GP FACTSHEET

Grace Kelly
Ladybird Trust

Children's
Cancer and
Leukaemia
Group

Childhood cancer: Care and treatment

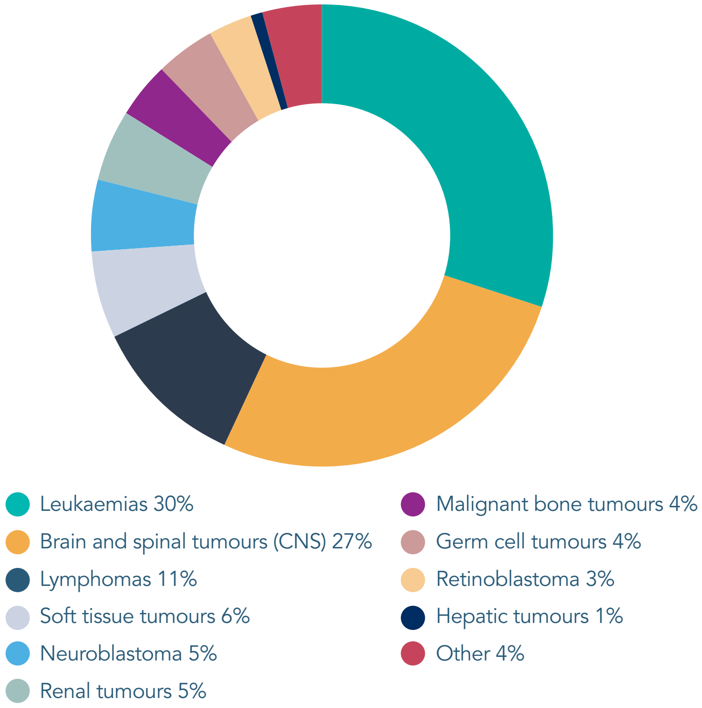
Information for general practitioners (GPs)

Childhood cancer is relatively rare, but it is still estimated that around **one child in every 500 will develop cancer by the age of 14 years in the UK.**[1] About 1,800 children in the UK are diagnosed with cancer each year, with a further 2,600 diagnosed by 24 years of age.[2&3] As such, an average GP practice in the UK would expect to see a case of cancer in a child or young person every 1.8 years. Cancer incidence rates are highest in children aged 0-4.

Improving treatments have resulted in increasing survival rates overall with 82% 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).

Cancer types

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 are mainly embryonal in origin, and include Wilms' tumours, bone cancers and soft tissue sarcomas.[1]



Taken from National Registry of childhood tumours, 2014.

Further information on signs and symptoms at diagnosis can be found in the NICE guidance, Suspected cancer: recognition and referral[4] and 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 Ladybird Trust.

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 is mainly **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 of the newer treatments may take place as part of a clinical trial.

Problems during cancer treatment

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 it 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 that they should 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 loss of weight 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. In addition 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 as such create fewer limitations in daily life but can cause discomfort on accessing in some children.
- At times, 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

This 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 get hair regrowth during treatment.

Exposure to viral infections

Measles and chicken pox can be fatal in immunocompromised children.

Exposure to chicken pox

Children who are on treatment for cancer or following haematopoetic stem cell transplant are immunocompromised. As such, if they have a significant chicken pox exposure, they will need their serostatus checking at the time of exposure.

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]
- Timing of exposure:
  - 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]

In the case of significant exposure, seek specialist advice on management due to the increased risk of severe disease and complications. A number of children may need varicella-zoster immunoglobulin prophylaxis or aciclovir and need to be carefully monitored.[7]

Be aware that chicken pox may be more difficult to diagnose in the immunocompromised as they may have an atypical rash, for example haemorrhagic lesions.[6]

Exposure to measles

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 chicken pox contact due to measles being highly infectious.

- Contact: There needs to be a very low threshold for follow up in the immunocompromised. For example, significant contact occurs if a child has entered a room within a short period after a case being present. They do not need to be in the same place at the same time to have significant contact.
- Timing: From five days before the rash develops to 4 days after.[7&8]

If a child has had significant contact of chicken pox 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 chicken pox, shingles or measles whilst on treatment for cancer or for 6 months after treatment, it should be immediately discussed with their oncology team and they should be admitted for treatment.

Other viral infections rarely cause problems except in the post bone marrow transplant setting.

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 a Education, Health and Care Plan (EHCP).

Psychological

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.

Vaccinations

for patients treated with standard dose chemotherapy, and haemopoietic stem cell transplant (HSCT) recipients.

Decisions around vaccination during treatment and following completion of standard dose treatment, and revaccination after HSCT, 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 and for a minimum of 12 months for HSCT recipients (the child's consultant will decide when to start 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 at 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 onto the patient.
- Varicella seronegative family members may receive the varicella vaccine to provide indirect protection to the child.
- Influenza vaccine is recommended annually for all children (and their close family members) whilst they are receiving chemotherapy and for six months after completing treatment. Please note that children who have undergone a HSCT, and those living in close contact with them (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.

What can GPs do to help?

- Put an alert on the child and the notes of 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 children 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.
- Remove children on treatment for cancer from regular immunisation recalls other than influenza as they cannot receive these vaccinations during treatment.

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Further information

Sources of information and support for GPs, other professionals, and childhood cancer survivors.

CLIC Sargent Outreach Information Resource

This online resource has been developed by CLIC Sargent, in partnership with CCLG, to support professionals who are supporting a child with cancer in the community.
www.cclg.org.uk/outreach

Childhood cancer information for healthcare professionals

A range of information for healthcare professionals caring for a child with cancer is available from CCLG, including further information for GPs.
www.cclg.org.uk/professionals

Information for patients, parents and carers

Several charities produce Information Standard accredited information for childhood cancer patients, their parents/carers and other members of their family.

Children's Cancer and Leukaemia Group
www.cclg.org.uk/publications

CLIC Sargent
publications.clicsargent.org.uk

Macmillan Cancer Support
https://www.macmillan.org.uk/information-and-support/childrens-cancer

Children's Cancer and Leukaemia Group | the EXPERTS in CHILDHOOD CANCER

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 and young people 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. **For more information, visit www.cclg.org.uk**

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Grace Kelly Ladybird Trust

The Grace Kelly Ladybird Trust is a children's cancer charity working to raise awareness of the signs and symptoms of childhood cancer and how it may present. We fund solid tumour research in children and young people and provide support to families as well. Our evidence based publications help raise awareness and provide information both to parents, carers and clinicians. The GKLT was set up in memory of 4-year-old Grace Kelly who passed away in 2014 to help Grace fulfil her wish of helping other children. Registered charity number 1167783

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