

Bio:

My name is Angeline O' Connor. I am a 38-year-old mother of 2 with lived experience of Pelvic Girdle Pain (PGP). I am a proud trustee at the Pelvic Partnership, a charity which supports women with PGP. I'm an active member of The Health and Social Care Alliance Scotland (ALLIANCE), and a member of the ALLIANCE Women's Health Plan Stakeholder Group. I'm the founder of 'pgpandme' and Co-host of the 'Let's Talk about Pelvic Girdle Pain' podcast. I'm hugely passionate about advocating for women's health and aim to bring change for our future generations.

PGP and me and the 1 in 5 women affected.

'Representation of the world, like the world itself, is the work of men; they describe it from their own point of view, which they confuse with the absolute truth.' Simone de Beauvoir

Pelvic Girdle Pain (PGP) is a condition that causes pain in the pelvic joints. It affects 1 in 5 pregnant women and can continue after birth. PGP symptoms can vary from each individual as well as the severity of such symptoms. PGP is a biomechanical joint problem which occurs as a result of abnormal movement and stiffness in one of the joints, causing pain and limited movement around this area. As such, the other joints and surrounding muscles have to compensate for its lack of movement. PGP can affect a woman's mental health, relationships with those around her, work life, self-esteem, confidence, intimacy with her partner. It can creep into every aspect of a woman's life.

Despite PGP affecting so many women (1 in 5), this condition is severely under recognised by our healthcare system. As such, access to proper treatment, support and pain relief can prove extremely difficult. In my experience, this is due to a lack of knowledge about the condition by health professionals. Women are often on the receiving end of medical gaslighting, being told that the pain is "all in their head" and "it will go after pregnancy".

In Spring 2022, the Pelvic Partnership conducted a survey, to explore women's experiences of pregnancy-related PGP within the last two years. When asked about access to treatment, support and pain relief for PGP, the results reported that 44% of women did not feel supported by their GP or midwife.

37% had mixed feelings about the support offered by their GP or midwife and only 17% felt supported by their GP or midwife.

Whilst these results did not arrive as a surprise, it is truly heart-breaking that, at one of the most vulnerable times in a woman's life, and while growing a true miracle, women report feeling unsupported. This is a huge failure, and it must not continue.

Whilst PGP can be extremely debilitating due to the limitations in a woman's physical abilities, it is imperative to recognise the affect it can have on our mental health. As part of the Pelvic Partnership PGP survey, 2022, women were asked about any mental health problems during and after pregnancy and if these were associated with their experience of PGP.

63% of survey respondents experienced a problem with their mental health during or after pregnancy. When asked what factors affected their mental health and wellbeing, 72% listed PGP as a factor in their mental health problems.

‘Long-lasting pain is very difficult to live with, and can affect many different aspects of people’s lives, for example personal relationships, activity levels, work-status. It can also result in a reduced quality of life and emotional distress, such as anxiety, low mood and depression.’ (NHS England, 2022).

Despite this acknowledgement, women are rarely probed about their mental health when discussing PGP with health professionals. Personally, I was never asked about the impact of PGP on my mental health, until I reached a point of experiencing regular suicidal thoughts. I began to feel that I no longer wished to live in constant pain. Such thoughts began to surface in March 2021, around four years after the birth of my second child. At this point, I had been living with PGP since January 2017 and it was relentless. Thankfully, I recognised that the suicidal thoughts should be addressed and reached out to my GP. This marked the first time that PGP and mental health were part of the same discussion, and it was instigated by me, the patient. From discussions with other women with lived experience of PGP, I have learned that I am not alone in having such dark moments due to this condition.

It is bad enough that the expected support is not available to treat women with PGP, however, this is made worse by the constant dismissal of this condition. In the earlier days of my PGP journey, I did not have a name for the pain. I had no idea why I was in constant agony. I attended appointments with GP’s and midwives in complete desperation for support. However, when met with a laissez-faire attitude, whilst already feeling vulnerable in pregnancy, it proved difficult to self-advocate. If health professionals would not take this pain seriously, then perhaps it should just be tolerated. Self-doubt takes over.

Recently, on my Instagram page ‘pgpandme’, women with lived experience of PGP were asked to define the condition in a few words. The responses are captured below:

PGP is...

- Depressing. The reason I now take anti-depressants.
- Relentless
- Exhausting – physical and mentally
- Misunderstood
- Debilitating
- Soul destroying. It has taken what should have been the best experience in the world from me.
- Scary
- Soul destroying. PGP changes you and not always for the better.
- Isolating
- As hard mentally as it is physically. It affects relationships with family due to pain and low mood.
- Misunderstood doesn’t quite cover it – people just don’t have a clue about it
- Guilt
- Lonely, people don’t understand or know how to help

- Makes the smallest tasks overwhelming
- Ruining life enjoyment
- Unbearable and constant
- The worst thing that I have ever gone through
- The saddest time of my life yet
- Unbelievably painful
- Debilitating, exhausting and relentless
- Felt like I was letting my other kids down, unable to move, constantly exhausted from trying to cope with the pain. Being unable to sleep and feeling completely useless / worthless while watching my other half run himself ragged trying to pick up the slack because I was unable to do anything but make it through the day.
- Excruciating, depressing, debilitating and takes a huge toll on your mental health.
- 11 years old
- A thief of pregnancy joy
- Life-stealing. Ruins one of the most special times of life. Physically and mentally draining.
- Feels like it traps you in a body that isn't yours.
- Expensive
- Misunderstood, under-diagnosed, excruciating
- Unfair. No matter how you've taken care of your health your whole life, you just may or may not be affected by it
- Emotionally draining to deal with
- A loss of independence
- It makes you feel weak for suffering so much
- Mentally and physically debilitating and draining
- Exhausting, isolating, misunderstood.

The responses above speak volumes about the reality of PGP from not one, but many women. Frustratingly, so many are suffering unnecessarily with a condition that is treatable!

Historical practice and obstacles in place

Having experienced PGP in both pregnancies, and on reflection of this, I have noted several reasons why little has changed in the approach. The Pelvic Partnership charity has been running for almost 20 years, yet we are still repeating the same message and giving out the same advice. We are not adequately supported by our NHS. Many people respond well to manual therapy, so we know that it is an effective way of treating the condition.

Of course, this is rarely available on the NHS. In some areas of England, manual therapy is available, however, it is a postcode lottery. In Scotland, it is not possible to receive manual therapy on the NHS. Conversely, the current approach is very 'hands-off' and self-management is encouraged. I believe this approach to be the case, mainly due to a lack of knowledge from healthcare professionals, such as GP's, midwives, obstetricians and physiotherapists. Women are repeatedly dismissed when seeking help for PGP. Many others and I have been on the receiving end of a lack of interest in concerns over the symptoms caused by PGP.

Personally, I attended my GP repeatedly after the birth of my son to seek support for PGP. On attendance to an appointment, with two kids in tow, I was told to “take ibuprofen and do some stretches from YouTube”. My son was 8 months old by this point and I understandably left the appointment feeling let down and distraught. I was desperate for help, and no-one seemed to be interested. In my opinion, this is due to a lack of knowledge of the condition. If the extent of PGP was truly understood, women would not be dismissed in this manner. Whilst I recognise that it is a wider issue than a lack of knowledge, as a minimum, an empathetic response should be taken.

Even if you are referred to a physiotherapist for treatment or have taken the self-referral route, the correct treatment is rarely available, and this is due to the lack of required skills held by this profession. Physiotherapists are encouraged to adopt a ‘hands-off’ approach in the treatment of PGP. Patients are often given a leaflet about how to avoid aggravating symptoms and told to go home and rest. The consequence of this is a further decline in symptoms. With PGP, we know that early intervention is key, however, each time a woman is sent away from an appointment, more precious time is lost. Sadly, the damage done is more difficult to reverse.

Many physiotherapists tell women that PGP will be gone after birth, that nothing can be done, but this is inaccurate advice and occurs because of a lack of skills. Manual therapy requires the adoption of specific techniques, such as, joint mobilisation and soft-tissue or muscle treatment including myofascial release, muscle energy techniques and trigger point release, with or without the use of dry needling. This takes a specific skillset, but it is performed by many manual therapy practitioners in private clinics and can be taught. The core skills are there but need to be expanded.

A common and well-known barrier to change within our NHS is funding, or rather a lack of! To upskill physiotherapists who treat women with PGP isn’t a small task, nor is it an inexpensive option. However, with the current approach, the following areas are undoubtedly costing a substantial amount of money; pain relief prescriptions, anti-depressants, anti-anxiety medications, accessing maternal mental health services, physiotherapist appointments, PGP support groups (where patients are taught how to perform daily activities to help reduce symptoms), pain clinics, support belts, walking aids such as crutches, walking sticks, wheelchairs, walking frames.

Neither of said approaches effectively treat PGP. So instead of wasting money on the above, it would make more sense to upskill physiotherapists in manual therapy and introduce this service in clinics around the UK.

There is also a severe lack of collaborative working between health professionals who treat women with PGP. I have spoken with maternal mental health teams who didn’t truly appreciate how much PGP can affect a woman’s mental health. They have admitted an assumption that PGP would be taken care of by midwives, who in turn have assumed it would be taken care of by physiotherapists. The reality is that no-one is really supporting these women adequately. All health professionals who treat with women with PGP should be aware of the condition and should be working together to ensure a supportive approach is adopted. Otherwise, it slips through the net and women are let down.

Ultimately, there is a known poor representation of women's health in general. Despite making up 51% of the population, women are repeatedly let down by our healthcare system. We are understood to have a higher pain threshold than men, which in turn, does not go in our favour. We are expected to deal with huge life changes, such as the menopause, without the right support. We are fobbed off repeatedly. It simply cannot continue.

Women are branded as 'superwomen' as we have proven over the years to have the ability to juggle family demands, careers, social pressures, a lot of what life throws at us. However, I do not accept this term. It is not a compliment. It is the result of generations of women being placed at the bottom of the ladder. Placing their own needs last. There is a well-known expression – 'you can't pour from an empty cup' and this is particularly relevant for modern women. We must look after ourselves, with care and attention, we must meet our needs, or we will be unable to care for those who rely upon us.

Overdue change

To bring the change that is so desperately needed, health professionals must work together to create the required multi-dimensional care plan to ensure that women with PGP are supported adequately. Acceptance of the need for change is a crucial step in this process. This will not happen overnight, but it needs to start somewhere.

Firstly, PGP deserves to be recognised for what it truly is. Not just pregnancy aches and pains that will go after birth, rather a biomechanical joint problem that, when left untreated, has the ability to, quite frankly, destroy a woman's life. Whilst recognition of PGP is paramount, alongside this must come education. Health professionals who are supporting women must be educated adequately in PGP, as at present, the extent of the condition is not recognised. Health professionals should be given a thorough teaching of the pelvic anatomy, including the biomechanics of the pelvic function. By understanding this core function, said individuals could adopt this as a base for future learning. Such as, what happens when things don't go to plan. At this point, it would be helpful to incorporate feedback from those with lived experience of PGP. Ultimately, these are the ones from whom lessons should be learned.

In his book, *The Body Keeps the Score*, Bessel Van Der Kolk states,

'Finally, my patients, to whom I dedicate this book – I wish I could mention you all by name – who taught me almost everything I know – because you were my true textbook – and the affirmation of the life force, which drives us humans to create a meaningful life, regardless of the obstacles we encounter.'

Ultimately, you cannot replace lived experience. Great lessons can be taken from those who have walked many days in the shoes of living with a health condition. Personally, I would enthusiastically dedicate time to share my experience with said health professionals. Many other women may do the same. By sharing our experiences so openly and honestly, the true reality of PGP could be understood.

Education through a combination of theory and lived experience would be ongoing, as new health professionals enter the industry. However, as always, collaborative working is key. Partners should work together in a way that provides a multi-disciplined approach to supporting

women with PGP. Examples of this include physiotherapists being trained in the skills and techniques needed to perform manual therapy. Walking aids and wheelchairs should be distributed, alongside manual therapy. Not all women with PGP require this support but many are being failed, and as such are putting unnecessary and avoidable pressure onto their bodies by walking without aids, when such support is needed. Other tools are beneficial such as bed rails to aid getting in and out of bed, a sacroiliac belt, which helps to support the pelvis. Belts are often distributed, but should not be placed on a misaligned pelvis, and should be used alongside manual therapy. Slide sheets could also be distributed, allowing for easier turning in bed.

Midwives play a crucial role in a woman's pregnancy, yet so many do not recognise PGP. Midwives can make an enormous difference in how a woman is supported in various areas such as appropriate birthing positions, recognition of varying severity of the condition, including disability, the impact on mental health, emotional support required to navigate the condition.

As standard, at a pregnancy booking appointment, women are asked if they are currently at risk of domestic abuse. If the answer is yes, a referral is made to a suitable support service. PGP should be no different. Women should be proactively asked if they are experiencing pain in or around the pelvic region. Of course, not all cases will be PGP, but this area should be explored and acted upon accordingly. This could lead to a physiotherapist referral, information on the Pelvic Partnership charity and further support available via this route, referral to their local maternal mental health team, pain management groups such as Pain Association Scotland.

Often, by obtaining a further understanding of pain and why it happens, an individual can feel empowered to support themselves better and in turn self-advocate. When pregnant with PGP, I would have welcomed all the aforementioned with open arms!

We must not forget loved ones who are supporting those with PGP. It is an incredibly challenging time for partners, kids, family, friends. Often, people feel helpless. They want to help but don't know how to. They sit on the side lines, seeing their loved one become physically and emotionally broken, sometimes overnight. Support groups for those supporting women with PGP would be highly beneficial.

To truly implement change, we must involve local governments, by executing policy change. Personally, I am a member of The Health and Social Care Alliance Scotland, the national third sector intermediary for a range of health and social care organisations. I am also an enthusiastic member of the Alliance Women's Health Plan Stakeholder Group. My intention in my role within this group is to raise awareness of PGP, through lived experience, and push for change to the current approach by influencing those responsible within The Scottish Government.

In conclusion, in September 2022, women with lived experience of PGP, were asked to respond with one wish for support in the resolution of this debilitating condition. The responses are listed below:

- Sleep as it would have made everything more bearable, but pain deprived me of sleep
- Effective NHS treatment
- For no more women to ever have it
- To be able to play with my daughter and cuddle / carry her (2 years old)
- Being able to go on short walks to keep up with some sort of fitness
- That it is a truly recognised condition and manual therapy is promoted by the NHS

- That it was more widely understood by the medical profession
- For more understanding and treatment of the NHS from the very beginning
- Just knowledge. I was handed a leaflet and sent on my way. No idea what to do...
- Pro-active guidance from doctors
- Not to have PGP but on a serious note, to receive the treatment that has been proven to work to treat it, as I am not able to afford to pay privately
- To start treatment earlier with a qualified healthcare professional

This is a desperate situation. No-one expects to be disabled due to pregnancy. Women expect and deserve to be supported properly. Life is too precious to live in pain, physically and emotionally. PGP is treatable and we know that early intervention is key. Let's aim to do better going forward.

References

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