

## New awareness paper published to help GPs diagnose childhood cancer

Tuesday 2 March, 2021

A paper on childhood cancer awareness has been published in the British Journal of General Practice (BJGP).

Titled 'Helping GPs diagnose children's cancer', it is written by Children's Cancer and Leukaemia Group (CCLG)'s Child Cancer Smart project team, working with the Grace Kelly Childhood Cancer Trust (GKCCT) and the Children's Brain Tumour Research Centre at the University of Nottingham.

Child Cancer Smart is a collaborative research project led by CCLG and the University of Nottingham, in partnership with the GKCCT, CLIC Sargent and Teenagers and Young Adults with Cancer (TYAC), that aims to reduce the time taken to diagnose cancer in children, teenagers and young adults by raising awareness of its signs and symptoms among the general public and healthcare professionals alike.

The paper explains that, while the risk of the GP making a diagnosis of cancer is very low, the risk for each child is significant and therefore not in their interests to be disregarded. The GP needs diagnostic support with enhanced awareness, training and guidelines, relevant to current day practice.

Ashley Gamble, CCLG CEO, said: "Childhood cancer is the biggest killer by disease of children in the UK, and many children can experience long delays to diagnosis, which can have a profound clinical impact.

"Delays can lead to more advanced disease at presentation and, subsequently, greater risk of death and poorer long-term health for survivors.

"This paper is an important part of what we are trying to do with Child Cancer Smart, in helping to raise awareness among GPs and reiterating the importance of early diagnosis."

Dr Jennifer Kelly, a GP and Director of the GKCCT, said: "Despite childhood cancer being the biggest medical cause of death of children in the UK, many professionals still believe it to be exceptionally rare.

"The aim of this paper is to challenge this fact and raise awareness of the issue amongst GPs.

"The paper emphasises the fact that although an average GP will only see a few cases on average in their career, the relative risk for each child is significant.

"This means childhood cancer is a diagnosis that must be considered."

A recent MORI public survey of child cancer knowledge demonstrated that the majority of the respondents underestimated the risk of cancer in children, selected symptoms predictive of adult, rather than childhood, cancers and did not recognise that disturbed growth or pubertal development were indicators of childhood ill health.

Child Cancer Smart will help measure and understand the time it takes to diagnose children and young people with all cancers across the UK and will start to address delays. A systematic review of the published scientific literature on signs, symptoms and diagnosis of childhood cancers is underway, the results of which will be used to develop high-quality clinical referral guidelines and learning resources for GPs, emergency medical practitioners and other healthcare professionals to help with symptom recognition and making appropriate referrals.

Condensing the range of presentations to a digestible format for communication is a critical step to promotion of enhanced awareness. The GKCCT has developed an easily interpreted awareness tool (referenced in the paper and available on the charity's website) as a template for refinement with the new evidence, as it is assembled, to meet industry standards for guidance.

Dr Kelly said: "This awareness card to teach the signs and symptoms of childhood cancer is already saving lives.

"The contents will further be refined with the evidence produced from the Child Cancer Smart study.

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“All individuals, organisations and care providers are free to order copies of these cards from our website.”

Child Cancer Smart hopes to build on the work of HeadSmart, an evidence-based national awareness campaign that has halved diagnosis times for children with brain tumours in the UK, the success of which is hoped to be replicated for all other cancers affecting children and young people.

Dr Shaarna Shanmugavadivel, a paediatrician and NIHR Doctoral Research Fellow at University of Nottingham, explained: “Child Cancer Smart is in its infancy but has the ability to sit side by side with HeadSmart as the UK’s leading childhood cancer awareness campaign, where both the public and professionals can access high-quality, evidenced-based decision support tools to ensure early diagnosis.

“The project is so incredibly important. Childhood cancer symptoms are non-specific and this can make diagnosis tricky.

“Child Cancer Smart will empower both healthcare professionals and the public with the knowledge and guidance to make the diagnosis.

“Childhood cancer is not preventable and so early diagnosis is the best way to ensure the best possible outcomes for our children and young people who are sadly diagnosed.

“Working together as healthcare professionals and parents will ensure that we’re asking the right questions to achieve this.”

Professor David Walker is the Child Cancer Smart research lead and Emeritus Professor with the School of Medicine at the University of Nottingham.

He said: “Child Cancer Smart offers a progressive awareness programme with national and international reach.

“Its success will be determined by the effective and efficient dissemination of messaging to the profession and the public.

“The collaboration between different organisations involved in the project is very important as it extends the reach of the awareness programme across multiple networks.”

Keeping childhood cancer in the spotlight remains integral to increasing awareness, and in December, childhood cancer research was the subject of a parliamentary debate, with Health Minister Jo Churchill referencing the national Childhood Cancer Diagnosis Study (CCDS), the results of which will help inform Child Cancer Smart’s work.

The study, which opened on the last day of Childhood Cancer Awareness Month (CCAM) in September 2020, is funded by CCLG and the National Institute for Health Research (NIHR).

Led by Dr Shanmugavadivel, it aims to understand the journey that children and young people across the UK experience from the start of symptoms until the diagnosis. Researchers will collect information about what symptoms they experience, who they go to see with them initially, and how long it takes before the diagnosis is reached.

Dr Shanmugavadivel said: “The Childhood Cancer Diagnosis Study is a national study looking at the diagnostic times and referral pathways for all children and young people diagnosed with cancer over a two-year period.

“We hope that this will, for the first time, give us a clear picture of childhood cancer diagnosis across the UK and help us to identify what factors affect diagnosis and future outcomes for these patients.

“The results of the study will help us to prioritise Child Cancer Smart awareness materials of certain cancer types or age groups which are experiencing longer diagnostic intervals.”

DOI link to this article: <https://bjgp.org/content/early/2021/02/22/bjgp21X715241>

Child Cancer Smart: <https://www.cclg.org.uk/ChildCancerSmart>

Childhood Cancer Diagnosis Study: <https://www.cclg.org.uk/CCDStudy>

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## **About Children's Cancer and Leukaemia Group (CCLG)**

**Children's Cancer and Leukaemia Group (CCLG) is a leading national charity and expert voice for all childhood cancers.**

Each week in the UK and Ireland, more than 30 children are diagnosed with 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.

## **About the Grace Kelly Childhood Cancer Trust**

The Grace Kelly Childhood Cancer Trust is a UK based children's cancer charity that concentrates on funding research and providing support for children with childhood cancer. The GKCCT works to provide education on the signs and symptoms of childhood cancer and how it may present and produce publications for both children and parents.

For more information, please see [www.gkcct.org](http://www.gkcct.org)

## **Notes to Editors:**

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