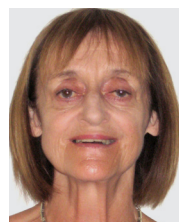


NHS is failing women with rare but serious pregnancy associated osteoporosis

The condition can cause spine fractures and leave women permanently disabled, yet patients are not receiving diagnoses or treatment owing to lack of awareness and discrimination. **Tessa Gooding** reports



Most people will be seen by professionals who often don't have an in-depth knowledge of rare bone conditions
Juliet Compston

Women with pregnancy associated osteoporosis (PAO)—a rare condition that causes spine fractures, height loss, and in some cases permanent disability—are struggling to access timely diagnosis and treatment, say experts, patients, and campaigners.

"The diagnosis is often missed," says Stuart Ralston, a rheumatologist who is leading research on PAO at the University of Edinburgh. "It strikes young women, usually previously healthy, out of the blue almost. Many come up with spine fractures during, or shortly after, pregnancy." Juliet Compston,

emeritus professor of bone medicine at the University of Cambridge, thinks that women with PAO struggle to receive diagnoses because: "most people will be seen by endocrinologists, rheumatologists, or obstetricians—who often don't have an in-depth knowledge of rare bone conditions."

Kassim Javaid, professor of osteoporosis and adult rare bone diseases at the University of Oxford, says that women face an uphill battle to get a diagnosis of PAO. "We live in a discriminatory healthcare system, so women's needs are often ignored. Patient stories consistently reveal healthcare teams thinking this is just pregnancy pain, whatever that is." He adds: "The killer statement I hear too often is, 'It hurt so much I couldn't even lift my baby.' If the back or hip pain is so bad that a mother can't lift her baby, you need to do something about it."

Many women with the condition report being denied radiography in the postnatal period because they are of child bearing age or breastfeeding. "Of course we shouldn't image every person with back pain," says Javaid, "but this is something different, and if it is that severe, you need to consider the benefits of imaging."

Some women end up paying privately for radiography or magnetic resonance imaging (MRI) to prove that they have fractures to help get a diagnosis and the care they need. "The sad thing is that nothing has changed in over 30 years," says Javaid. "We've failed in the NHS to address this."

Injustices in treatment access

After receiving a diagnosis, many women struggle to access timely and appropriate treatment. Medication is often needed to help fractures heal and to help women recover a healthier bone density, in preparation for the menopause when women can lose up to 20% in five to six years.

In England, however, no osteoporosis treatments are licensed for premenopausal women.

The comparative injustice is that patients in Scotland can access teriparatide (a daily injection similar to parathyroid hormone to help bones rebuild) on the NHS. The cost of teriparatide has reduced significantly owing to the availability of several biosimilars. "The Scottish Medicines Consortium looked at it again, and it was much more open," says Ralston. "In Scotland, [premenopausal women with severe osteoporosis] can use teriparatide under the care of a specialist."

In 2021 NHS England extended the routine commissioning of teriparatide to include men over the age of 18 who meet the same stringent criteria as postmenopausal women. It found that their exclusion by NICE was "a manifest example of discrimination based on gender (a protected characteristic under the Equality Act 2010)." But the same review has not been carried out for premenopausal women.

David Reid, a rheumatologist for private healthcare provider HCA UK and a specialist in osteoporosis, thinks that medical lobbying is needed. "You have to get some standards of care for PAO, recognising that the advised drugs are not licensed. You then have to get those standards out to the local health authorities and health planners to allocate some budget for this because that's the only way people are going to get appropriate treatment."

"Since I've retired, I'm practising entirely in the private sector," he adds. "I could give people this sort of treatment off licence if they can afford it, but I don't think I should have to." He tells *The BMJ* that "the issue with getting a licence is, firstly, you need a better definition of PAO, and secondly, you need a large trial."

There is hope that the matter might finally be tackled through the NICE committee established to update the osteoporosis guidelines for all patients over 18, although PAO and treatment access for premenopausal women are not specifically on the agenda. Its recommendations are due to be published in early 2025.

DIAGNOSING PAO

There are no NHS or National Institute for Health and Care Excellence (NICE) guidelines on PAO. The diagnosis is indicated clinically by severe back pain and height loss in late pregnancy or within a few months of delivery. It is confirmed by finding vertebral fractures on radiography or magnetic resonance imaging and finding low bone mineral density on dual energy x ray absorptiometry (DEXA; although if there are lots of vertebral fractures in the lumbar spine, DEXA might not be possible).

Hip pain (caused by localised osteoporosis of the femoral neck) is a less common manifestation and is separate from spinal osteoporosis. It's also called transient osteoporosis of the hip and can be associated with a fracture at that site.

Patient case study: Jane lost five inches in height over two pregnancies owing to her fractured spine

Jane had back pain from July 2019, when her first baby was 1 month old, and had already lost three inches in height by then. But she didn't get a diagnosis of PAO until August 2022, eight months after her second baby was born—by which time she had lost a further two inches.

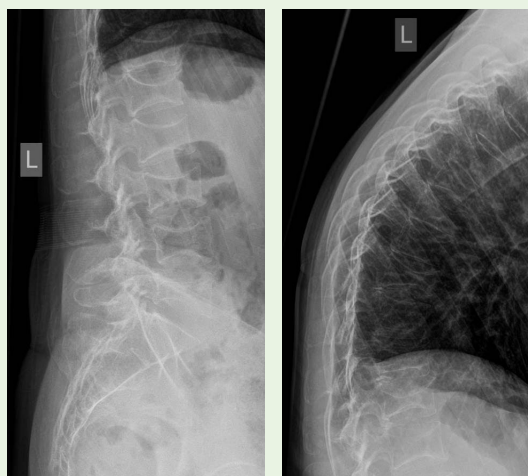
In 2019, Jane's request for radiography was declined by GPs. After she had her second child, her GP referred her for radiography, which showed multiple spinal fractures. An MRI confirmed fractures in 10 vertebrae and a bone density scan showed severe osteoporosis with a t score of -4.1 in her spine. (The t score compares someone's bone density with a healthy 30 year old of the same sex and is used to help diagnose low bone mass (osteopenia) and osteoporosis.)

Jane's vertebral fractures caused kyphosis, a curvature of the spine whereby the top of her back is rounded. Her ribs now sit inside her hips and her stomach sticks so far out she looks pregnant. She can't walk very far, has to

sit down often, and is scared to lift, bend, or attempt many exercises.

Because no treatment is available on the NHS in England to premenopausal women with osteoporosis—either through a licence or routine commissioning—her clinician submitted a special funding request to the local healthcare authority. Five months later Jane started a daily injection of teriparatide (a synthetic form of the parathyroid hormone), which she will continue for two years in the hope of improving her bone density and reducing the chance of further fractures. She will then have a yearly bisphosphonate infusion to maintain any gains.

Jane found the PAO UK Facebook group just after she received the diagnosis. "We all help each other, and I honestly don't know what I would have done without them," she says. "I really hope we are successful in our push for change. I feel incredibly upset that I wasn't taken seriously by my doctors or my husband. This condition has impacted my whole life and my children's lives."



Jane's MRI scan in 2022 showed fractures in 10 vertebrae after her two pregnancies, the first in 2019



Women's needs are often ignored
Kassim Javaid



To get a drug licence you need a better definition of PAO and a large trial
David Reid

Risks not recognised

Another concern is the known potential risks of the anticoagulant heparin—often used to treat thrombosis in pregnancy. These risks are not always flagged to enable a woman to make an informed choice. A recent PAO case series co-authored by Ralston found that half of the women in the cohort had been given unfractionated heparin or low molecular weight heparin (LMWH). The paper says, "Several clinical studies have reported associations between heparin use in pregnancy, increased bone loss and fractures."

The British National Formulary (BNF) entry for unfractionated heparin says: "Maternal osteoporosis reported after prolonged use," but the entry for LMWH doesn't say anything about osteoporosis. Ralston says: "There have been studies suggesting LMWH might be less likely to cause bone loss than unfractionated [heparin], but the studies have been small."

The NHS website promotes heparin for treatment of deep vein thrombosis (DVT) in pregnancy, without mentioning any health

risks or cautions. Reid is surprised that heparin is still being used for DVT for long term use, even LMWH. "There were some studies many years ago about the risks, but the NICE guidelines updated in 2019 still recommend the use of LMWH during pregnancy and the six week postpartum period."

In the first legal settlement for a woman with PAO, in autumn 2023, a patient received a seven figure sum for a string of errors at two London hospitals. Her case included being told to rest, rather than mobilise and stay hydrated, which contributed to her developing DVT, which in turn led to her being prescribed treatment doses of LMWH that, her solicitor Jamie Green argued, materially contributed to her developing PAO. Green is also pursuing further claims for delayed diagnosis and treatment of PAO.

Emerging findings from the first phase of Ralston's research—intended to be published later this year—indicate that quality of life doesn't return to normal even after diagnosis and treatment. "Though you might have a PAO diagnosis, and though you might be treated,

the effects on quality of life persist since the deformity from spine fractures can't be undone," he says. "A longer term aim is to find out if there are any characteristics of women with PAO that might allow healthcare professionals to have a heightened awareness of who may be susceptible to PAO going into pregnancy," Ralston adds.

In February 2024 the peer support group PAO UK (www.facebook.com/paogroupuk) launched a campaign called #Measurethatmum to help women with the condition get diagnoses. Ralston thinks that the campaign could educate midwives and other healthcare professionals that back pain plus height loss is a red flag and should be further investigated.

The clinicians and researchers interviewed for this article are supporting the set-up of a new PAO UK charity (either as trustees or clinical advisers) that will advocate for change in the diagnosis, access to treatment, continuity of care, and potential medication risks of PAO.

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As a doctor with pregnancy associated osteoporosis, I know the NHS can do better

Women face misdiagnosis, delays to treatment, and additional psychological trauma

Pregnancy associated osteoporosis (PAO) is rare and comes with various challenges around diagnosis and management. Quantifying its true incidence is difficult, with missed diagnoses and the use of private healthcare likely leading to an underestimation of affected pregnancies.

I have pregnancy associated osteoporosis and am also a doctor, but despite my profession and previous knowledge, I experienced the same traumatic diagnostic journey as many women with the condition. Testimonies from these women show that little has changed in 30 years, and they highlight the systemic failures that continue to lead to delays in diagnosis, misdiagnosis, variable management, and add to the psychological trauma already associated with this condition.

This article comes as we hear harrowing testimonies from the UK's Birth Trauma inquiry. This long overdue inquiry calls for an overhaul of the UK's maternity and postnatal care after finding poor care is "all too frequently tolerated as normal." An overriding complaint from families in the inquiry was "not being listened to when they felt something was wrong," a statement that I, and many other mothers, can sadly relate to.

Diagnostic journey

My diagnostic journey was not an easy one. From my second trimester I experienced pelvic and lower back pain that was so severe I was unable to move unaided, and resulted in a prolonged hospital stay. I still struggle to talk openly about details of that time and will never forget the pain.

I remember questioning what it was about me that meant doctors did not believe the severity of my pain. The sense that something was wrong, although I did not know what, was ever present. Ultimately, my analgesia dose was reduced and I learnt to stop complaining.

After a very difficult pregnancy and spontaneous premature birth at 35 weeks, the diagnosis of PAO was ultimately made



I have lost count of how many vertebrae and ribs I've fractured, but for most of us with PAO it reaches double digits

six weeks post partum—incidentally from a magnetic resonance imaging scan performed because I had symptoms of suspected cauda equina. While my "cord was fine," not much else was. I have since lost count of how many vertebrae and ribs I've fractured, but for most of us with PAO it reaches double digits. I will never truly know how bad my bone density got as my whole lumbar spine was affected, rendering bone density scans unreliable.

There are almost 500 members in our private Osteoporosis and Pregnancy International Support Group, all of whom carry a unique experience and trauma in relation to this condition, but all have similar diagnostic journeys that have left them mistrustful and wary of their medical teams and healthcare systems. Missed or delayed diagnosis is rife, with most women, including myself, initially being dismissed as "not coping with the normal pressures of pregnancy."

For some, the only option is to pay for private imaging after requests are denied by their care team. The support group helped me to heal in those early days when I was isolated not only by a global pandemic, but also by a traumatic pregnancy and physically disabling condition.

Despite the challenging diagnostic journey, I personally cannot fault the care

I received thereafter. Unfortunately, this is not representative of most women with PAO. Management of my condition has been led by a bone metabolism/endocrine specialist, but if I lived 50 miles east it would be a rheumatologist—that is, if I were lucky enough to have a specialist at all within my health board.

Basic barriers to care

As pointed out in the feature article (p 266), these basic barriers—such as no official diagnostic criteria and uncertainty in classification or ownership—can lead to such variations in access to care. My regular specialist appointments during those early years were as much about discussing my physical health as acknowledging the psychological effects and inevitable frustration of living with such a diagnosis.

This ability to simply listen is what set this specialist above any other healthcare professional at that time, and highlights the importance of psychological support for women with PAO.

I am fortunate to be living in Scotland where there is no barrier to me accessing teriparatide. But inequalities in healthcare across the UK and limited access to medications for PAO create a "postcode lottery" for access to treatment. This is particularly evident when licensed drugs are needed for unlicensed uses, such as in the treatment of PAO. I fear that access to these drugs for all, and knowledge of the condition, are unlikely to improve unless we as a patient group really fight for them.

I am not alone in feeling a deep sense of loss and grief because of this condition. I will not be having any more children. But I can honestly say that while I, like most of us, mourn the loss of the pregnancies we hoped for—the breastfeeding journeys cut short, the relationships damaged, and more literally the height we lost as our bodies were irreversibly changed—I would not change anything for the world. The calcium I lost went to a good home, my son.

Kirsten Furley, patient author, ST7 paediatrics, Glasgow

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