Leading children's cancer charity releases vital new referral guidelines

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Children's Cancer and Leukaemia Group (CCLG) has released new referral guidelines for suspected cancer in children and young people today.

A crucial new resource, the CCLG ***'Referral guidance for suspected cancer in children and young people'*** is a tool to support GPs, paediatricians and other healthcare professionals in identifying potential cancer in children and young people. The guidelines will act as a supplementary resource to those produced by the National Institute for Health and Care Excellence (NICE) for suspected cancer referral, which were first published in 2005 and revised in 2015.

The NICE guidelines – *'NG12 Suspected cancer: recognition and referral'* - cover the identification of symptoms that could be caused by cancer in people of all ages and outlines appropriate investigations in primary care and the selection of people to refer.

Dr James Nicholson, Consultant Paediatric Oncologist and former CCLG Chairman, said: "While the 2015 guidance presented most of children's malignancies alongside their adult counterparts, there are many differences in incidence, presentation and types of malignancies seen in the younger age group.

"Guidance specific to children was therefore needed on the key symptoms and signs of children's cancers, which also have a number of differences in referral pathways and care compared to those of adults.

"Drawing on the expertise of CCLG's multi-disciplinary professional membership, as well as colleagues from primary and secondary care, the evidence-based supplement will serve as a vital reference point for those working in primary care. The expert opinions and information will help streamline suspected cancer referral in children and optimise outcomes by addressing any gaps in information and issues around the referral of children."

Cancer is the biggest cause of disease-related deaths in UK children aged 1-15 years old, responsible for over one in five deaths of children in this age group, with delays to diagnosis a common problem. Such delays may lead to more advanced disease at presentation and, subsequently, greater risk of death and greater morbidity, with early identification of the disease likely to reduce these risks.

Diagnostic delays may contribute to poorer cancer outcomes in the UK when compared to other European countries, where similar treatment strategies are used. There is evidence to suggest that tumours presenting in the UK are larger, more advanced and require more therapy.

Dr Geoff Shenton, CCLG Executive member and Consultant Paediatric Haematologist, said: "A cancer diagnosis at an advanced stage can mean treatment is less effective and long-term health issues often arise as a result of more intensive treatment and its side effects. We aim to reduce delays in diagnosis by providing this framework to direct referral pathways and communication.

"Cancer symptoms can be vague and similar to common childhood illnesses, while children often can't express symptoms clearly, making cancer difficult to spot. The new guidelines emphasise a necessity for healthcare practitioners to exercise high levels of suspicion and to consider cancer in a differential diagnosis in a child presenting with unexplained symptoms."

One example of the importance of viewing a child's symptoms with a high level of suspicion is with those associated with Spinal cord compression (SCC). SCC is a severe, often irreversible complication of intraspinal or paraspinal pathology which greatly increases morbidity for patients, regardless of underlying illness. Back pain in children must be met with great suspicion, and any unusual neurological changes taken seriously. Patients presenting with symptoms or signs of SCC must be investigated and treated immediately. The urgency for investigation increases if any neurological deficit is identified; irreversible paraplegia may rapidly develop unless decompression is achieved.

Evidence also suggests the 'two-week wait' system, used by GPs to ask for an urgent referral when patients show symptoms indicative of cancer, is not effective for children and is infrequently used. At

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most, 1-3% of referred children are ultimately diagnosed with cancer via this pathway, while conversely, over 95% of children with cancer don't reach the oncology service this way. Accordingly, the new CCLG guidelines recommend referrals for suspected childhood cancer shouldn't rely on this route. A telephone discussion with an acute paediatrician (or paediatric haematologist or oncologist) should be had, and in cases where cancer is strongly suspected, referrals should be made immediately by telephone.

Ashley Gamble, CCLG Chief Executive, added: "Suspected cancer referral can be highly traumatic for children and their families. But while it can be difficult to identify those who need further investigation, and distressing for families to be referred when it's found not to be cancer, the consequences are far worse if a child isn't referred when it is cancer.

"Delays in diagnosis will not only impact a child's chances of survival and their quality of life but will inevitably have a detrimental impact on the family's confidence in the medical system."

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About Children's Cancer and Leukaemia Group (CCLG)

CCLG is a leading national charity and expert voice for all childhood cancer.

As the UK and Ireland's professional body for those working in the field of childhood cancer, our network of dedicated professional members work together in treatment, care and research to help shape a future where all children with cancer survive and live happy, healthy and independent lives.

We fund and support innovative world-class research and collaborate, both nationally and internationally, to drive forward improvements in childhood cancer. Our award-winning information resources help lessen the anxiety, stress and loneliness commonly felt by families, giving support throughout the cancer journey.

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