

Children's pain 'swept under the carpet for too long'

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When 12-year-old Caitriona Roberts went to her doctor because she was experiencing pain and swelling in her ankle, no one knew quite what was up.

Initially written-off as 'just a sprain' which would go away, she would spend the next six months living in almost constant [pain](#) until interventions from a diligent doctor referred her to a specialist who diagnosed [juvenile idiopathic arthritis](#)—an [autoimmune condition](#) the now 28-year-old has lived with and managed ever since.

Belfast resident Caitriona is not alone in experiencing chronic pain in childhood, which typically increases during puberty. Up to 10% of young people experience disabling chronic pain into early adulthood, with conditions including [arthritis](#), other types of musculoskeletal pain, recurrent abdominal pain, and headaches. Yet, according to the authors of a major new report released today (Tuesday 13 October 23:30), how paediatric pain is recognised, assessed and treated has gone under the radar for too long.

The findings of the Lancet Child and Adolescent Health Commission, the first of its kind ever to address the issue, suggest that much more needs to be done to help young people like Caitriona by making pain matter across society. The research was led by the Centre for Pain Research at the University of Bath, supported by Versus Arthritis and the Mayday Fund, and reflects the views and opinions of multidisciplinary medical professionals, as well as patients, including

Caitriona, whose experiences fed into the work.

The report suggests that change in paediatric services over the past 40 years in terms of pain recognition, diagnosis, assessment and management is slow. The last major intervention in the field came in the 1980s when, remarkably, for the first time, it was recognised that babies experienced pain—astonishingly, up until that point, a number of routine and major operations, including for heart surgery, were carried out without anaesthetics. The report speculates that much of what we do (or fail to do) for children in pain today might come to be seen as unwise, unacceptable or unethical in the next 40 years.

In calling for four key goals—to make childhood pain matter, to make it understood, to make it visible and to make it better—the authors argue that there must be widespread recognition that too many children live with pain and that not enough is being done to support them from diagnosis through to management of long-term conditions. These goals range from 'biological' (e.g. medication) to psychological treatment / management (e.g. CBT) and to [social support](#) (e.g. better support for parents, schools and careers). Achieving these goals would transform the lives of children for the better they say.

Dr. Emma Fisher, Versus Arthritis Career Development Fellow at the University of Bath, who led the work explains: "Among health-care professionals, it is easy to agree that no child should experience pain if that pain can and should be prevented, avoided, or successfully treated. In practice, however, we know there is ample evidence that children frequently experience preventable pain, and that in high-income settings, with advanced health-care systems and highly educated and regulated health professionals, children and young people experience pain that often goes unnoticed, unreported, or is not responded to, across healthcare including in the Emergency Department, post-surgical care, and in tertiary care.

"This really matters, both for those experiencing pain and those around them but also across wider society. We know that chronic pain experienced in childhood is likely to feed through to adulthood and this has long-term health and economic costs associated. This Lancet Child and Adolescent Health Commission is a call to action on funders, researchers and policymakers more broadly to sit up and listen to the fact that too many of our young people are in pain and need help."

Among its many recommendations, the Lancet Child and Adolescent Health Commission calls for an end to children experiencing pain when receiving routine vaccinations, drawing on the findings and recommendations from a seminal study published in 2015. Dr. Fisher adds: "For many parents and children, a trip to the doctors for routine inoculations will be a stressful and painful experience. This does not have to be the case—we know how we can make the experience less painful for young people, but we're not doing it. This is just another example of how pain has been accepted as an everyday feature of growing up."

Professor Christopher Eccleston, Director of the Centre for Pain Research at the University of Bath, explains: "In this report we present four transformational goals: to make pain matter, be understood, visible, and better. We need to advance our understanding of pain, especially in paediatrics, and we need to translate our discovery to improve the lives of people in pain. Building on today's Lancet Child and Adolescent Health Commission, we need to find better ways to break out of our silos and work together as researchers, funders and policymakers to make quick and effective progress and ensure that young people like Caitriona have a different and better pain journey."

Caitriona agrees. She has been working with the researchers from Bath, the USA, Canada, Europe, and New Zealand on this report, adding her voice on behalf of a community of young people who are living with

pain. She adds: "I think this issue has been swept under the carpet for too long. Still today, over 15 years on from my diagnosis with arthritis, I find people, including medical professionals, unaware of the condition or its effects on my day-to-day life. And when I speak to other young people, I find that sadly, very little seems to have changed in terms of how they experience pain or the support they receive.

"I was lucky. I was diagnosed by an incredible doctor—Dr. Rooney—who not only identified my condition after others ignored it, but who worked with me throughout childhood and beyond. She really understood the effects of arthritis on my life, not just the physical ones but the emotional too and she helped me so much: she really deserves an award. Not everyone is as lucky, which is why the issues the report raises are so important."

Having completed two degrees from Queens and Ulster in Northern Ireland, Caitriona now works in law, alongside volunteering for Versus Arthritis helping other young people going through similar diagnoses. "Versus Arthritis were so pivotal in supporting me when I was first diagnosed that it's fantastic to be able to give back and help other [young people](#). Working together and talking as a community we're able to share our experiences and shape interventions like this. And when you can help people in that way, well, there is no better feeling."

Zoe Chivers, Head of Services at Versus Arthritis who co-funded the Lancet Child and Adolescent Health Commission says: "People living with arthritis deal with the dismissal of their condition every day and the Commission findings detail the consequences of this for children in pain.

"Parents tell us about the struggle they have convincing their GP that their child's illness is more than growing pains; we know that the existence of specialist child rheumatology services can make the difference between walking to school or needing a wheelchair. While the

focus, attention, and dedication in providing quality services to children is consistently in place for conditions like cancer it's woefully absent for childhood arthritis and [chronic pain](#).

"As a society we need to understand that dismissal of arthritis comes at high price and that adults and children living in pain with the condition should no longer be expected to pay it."

More information: Christopher Eccleston et al, Delivering transformative action in paediatric pain: a Lancet Child & Adolescent Health Commission, *The Lancet Child & Adolescent Health* (2020). [DOI: 10.1016/S2352-4642\(20\)30277-7](#)

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