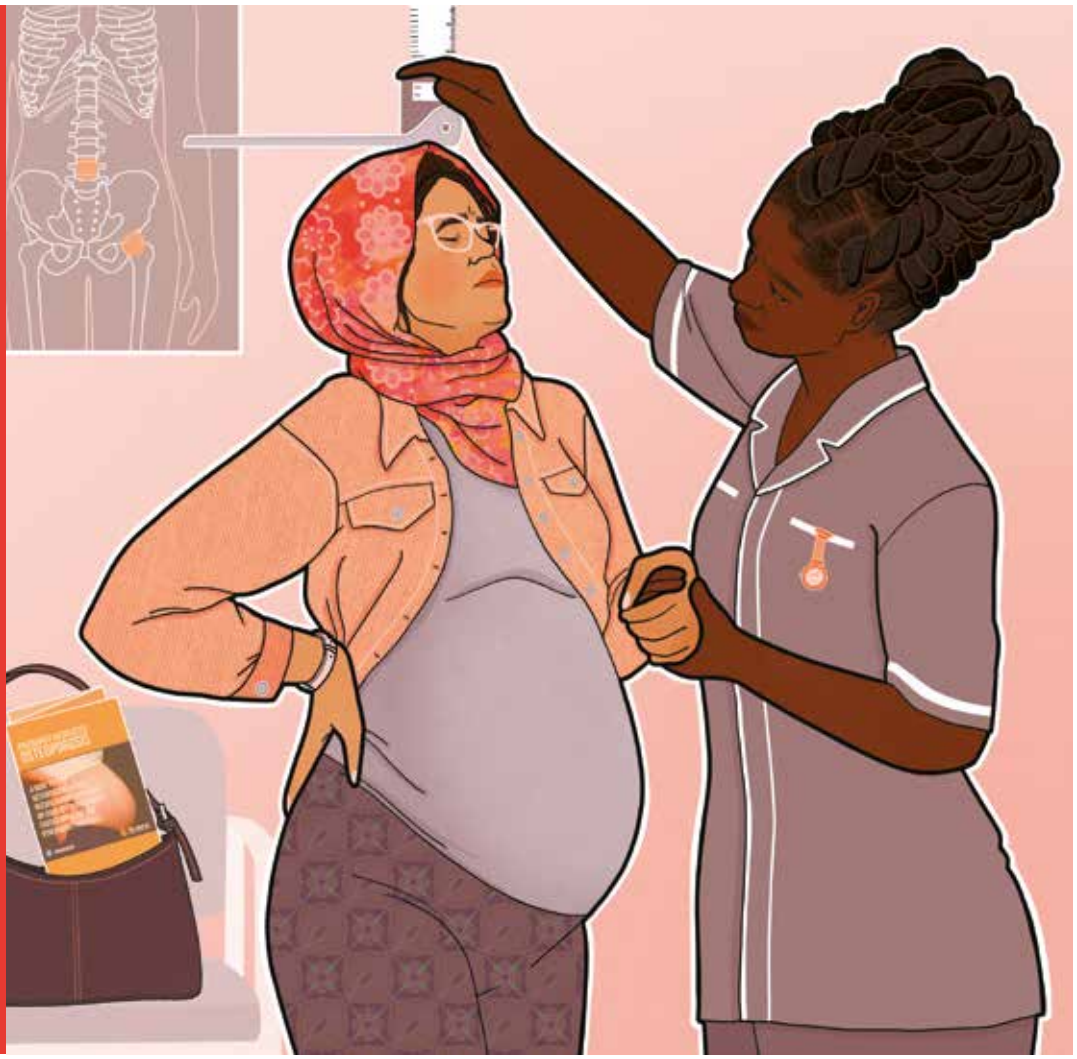
PREGNANCY ASSOCIATED OSTEOPOROSIS

SUMMARY

Pregnancy-associated osteoporosis (PAO) is a rare and debilitating bone disease which affects young pre-menopausal women, typically presenting with vertebral fractures in the third trimester or post-partum stages of pregnancy and lactation. In the September 2024 issue of The Practising Midwife we published a Spotlight article on this disease, this Voices article provides the thoughts of patients, to enable a greater disease understanding among midwives.



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WHAT IS PAO?

PAO is a rare type of osteoporosis, of as yet unknown cause, which causes reduced bone mineral density (BMD), severe pain, vertebral fracture, height loss and a heavily restricted ability to perform normal daily activities.[1] Recent work published by the University of Edinburgh suggests the disease might affect as many as four in 100,000 women.[2]

This year, we distributed a survey through an international support group on Facebook, and collated responses related to the lived experience of PAO. We report some responses below, including comments from some of the UK Mothers who, along with the authors, have applied to be founding trustees of a new charity. Co-author Karen says:

'It is heart breaking nothing has changed or improved in over 30 years since I was eventually diagnosed after terrible difficulty and dismissal by frontline healthcare professionals.'

LACK OF BELIEF

The dismissal of severe pain, often caused by multiple vertebral fractures, can cause significant distress to new mothers unknowingly living with PAO. In many cases, women are not physically able to pick up their new-borns.

'If a new mother can't lift her baby then there is something seriously wrong.'

Several respondents to the survey reported that they received threats of involvement of child services, with some being given an incorrect diagnosis of post-natal depression or postpartum psychosis as an explanation of their symptoms.

'*I spent the first three years treated like a psychiatric patient, I was told I suffered from anxiety and depression. My life became a nightmare after my first birth, the pain was horrible and I couldn't even walk, but the doctors didn't listen to me. It has been an awful experience.'*

Lack of belief from healthcare professionals can exacerbate the trauma surrounding PAO diagnosis. Women face months of pain and psychological impact before they reach the appropriate services for diagnosis, with many forced to pay privately.

'*It is traumatising in that period of time you cannot physically look after yourself or your child but are being told by every professional that there is nothing wrong, you are basically making it up.*'

We asked respondents to our survey how long it took them to be diagnosed with PAO. The median time to diagnosis was six months, with some individuals reporting that it was several years before they were diagnosed.

'*Earlier diagnosis will mean less fractures, quicker healing, greater understanding for self and others.*'

Respondents noted that a shorter time to diagnosis would have had a significant benefit to them, and that having the knowledge of their vertebral fractures would encourage them to make lifestyle changes to prevent further permanent damage or cease breastfeeding as a bone protection measure.

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NEED FOR EDUCATION OF HEALTHCARE PROFESSIONALS

One respondent to the survey told of her lengthy journey to diagnosis. Her back pain had presented during pregnancy and she presented with severe back pain at six weeks port-partum, but was told by the GP that it was a strain. At nine weeks post-partum she was informed that she had pulled a muscle. Throughout her diagnostic journey she was advised to simply continue with physiotherapy and was given painkillers. After eight months of agony, a private rheumatologist agreed to do an MRI. That MRI found nine vertebral fractures. She noted:

'*Not once in my three pregnancies had anyone talked to me about calcium. It seems really important now that I know how calcium is taken from the body during pregnancy and lactation.*'

By raising awareness of the symptoms and signs of PAO, it is hoped that cases are picked up much more quickly by frontline maternity care providers.

Morag Park, a UK health visitor and PAO diagnosed Mother, says:

'*I was diagnosed with PAO after my second pregnancy. It took ten months since initial onset of pain to diagnosis and involved multiple GP appointments... My mental health was severely impacted as I needed so much help and couldn't leave the house alone... I am 13 years post diagnosis and still have chronic pain and struggle with loss of confidence due to the change in my shape and loss of height. I have huge guilt about all the activities I have been unable to do with my daughter especially as I did them with my son... I have agreed to step up as a founding new PAO charity trustee as there is still so little awareness of this debilitating condition especially within midwifery and health visiting... I have not met anyone in 13 years that has ever heard of this condition.*'

THE PSYCHOLOGICAL IMPACT OF PAO

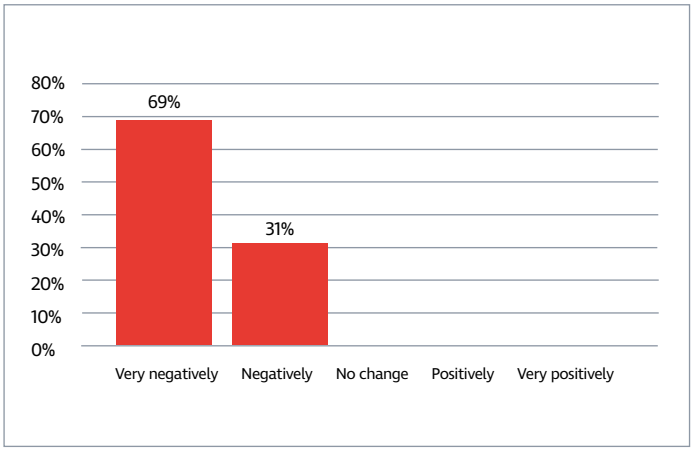
Several survey respondents reported feeling traumatised by their diagnostic journey. Previous research reveals common causes of psychological distress in women living with PAO are underestimation of symptoms by healthcare professionals, length of time to diagnosis, limitations to normal daily activities, pain and incapacity to care for the newborn child.3

Caroline Driscoll, one of the UK PAO Mothers and founding trustees, says:

'*Having gone through two pregnancies and fracturing in both, I can't understate how traumatic this experience was, especially happening a second time. If I had been diagnosed after my first pregnancy I may have been able to avoid it happening after my second pregnancy.*'

PAO can have a devastating impact on those who develop the condition. Our survey revealed that every single respondent felt their mental health was negatively impacted by their diagnostic journeys with the majority (69%) reporting that it was very negatively impacted (see *Figure 1*).

Figure 1: Graph showing survey responses to the question: **'Do you feel your mental health was impacted by your diagnostic journey?'**



WHAT CAN MIDWIVES DO TO HELP?

As part of the survey, we asked participants to tell us what they would like to say to midwives:

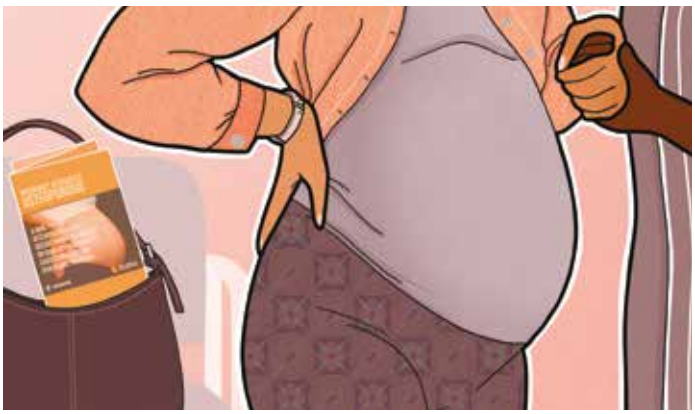
'*I would tell them not to ignore or normalise the pain of a pregnant woman or a woman who has recently given birth. Nor a strikingly hunched back, or a mother who is not even capable of holding her baby in her arms.*'

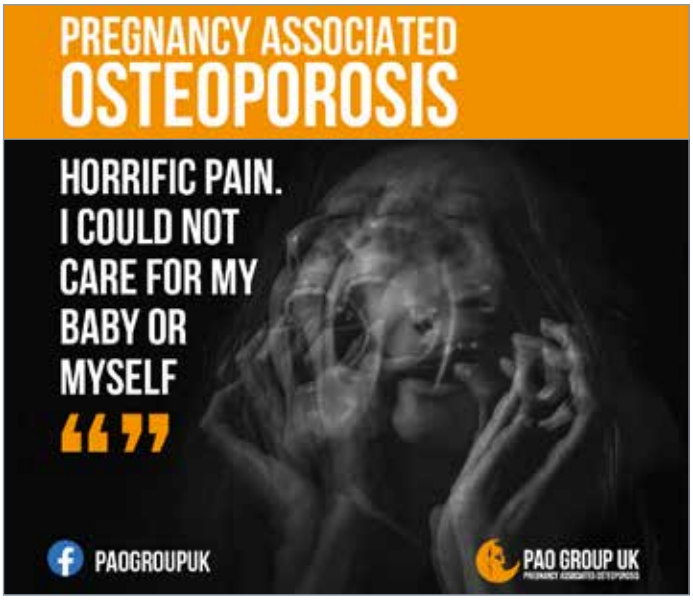
In a recent case-sample-based analysis of 836 diagnosed mothers, the authors describe PAO as 'a battle for the wellbeing of two individuals' and state 'early diagnosis is mandatory for a good outcome'.[4] This was reflected in our survey:

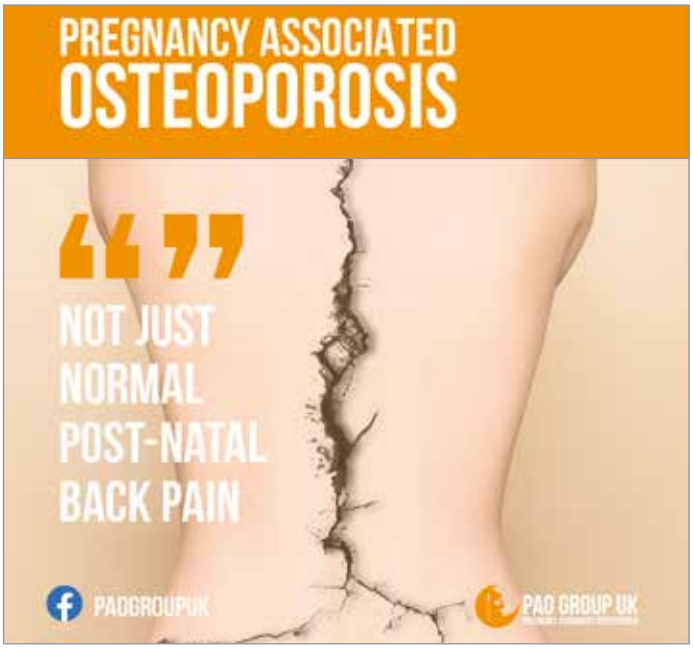
'*Earlier diagnosis... will mean the trauma associated with that time of debilitating pain when my pain was dismissed is gone.*'

Midwives should be vigilant for the three following red flags in pregnant and post-partum women: loss of height, severe back pain and mother's struggling to care for their child, or indeed themselves. **TPM**

For more information on PAO read Tessa Gooding's blog, 'We want change for Mums with Pregnancy Osteoporosis' published September 2024. Visit www.All4maternity.com.







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