancy pain and I should push through it." – Service user

"Better training for midwives and GPs including that PGP can continue after birth." – Service user

“Midwives need more knowledge on PGP and this charity so they can signpost appropriately & they need to stop telling us it will disappear immediately once the baby pops out!” – Service user

“A core focus should be on updating the knowledge of midwives and consultants. During my pregnancy, the consultant measuring my bump, despite being informed, pressed so heavily on my pubic bone to gauge the measuring point that I was in pain for 2 weeks after. The midwives insisted on practice post birth with stirrups that caused me pain, and sent me home from hospital twice in labour. Despite them being informed that car travel wasn't possible for me comfortably.” – Service user

As suggested above, the booking appointment with the midwife is a clear intervention point where PGP can be raised, to share key strategies to manage any symptoms and refer to ongoing treatment as required. Early intervention is crucial with PGP to ensure appropriate management and effective treatment during pregnancy, to reduce the physical and mental health impacts during pregnancy and expedite postnatal recovery for those for whom symptoms can continue postnatally.

If ongoing gaps in knowledge and understanding continue, this will leave more and more women in pain during and/or after pregnancy, with ongoing impacts on women's willingness to report other healthcare symptoms and therefore impact on their health issues. We discuss the impact of this medical gaslighting in our [award winning essay for the Heather Trickey Prize](#).

2. Insufficient treatment options available on the NHS

PGP can be safely and effectively treated with hands-on treatment from a physiotherapist, osteopath or chiropractor using a range of hands-on techniques, including manual therapy, to treat the cause of their pain in and around the pelvic joints. When women reach out to us in pain, we encourage them to go to the GP or midwife, describe their pain and how it is affecting them and ask for a referral for NHS physiotherapy to treat the cause of their pain.

While many NHS physiotherapists have the skills, experience and time to treat PGP during and after pregnancy using hands-on manipulation and mobilisation of the pelvic joints, we hear from too many women that they are unable to get the treatment they need on the NHS, due to a range of factors:

- Local policy enables women to only access telephone or video physiotherapy appointments or group classes, which offer generic advice and exercises only. A hands-off, generic approach would not treat the cause of their pain and risks dismissing their pain.

- Many Trusts also have policies in place that separate the treatment of PGP from incontinence, overactive pelvic floors and other pelvic floor dysfunctions. In practice, treatment for pelvic floor problems is normally offered by women's health physiotherapists, focusing on early intervention and prevention, while PGP is treated by the MSK physiotherapists with different referral and monitoring methods, less focus on early intervention and less engagement with the midwifery and antenatal teams. Furthermore, a joined-up approach in treating PGP and pelvic floor problems would also make clinical sense, given how many women may experience PGP and pelvic floor dysfunction.
- Inconsistent self-referral models across NHS England, leading to confusion about how to ask for a referral or self-refer for physiotherapy treatment and if women can self-refer or ask for a referral for other healthcare practitioners, such as osteopaths or chiropractors.

Due to limited access to treatment on the NHS, women are being forced to look elsewhere. As a result, too often it is only women who can afford to pay for private treatment who are able to become pain-free. In a cost of living crisis, it is becoming increasingly hard for some women who are pregnant or have young children to budget for this and there are very few third sector organisations who are able to support them financially to access treatment.

“Training needed for NHS physios regarding manual therapy. Women should not have to pay for effective treatment which can only be provided by private sector!” – Healthcare practitioner

“I also strongly feel that appropriate treatment should be on the NHS. It's not reasonable that we should all have to seek help at a huge cost to us when any other condition would be treated properly via the NHS. The overwhelming feeling I have is being let down in my hour of need.” – Service user

3. Perinatal mental health support to acknowledge the mental health impacts of PGP

As members of the Maternal Mental Health Alliance, we welcome the government's commitment to improving the mental health and wellbeing of women during and after pregnancy.

Women with PGP have a higher reported risk of developing a perinatal mental health condition (Gutke et al, 2007) and given the physical and emotional toll of living with severe pain, this is not surprising. This also correlates with feedback from our service users, who are feeling the impact of living with pain, feeling isolated and not getting the care, support and treatment they need. Indeed a significant part of our support service is addressing the initial mental health impacts of PGP, to give women the tools and confidence to get the treatment



16 The Cleave, Harwell
Oxfordshire OX11 0EL
01235 820 921

pelvicpartnership.org.uk
contact@pelvicpartnership.org.uk

they need. Without acknowledging the mental health impacts, it is hard for many women to become pain-free.

About the Pelvic Partnership

The Pelvic Partnership is a small charity offering support and information to women experiencing PGP. Led by women with lived experience of PGP, the charity seeks to support women with PGP to get the tools and confidence to become pain-free, while at the same time raising awareness about PGP and its treatment.

“I felt desperate and so alone until I found your helpline. Thanks so much for putting me on the right path to recovery. Thanks to you I found a physio who could provide manual therapy; two months ago I just wouldn’t have believed how far I could progress.” – Service user

We are concerned about the impact on the physical health and emotional wellbeing on women and birthing people across the UK as a result of these policy challenges. These women are often pregnant or recently postnatal, and may be vulnerable.

We would welcome the opportunity to speak with you and your team about this in more detail.

Yours sincerely,

Sarah Fishburn
Chair of the Pelvic Partnership, Registered Charity 1100373