



Children's
Cancer and
Leukaemia
Group

the EXPERTS
in CHILDHOOD
CANCER

Childhood cancer: Care and treatment

Healthcare information for general practitioners (GPs) who are involved in the care of a child or teenager with cancer

In partnership with



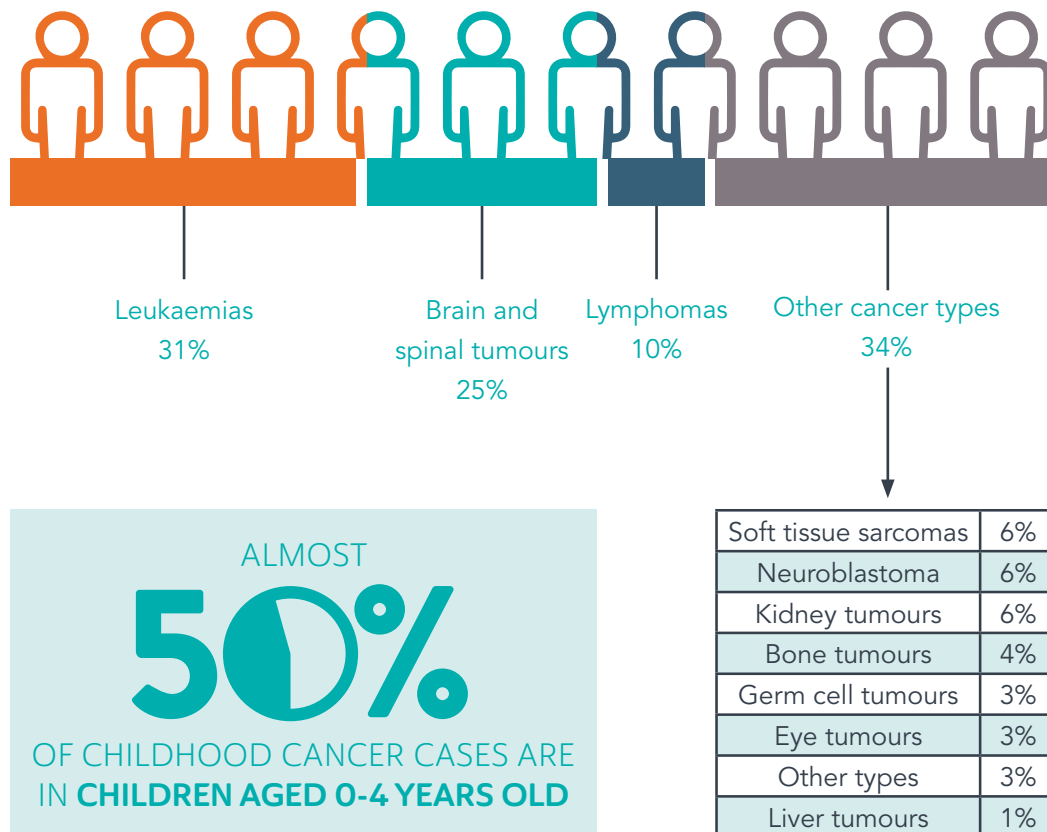
Grace Kelly
Childhood
Cancer Trust

About childhood cancer

- Childhood cancer accounts for around 1% of all cancer diagnoses, but cancer in children is not rare; around one child in every 450 will develop cancer by the age of 15, and one in 370 by age 20.¹
- About 1,645 children are diagnosed with cancer each year in the UK, with a further 2,110 cases in young people up to age 24.¹
- The risk of a child developing cancer is comparable to the risks of other common childhood conditions such as diabetes, epilepsy and bacterial meningitis.²
- The incidence of childhood cancer has increased by 15% since the 1990s¹ with a slightly higher incidence in boys than girls.
- Cancer incidence rates are highest in children aged 0-4.¹
- In the UK, cancers are responsible for 7% of deaths among 0-14 year olds.¹
- Improving treatments have resulted in increasing survival rates overall with 84%¹ of children diagnosed surviving 5 years. However, survival rates vary greatly between cancer types, from in excess of 99% for retinoblastoma down to 0% for DIPG (a rare form of brain tumour).
- Approximately 2 out of 3 survivors will have a long-term side effect related to their cancer treatment, which may affect them throughout their life

Types of cancer in children

The spectrum of cancer in children differs markedly from that in adults. The most common are **leukaemias**, **brain tumours** and **lymphomas**. These form approximately two thirds of cases. The remaining third include kidney tumours, bone cancers and soft tissue sarcomas.¹



Signs and symptoms of cancer in children

The CCLG resource '**Referral guidance for suspected cancer in children and young people**'³ which can be downloaded or ordered free of charge from www.cclg.org.uk gives information on signs and symptoms of cancer in children and young people at diagnosis. Further details can be found in the NICE guidance, Suspected cancer: recognition and referral⁴ as well as the RCGP e-learning module on the signs and symptoms of cancer in children and young people.

Signs and symptoms awareness cards for GPs can be ordered from the **Grace Kelly Childhood Cancer Trust**.⁵

Treating children with cancer

Care of children with cancer is typically at one of 21 principal treatment centres (PTCs), often with a local shared care arrangement (paediatric oncology shared care units, POSCUs).

Treatment mainly involves surgery, chemotherapy and radiotherapy. Certain high-risk patients may require high-dose chemotherapy or total body irradiation, followed by a haematopoietic stem cell transplant (HSCT) which may be autologous (from the child themselves) or allogeneic (donor).

Certain cancer types are increasingly utilising other treatment modalities such as immunotherapy (designed to target specific cancer cells) or MIBG therapy (targeted radiation treatment for use in certain children with neuroblastoma). Many treatments take place as part of a clinical trial.

Principal treatment centres (PTCs) in the UK and Ireland

- 1 **Aberdeen:** Royal Aberdeen Children's Hospital
- 2 **Edinburgh:** Royal Hospital for Children and Young People
- 3 **Glasgow:** Royal Hospital for Children
- 4 **Newcastle-Upon-Tyne:** Great North Children's Hospital, Royal Victoria Infirmary
- 5 **Leeds:** Leeds Children's Hospital, Leeds General Infirmary
- 6 **Sheffield:** Sheffield Children's Hospital
- 7 **Nottingham/Leicester:** East Midlands Integrated Service at Queen's Medical Centre, Nottingham and Leicester Royal Infirmary
- 8 **Cambridge:** Addenbrooke's Hospital
- 9/10 **London:** Great Ormond Street Hospital for Children and University College Hospital London
- 11 **Sutton:** Royal Marsden Hospital
- 12 **Southampton:** Southampton Children's Hospital, Southampton General Hospital
- 13 **Bristol:** Bristol Royal Hospital for Children
- 14 **Cardiff:** Noah's Ark Children's Hospital for Wales
- 15 **Oxford:** Oxford Children's Hospital, John Radcliffe Hospital
- 16 **Birmingham:** Birmingham Children's Hospital
- 17 **Liverpool:** Alder Hey Children's Hospital
- 18 **Manchester:** Royal Manchester Children's Hospital
- 19 **Dublin:** Our Lady's Children's Hospital, Crumlin
- 20 **Belfast:** Royal Belfast Hospital for Sick Children



Problems during cancer treatments

Families of children with cancer will have been given instructions by their treatment centre on what to do when their child is unwell and which medication can be taken. Non-steroidal anti-inflammatory drugs and certain other medications should not be used in paediatric oncology patients. If in doubt, seek guidance from the treating team via the ward or emergency number that families are given.

During treatment, most physical problems of a child with cancer are more likely to be dealt with directly at the specialist centre or their shared care centre but, at times, they may present in General Practice.

Bone marrow suppression

Neutropenia

- Children receiving chemotherapy are at much **greater risk of infection** than their peers. Typically neutropenia can occur 7–10 days after a treatment block but depends on the child and the treatment they receive.
- If **febrile** and **neutropenic**, the child will be started on IV broad spectrum antibiotics empirically.
- **Paracetamol is not recommended** for pain or fever at home when on treatment. The family should have a pain treatment plan from the hospital.

Anaemia and thrombocytopenia

Blood and platelet transfusions are often required when levels fall or if the child becomes symptomatic. Thresholds for transfusion vary depending on underlying diagnosis and whether receiving radiotherapy.

Oral symptoms and care

Mouth ulcers and **oral thrush** are common in children on treatment. Advice is to continue good oral hygiene by brushing teeth twice daily with a soft toothbrush and fluoride toothpaste. Any dental work should be done when blood counts are normal. Usually, the child's clinician would communicate directly with the dentist.

Gastrointestinal effects

- **Sickness, nausea** and **loss of appetite** are all common side effects of chemotherapy. Children are often placed on one or more antiemetics during treatment blocks to try and reduce this.
- **Feeding** and **weight loss** can be problematic for many children on treatment. Families are encouraged to offer small amounts of high calorie foods regularly. If weight is not maintained or feeding is causing pain or distress, children may need supplemental or complete nasogastric feeding. Occasionally, total parenteral nutrition is required.
- **Nasogastric tubes** are used for medication administration. Some children opt to have a nasogastric tube for medications even if not required for feeding. Percutaneous endoscopic gastrostomies are used for children who will receive radiation or other therapy in the head and neck region or the child is unable to tolerate an NG tube.

Central venous access

- **Central venous catheters** or other implantable vascular access devices (ports) are routinely used for treatment of children undergoing intensive treatment.
- Central venous catheters need to be **kept clean and dry** and should not be submersed in deep baths or swimming pools due to risk of infection.
- Ports sit subcutaneously, and create fewer limitations in daily life but can **cause some discomfort** when accessed.
- Lines and ports **can become infected**, and as such, even if a child is not neutropenic, if they have a pyrexia, the treating team will need to assess them.

Alopecia

Hair loss is a very common and well known side effect of chemotherapy. Children are offered wigs, but many prefer to wear a hat or headscarf as they are more comfortable. Alopecia is usually reversible on stopping treatment. Children undergoing cranial irradiation may also suffer from more localised hair loss. Those on maintenance therapy for leukaemia generally have hair regrowth during treatment.

Exposure to viral infections

Measles and chickenpox can be fatal in immunocompromised children.

Exposure to chicken pox	Exposure to measles
Children who are on treatment for cancer, or following haematopoietic stem cell transplant (HSCT), are immunocompromised: if they have a significant chickenpox exposure, they will need their serostatus checking at the time of exposure. ^{6,7}	Children who have had a significant exposure to measles need to have passive immunisation regardless of antibody status. The level of exposure required is much less than for chickenpox contact due to measles being highly infectious. ^{7,8}
Significant exposure dependent on:	
Contact: continuous home contact, contact in the same room (such as a classroom) for 15 minutes or more, contact in large open wards or face to face contact. ⁶	Contact: there needs to be a very low threshold in the immunocompromised. They do not need to be in the same place at the same time to have significant contact. For example, significant contact occurs if a child has entered a room within a short period after a case being present.
Timing: Chickenpox or disseminated zoster – from 48 hours before onset to five days after onset of rash. Localized zoster in exposed lesions such as ophthalmic zoster – day of onset of rash until crusting of lesions. ⁶	Timing: from five days before the rash develops to four days after. ⁸
<p>In cases of significant exposure, seek specialist advice due to the increased risk of severe disease and complications. Children may need varicella-zoster immunoglobulin prophylaxis or aciclovir and need to be carefully monitored.⁶</p> <p>Be aware that chickenpox may be more difficult to diagnose in the immunocompromised as they may have an atypical rash, for example, haemorrhagic lesions.⁶</p>	

If a child has had significant contact of chickenpox or measles or you are unsure, speak to the child's oncology team. If there is any doubt, it will be treated as a significant contact. If a child develops symptoms suggestive of chickenpox, shingles or measles whilst on treatment for cancer or for six months after treatment, it should be immediately discussed with their oncology team. Other viral infections rarely cause problems except in the post bone marrow transplant setting.

Vaccinations

Decisions around vaccination during treatment and revaccination following completion of treatment, will be made by the child's consultant based on the treatment the child has received and the relevant CCLG guideline.

All live vaccinations must be avoided in children actively receiving treatment, and for six months after treatment has been completed for children treated with standard-dose chemotherapy. HSCT recipients should not have live vaccinations for a minimum of 12 months (the child's consultant will decide when to start the revaccination schedule for this group of patients). Although non-live vaccines can be given safely during treatment, the immune response is likely to be poor. Vaccination may be considered provided the child's general condition is stable and is expected to stay so for three weeks from vaccination. Vaccination should be avoided during the period that the patient is receiving steroids (the immune response will be suboptimal) or the patient is neutropenic (neutrophil count <0.5).

- Children treated with standard dose chemotherapy should receive booster doses of vaccines six months after completion of treatment.
- Children who have had an allogeneic HSCT or autologous HSCT should receive a full revaccination programme starting no sooner than 12 months after the transplant. This will be directed by the patient's consultant.
- Siblings of the child with cancer should be fully immunised to minimise the risk of passing infection on.
- Varicella seronegative family members may receive the varicella vaccine to give indirect protection to the child.
- Annual influenza vaccines are advised for all children (and close family members) whilst they are receiving chemotherapy and for six months after completing treatment. Children, and close family members, should be offered the inactivated IM influenza vaccine and not the live attenuated nasal vaccine.
- The patient's consultant will send a vaccination schedule for each individual patient.

Education and social impact

- During intensive therapy, children will inevitably **miss significant amounts of school**. When well enough, however, they are encouraged to attend, often on a part-time basis.
- **Hospital schooling** or **home tuition** can be arranged to help in some cases. Support staff at treatment centres often liaise directly with schools and home teaching services to address the child's educational needs.
- As well as missing education, children undergoing such intensive treatments **miss out on social interactions** with peers and every day experiences. Chemotherapy can often cause a degree of hearing loss, which can also make social interactions more challenging for a child who has been away from school for a while.
- Some children returning to school, for example, following treatment for brain tumours, may have **special education needs**. As such, they may require an education, health and care plan (EHCP).

Psychological issues

Children with cancer may often spend a lot of time with their primary care giver, and as such they may develop separation anxiety or feel that they are struggling to socialise with their peers. Often, these problems come to light at the end of treatment when they are returning towards a degree of normality. These children may just need reassurance or support, but at times need psychological input as well.

What can GPs do to help?

- Put an alert on the notes of the child and close family members making it **easier to get a same day appointment** if needed to fit round unpredictable admissions for the child.
- If the child needs to attend, offer the option to **sit in a side room** away from other unwell people as the child may be immunocompromised.
- Place the child on the **practice cancer MDT register** so members of the team can remain up to date.
- Give the child a **named GP for the family** to contact if needed.
- Be aware and **avoid regular immunisation recalls** other than influenza for children on treatment for cancer as they cannot receive these vaccinations during treatment. CCLG produces a guideline for reimmunisation following treatment which is available from the child's oncology team.

References

1. Public Health England. Children, teenagers and young adults UK cancer statistics report 2021. Published February 2021.
2. British Journal of General Practice 2021: Vol 71: Issue 705. Helping GPs to diagnose children's cancer, David A. Walker. Retrieved on 25.01.23 from www.bjgp.org/content/71/705/151
3. CCLG referral guidance for suspected cancer. Retrieved on 25.01.23 from www.cclg.org.uk/referral-guidance
4. NICE (2015). Suspected Cancer: Recognition and Referral. Retrieved on 23.11.22 from www.nice.org.uk/guidance/ng12
5. Grace Kelly Childhood Cancer Trust: Regional red flags awareness cards. Retrieved on 30.01.2023 from www.gkcct.org/medical-professionals/information-for-professionals/signs-and-symptoms-of-childhood-cancer/
6. CDC, 2016. Chickenpox (varicella): People at high risk of complications. Centers for Disease Control and Prevention. Retrieved on 30.11.22 from www.cdc.gov/chickenpox/hcp/
7. UK Health Security Agency 2023: Health protection in children and young people settings, including education. Managing specific infectious diseases. Retrieved 25.01.23 from www.gov.uk/government/publications/health-protection-in-schools-and-other-childcare-facilities/managing-specific-infectious-diseases-a-to-z
8. Public Health England, 2013a. Immunisation against infectious disease - "The Green Book". Chapter 21 - Measles. Public Health England. Retrieved on 30.11.22 from <https://www.gov.uk/government/publications/measles-the-green-book-chapter-21>

i FURTHER INFORMATION

Childhood cancer information for healthcare professionals is available from CCLG, including further information for GPs and those who are supporting a child with cancer in the community

www.cclg.org.uk/professionals

www.cclg.org.uk/outreach-information

Resources for healthcare professionals are available from the Grace Kelly Childhood Cancer Trust, including further information for GPs on early diagnosis and care of children with cancer in the community

www.gkcct.org/clinicians

Macmillan Cancer Support offers support and advice to those affected by cancer.

www.macmillan.org.uk

Young Lives vs Cancer offers practical support to children and young people with cancer and to their families

www.younglivesvscancer.org.uk

CCLG booklets for parents and families can be downloaded or ordered FREE of charge

www.cclg.org.uk/publications

Grace Kelly Childhood Cancer Trust booklets for parents and families can be downloaded or ordered FREE of charge

www.gkcct.org/information



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.

CCLG publications on a variety of topics related to children's cancer are available to order or download free of charge from our website. If you have any comments on this booklet, please email us at publications@cclg.org.uk.

We are grateful to all those who have contributed to this publication. We make every effort to ensure that information provided is accurate and up-to-date at time of printing. We do not accept responsibility for information provided by third parties, including those referred to or signposted to.

This CCLG factsheet was produced and funded in partnership with The Grace Kelly Childhood Cancer Trust.

© CCLG 2023
This edition: February 2023
Next review date: February 2026

Children's Cancer and Leukaemia Group
Century House, 24 De Montfort Street
Leicester LE1 7GB

0333 050 7654
info@cclg.org.uk | www.cclg.org.uk

 ChildrensCLG   CCLG_UK

Registered charity in England and Wales (1182637) and Scotland (SC049948).



The Grace Kelly Childhood Cancer Trust is a national charity based in Worcestershire which provides vital support to families affected by childhood cancer.

The Trust was set up in memory of four-year-old Grace Kelly who passed away in 2014 from a rare form of childhood cancer.

We fund research into rare childhood cancers, work to educate families and clinicians about the signs and symptoms of childhood cancer and produce information booklets that are written by medics to explain to parents and children about the treatments they are facing.

We provide financial, practical, and emotional support to local families through our family support service at the charity, giving families a listening ear at the time when they need it most.

Our information booklets and further information can be downloaded or ordered free of charge from our website.

Because the children of today all deserve a tomorrow.

Grace Kelly Childhood Cancer Trust
The Piggery, Cowsden Hall Farm, Cowsden,
Upton Snodsbury, Worcestershire WR7 4NZ

01905 885777
contact@gkcct.co.uk | www.gkcct.org

 [gracekellychildhoodcancertrust](https://www.facebook.com/gracekellychildhoodcancertrust)   [gracekellytrust](https://www.instagram.com/gracekellytrust)

Registered charity number 1167783