

Doctors given new tools to recognise childhood bone cancer symptoms sooner

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New guidance on childhood bone cancers aims to save “lives and limbs” by helping healthcare professionals spot warning signs earlier after research showed long waits for diagnosis.

Child Cancer Smart is a new public and professional awareness campaign from CCLG: The Children & Young People’s Cancer Association that is working to shorten diagnosis times for children and teenagers with cancer.

The campaign is updating and strengthening guidance for healthcare professionals across the country, with new guidelines and resources planned for each of the main childhood cancer types. The resources released today aim to help GPs and other healthcare professionals recognise and diagnose bone cancer faster in under-18s.

The resources have been developed on the back of comprehensive research, including the Childhood Cancer Diagnosis Study, a University of Nottingham-led project that investigated the referral and diagnosis pathways of nearly 2,000 UK children and teenagers diagnosed with cancer between September 2020 and March 2023.

Dr Shaarna Shanmugavadivel, a paediatric emergency medicine doctor and CCLG Child Cancer Smart Research Fellow in the School of Medicine at the University of Nottingham, said: “Bone tumours had the longest times to diagnosis in the Childhood Cancer Diagnosis study, with only 50% of children and young people being diagnosed within 12 and a half weeks.

“Compared to kidney cancer, which had the shortest time to diagnosis, bone tumours took an average of two and a half months longer.”

Speeding up diagnosis is vital for improving outcomes, said Dr Shanmugavadivel.

“Early diagnosis of bone tumours can be both life- and limb-saving,” she explained, with the level of treatment needed at a later stage of the cancer having a serious long-term impact on survivors.

Dr Tim Ritzmann, Honorary Consultant Paediatric Oncologist at Nottingham University Hospitals NHS Trust and clinical lead for Child Cancer Smart, said: “Late diagnosis may result in more radical surgeries as tumours may grow bigger and spread.

“Earlier treatment could result in better outcomes, preventing amputations and improving survival from this type of cancer.”

Child Cancer Smart’s new support for professionals, accessible through the CCLG website, includes:

- updated referral guidelines to help GPs recognise symptoms and know when to act
- a decision-support tool to guide faster, more confident clinical decisions
- a comprehensive list of the most common bone cancer symptoms

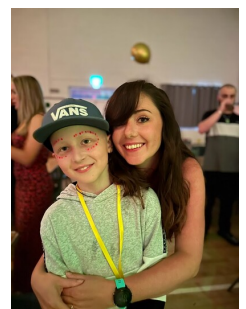
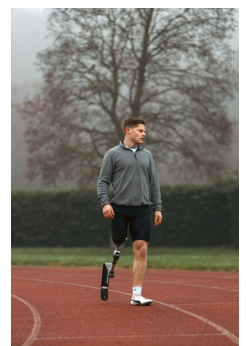
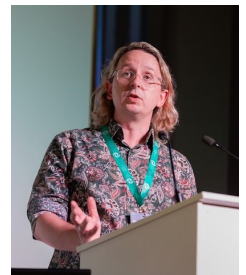
Ashley Ball-Gamble, Chief Executive of CCLG and co-author of the Childhood Cancer Diagnosis Study, said: “Every week matters when it comes to diagnosing bone cancer, so our aim is to make that process as straightforward as possible.

“Our new decision-support tool, built on evidence-based referral guidelines, gives clear and practical recommendations – whether to refer, review or reassure. We hope it will help healthcare professionals feel more confident in recognising potential cases of bone cancer and taking the right action at the right time.”

Alongside the clinical guidance, Child Cancer Smart has also published resources for the public, which show the top symptoms of bone cancer and encourage families to seek medical advice if they have concerns.

Bone cancer is more common among teenagers and young adults, an age group that the Childhood Cancer Diagnosis Study found particularly struggled to get speedy diagnoses.

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In 2018, Olly Liddle was diagnosed with osteosarcoma aged 13 after noticing knee pain and a small lump. Now 20 years old and a fitness instructor, he credits his GP's swift action with potentially saving his life.



"Cancer was the last thing I thought my injury could have been," he said. "However, my cancer was found to be extremely aggressive. If I hadn't been sent for an X-ray right away by my GP, the situation could have deteriorated, and I may not be here now."

Olly's experience shows the life-saving impact of early referral. But as Child Cancer Smart stresses, every week matters. Even with a quick diagnosis, Olly underwent a leg amputation which thwarted his ambition of playing professional rugby.

Nichola Shilton's son Oliver was diagnosed with Ewing sarcoma in 2022, aged 10, after several weeks of worsening joint pain. Despite also being diagnosed faster than the average, his cancer relapsed in 2023 and Oliver died in June 2024. Nichola wishes that people knew more about childhood cancer, its diagnosis, and the risks of relapse.

She said: "A quick diagnosis is so important, especially for childhood cancers. Even though we feel that Oliver's cancer was caught as early as possible, it had already started to spread. This significantly increased his chances of relapse and meant some of the treatment options were no longer viable."

While Oliver's parents were thankful of how the healthcare professionals managed their concerns throughout diagnosis, Nichola said other parents had a "harder time". She hopes that Child Cancer Smart can speed up diagnosis for all families, adding: "More people being aware of childhood cancer symptoms means that more children have their cancers caught sooner – and so hopefully have a greater chance of survival."

Information on bone cancer and Child Cancer Smart can be found on CCLG's website: <https://www.cclg.org.uk/bone-tumours>

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