



## 2023 survey highlights

In May 2023, the Pelvic Partnership launched an online survey exploring women's and birthing people's experiences of pregnancy-related pelvic girdle pain (PGP) within the last two years. We had over 100 responses in four weeks, with many women sharing stories of limited access to support and treatment.

The findings of this survey are summarised below and will shape the Pelvic Partnership's policy and advocacy efforts over the coming 12 months. We have also included quotes from the survey, highlighted in blue.

### Women and their pain

To get an idea of the demographics of our survey respondents, we started by asking several more general questions about them and their pregnancies:

- 50.5% were pregnant at the time of completing the survey,
- 65.7% had experienced PGP in a previous pregnancy,
- 99.1% identify as a woman,
- 66.4% are aged 26-34 years and 28% are aged 35-40 years and
- 89.7% are White, 7.5% are Asian or Asian British, 1.9% are from Mixed or Multiple ethnic groups and 0.9% are from Another ethnic group.

With regards to the geographic spread of our service users, we also asked survey respondents which region they live in (and therefore availability of treatment in different parts of the UK. While there is a good spread across the UK, over 37% of respondents are based in London and the South East. The smallest proportion of respondents are from Wales and Northern Ireland, which interestingly mirrors the areas where there were the fewest number of recommended practitioners on our website.

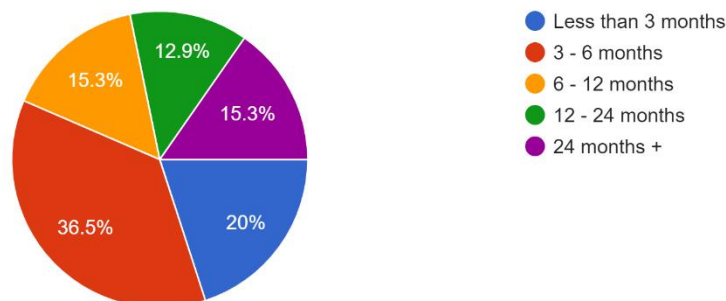
We also asked the survey respondents if they were currently experiencing PGP, and if so, how long since their pain started:

- 77.4% were currently experiencing PGP (up from 67.5% in our 2022 survey)
- Of those, more than 40% had been in pain for more than 6 months (down from more than 50% in our 2022 survey)



## 2. If you are currently experiencing PGP symptoms, how long since the pain started?

85 responses

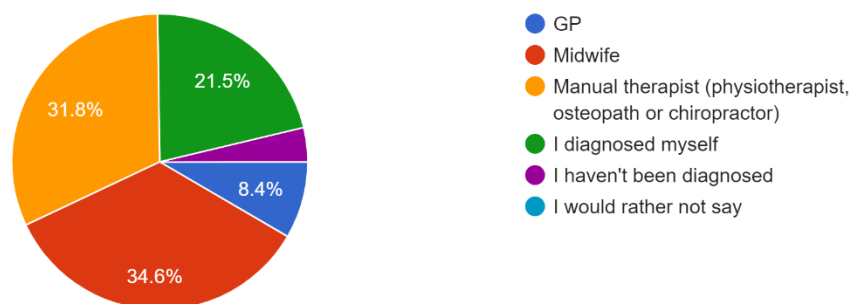


This reinforces our anecdotal evidence from engaging with women with PGP, that most women reach out to us when they have been experiencing PGP for more than three months.

It is also important to pin down how women are diagnosed with PGP and by whom. While nearly 35% were diagnosed by their midwife, a large proportion were not, with many diagnosing themselves:

## 9. How were you diagnosed with PGP?

107 responses



In response to growing comments from our service users, we asked respondents if they were hypermobile which affects some women with PGP. While the majority of respondents are not hypermobile (55.1%) while more people didn't know (22.4%) than answered yes (21.5%).

## How PGP has impacted women's lives

From our ongoing engagement with women with PGP, we know that PGP can affect different women in very different ways. To get an idea of the extent to which women's

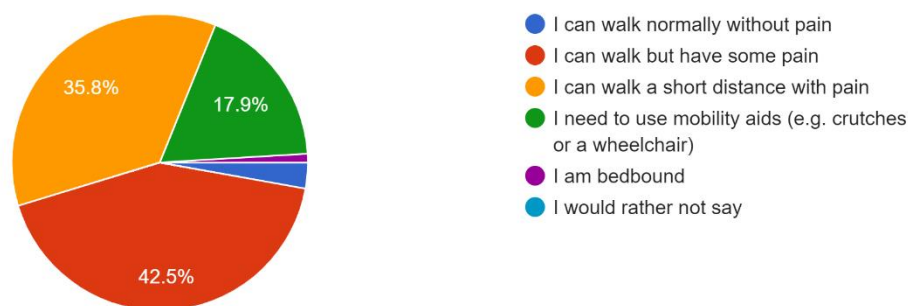


lives have been affected by their pain, we asked them to quantify their pain levels by asking how mobile they were:

- Only 3% of survey respondents can walk normally without any pain (down from 6% in our 2022 survey)
- 78% of survey respondents can walk with pain (down slightly from 80% in our 2022 survey) and
- 18% of survey respondents need to use mobility aids (crutches and/or wheelchair) (up from 13% in 2022).

### 13. How does your PGP affect your mobility?

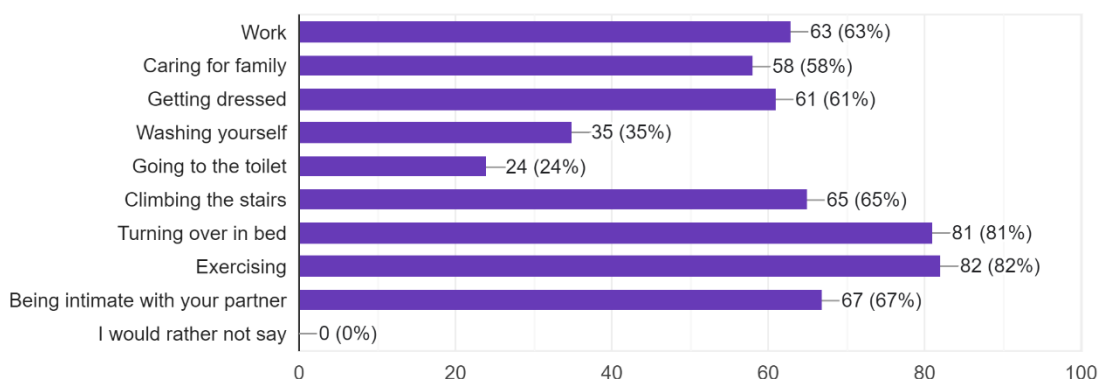
106 responses



We also asked respondents to share the extent to which PGP had affected their ability to do certain activities. As the below graph shows, exercise was the activity most affected by PGP (82%), followed by turning over in bed (81%), being intimate with your partner (67%) and climbing the stairs (65%). A high number of people shared that work (63%) and caring for family (58%) were impacted, which have economic and productivity implications.

### 14. Does your PGP affect your ability to do the following activities:

100 responses





*“Very sore and uncomfortable. Cannot be in the same position for too long, be it standing, sitting or lying down. I have an active job and so it makes it hard to do it.*

*“I’ve never felt pain like it. I am in constant pain and it leaves me feeling helpless and miserable most days.”*

*“It left my immobile and depressed for many weeks. I am not immobile anymore but still in pain everyday. It affects my sleeping too. Not only do I struggle to care for myself and my toddler but my husband has had to take on a larger share of chores and do all the driving. I get snappy because I’m tired and in pain and it’s taking a toll on my relationships.”*

*“It made me immobile at times. The pain was excruciating and worse than what I experienced with childbirth. It mainly impacted by hips and inner thighs.”*

*“I first felt the heavy pressure and pains mostly when I was moving in bed, and it then progressed to when I was getting dressed and finally to walking. It got to the point where I was almost too scared to have to move while in bed as the pain was severe. I am a teacher so I’m on my feet all day, and I ended up almost hobbling around as I couldn’t walk normally. Intercourse was far too painful and I couldn’t do certain exercises or activities which I relief on for my mental health, so I was feeling immobile and moving less which brought on low mood.”*

## PGP and healthcare practitioners

A key indicator of access to treatment, support and pain relief for women with PGP is how supported they feel in early appointments with healthcare practitioners, especially their GP and their midwife.

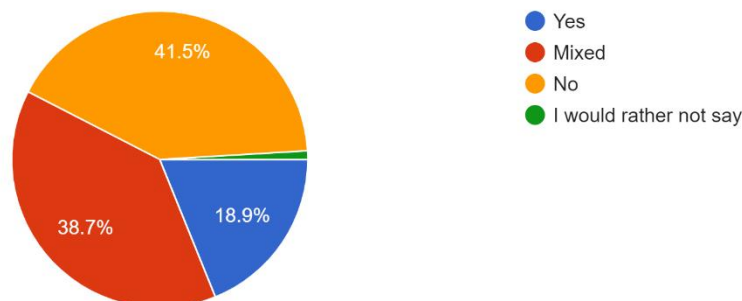
Unfortunately, we found:

- Only 19% responded that they did feel supported by their GP or midwife (up slightly from 17% in our 2022 survey),
- 42% did not feel supported by their GP or midwife (down slightly from 44% in our 2022 survey), and
- 39% had mixed feelings about the support offered by their GP or midwife (up slightly from 37% in our 2022 survey).



11. Did you feel supported by your GP/midwife?

106 responses



*“Midwife told me to suck it up. GP just signed me off work. The only one who helped was the physio I found through the Pelvic Partnership.”*

*“I was told by my midwife and GP – it’s just one of those things that comes with pregnancy [...] very limited support and really impacted my mental health.”*

*“Nobody really cared”*

*“Very dismissive, “It will stop when the baby is born” and my baby is 20 months old and I’m still experiencing issues/pain that I had when the PGP started in my second pregnancy.”*

*“Told it was all normal and to just take painkillers even though some days I’d be sobbing with pain.”*

## Access to NHS manual therapy

Unfortunately many women have shared with us that they have not been offered face-to-face physiotherapy appointments on the NHS. In the survey, we defined manual therapy and asked our respondents if they had been offered manual therapy on the NHS:

- 86% of survey respondents had not been offered manual therapy on the NHS (up from 80% in our 2022 survey), and
- Of those, only 29% were fairly confident it had improved their condition.

Instead women were either offered either nothing or a range of alternative treatments, including:

- Individual in-person appointment with exercises and advice,



- Telephone or video appointments with exercises and advice,
- Group class with exercises and advice,
- Lost referrals for NHS physiotherapy services,
- Nothing offered, and
- Given a support band or crutches.

*“Referred to physio at hospital offered a support band until I cried and said I was in agony. Had a physio session where I was shown how to get out of bed. Ended up on crutches.”*

*“I saw a physio who said she couldn’t help me at all. She said it was too late in my pregnancy to do anything (I was 30 weeks at the time) including exercises or stretches.”*

*“Was referred to physiotherapy by midwife, attended one class session and advised to contact the team if needed.”*

*“Referral to NHS physio led to an exercise in pregnancy group and crutches, denied manual therapy when asked in spite of pain so limiting I could barely walk 5 steps. Accessed physio privately which helped significantly.”*

*“Very little help from NHS physio, was part of a group session, given two different types of belts and told there was nothing they could do until after birth and then I would have to wait 8 weeks and if I’d not had an appointment by 12 weeks postpartum then I would be discharged from their service.”*

## Access to private manual therapy

For a broader picture of access to manual therapy, we also asked the same question for manual therapy from private practitioners, including physiotherapists, osteopaths and chiropractors:

- 53% of survey respondents had had private manual therapy (down from 59% in our 2022 survey)
- Of those, 74%% were either very confident or fairly confident that it had improved their condition (down from 82% in our 2022 survey)

While many women who reach out to us to utilise private practitioners for hands-on treatment, issues around affordability have been raised to us many times, with treatments costing around £50-80 for a first session. With this in mind, we asked what reasons survey respondents had for not having private manual therapy:



- 60% of survey respondents said it was because they couldn't afford the cost of private manual therapy (down from 76% in our 2022 survey)<sup>1</sup>.

For those survey respondents who had had private manual therapy who had had private manual therapy, we asked how they had found their practitioner:

- 37% used the Pelvic Partnership list of recommended practitioners (down very slightly from 36% in our 2022 survey),
- 15% followed a recommendation from a friend or family member (down from 32% in our 2022 survey), and
- 29% did an internet search (down from 32% in our 2022 survey).

## Women's experience of PGP and mental health problems

In previous surveys we have asked women about any mental health problems during and after pregnancy and if these were associated with their experience of PGP:

- 57% survey respondents experienced a problem with their mental health during or after pregnancy (down from 63% in 2022).

*"It has affected me mentally, not being able to do normal daily activities without help gets me down."*

When asked what factors affected their mental health and wellbeing, many listed PGP as a factor in their mental health problems, along with pregnancy and COVID-19.

*"PGP had the biggest impact on my mental health in all three of my pregnancies. There is no doubt on the cause as the lack of mobility and pain it has caused me has been hard to cope with especially with my little ones."*

*"PGP made it harder to look after my well-being as used to exercise and socialise regularly but no longer able to do either of these due to PGP."*

*"PGP was a great difficulty in my mental health through pregnancy. I often felt completely useless when I couldn't do basic things like get myself up the stairs or get in and out of the bath on my own. I relief heavily on others. Similarly hyperemesis in the first trimester really had an impact on my mental health."*

We also asked respondents to share what mental health support they received. Responses included:

- medication,
- counselling or talking therapy,
- support from the perinatal mental health midwives, and

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<sup>1</sup> Low response rate for this question but still indicative that affordability is still an issue for many women trying to access private treatment.



- GP signed them off work.

## Advice for other women with PGP

For the first time in 2023 we also asked women to share some advice they would give to someone else with PGP:

*“Ask for support and explain how it affects you.”*

*“Speak to others as it provides comfort that its not just you going through the hideous pain. Get manual therapy as soon as you can.”*

*“Do not settle for a “we can’t help” – keep pushing.”*

*“Get it treated as soon as possible and don’t let your midwife/GP just ignore you.”*

*“Pace yourself and remember you’re growing a human.”*

*“Persist with your midwife, be demanding with NHS physio but if you can afford to go private then do. Find your village who support you. Rest as much as you can.”*

*“See a manual therapist, join the Pelvic Partnership Facebook support page.”*

## Engagement with the Pelvic Partnership

In this survey we discovered that most service users had found the Pelvic Partnership on social media or an internet search (87.9%). Most survey respondents shared that they had been received help, information and support by the Pelvic Partnership on:

- Pelvic Partnership website and free resources (62%),
- Pelvic Partnership Instagram and Facebook (46%),
- Pelvic Partnership Facebook support group (25%), and
- Pelvic Partnership telephone helpline (9%).

We also asked respondents what further work we need to do as a charity:

*“More visibility in hospitals/midwife clinics would be great. Perhaps more adverts on Google with AdWords but I know this can be costly.”*

*“Raising awareness with midwives. I was told I did not have PGP because I didn’t have pain in the centre of my pelvis and it was too early in pregnancy.”*

*“Lobby for NHS support and training.”*

*“Campaigning for more awareness of PGP and how GPs can support the need for manual therapy.”*





*“Educate antenatal midwives and GPs on PGP and manual therapy so they refer people to the support they need.”*

*“More awareness of your services so we can get more recommended practitioners in more areas as there aren’t any close enough to me.”*

*“I find your posts very repetitive “get manual therapy” and not much else. I would like to see data, infographics, diagrams, personal stories, really simple and easy suggestions of how to help yourself – I feel much of what I see is signposting and that is a bit limiting to your potential impact.”*

For further details about the survey, please contact our co-ordinator on [contact@pelvicpartnership.org.uk](mailto:contact@pelvicpartnership.org.uk).