Cancer in Children and Young People

Cancer in Children and Young People (CYP) encompasses multiple distinct types of cancers diagnosed in those aged 0-24 years. Typically, childhood cancers are defined as cancers in those aged 0-14 years and young people's cancers in those aged 15-24 years. However, be aware that age ranges for local referral pathways may vary.

Around 130 children (aged 0-14 years) and 180 young people (aged 15-24 years) are diagnosed with cancer in Scotland each year (average over 2018, 2019, 2021)[87].

In Scotland, 31% of children aged 0-14 years with cancer were diagnosed with leukaemia, and 26% were diagnosed with brain/CNS tumours (2012 – 2021)[87]. Survival for children with cancer is high, with 85% of children expected to live for five years or more after their diagnosis (over years of diagnosis 2011-2016)[87].

23% of 15-19 year olds with cancer were diagnosed with lymphoma, 17% with carcinomas and a further 17% with CNS tumours (2012-2021)[87].

25% of 20-24 year olds with cancer were diagnosed with carcinomas, 18% with lymphoma, and 16% with melanoma (2012-2021). Cancer survival among young people is high, with 90% expected to live for five years or more after their diagnosis (years of diagnosis 2011-2015)[87].

Large variation is seen in diagnostic intervals by cancer type and it is common for patients to see a health professional three or more times before referral[88]. Longer intervals may result from non-timely help seeking for symptoms and a lack of awareness of cancers in CYP[89,90].

As cancer in CYP is uncommon, health professionals may not always initially suspect cancer and investigate other benign causes first, potentially leading to pathway delays or emergency presentation. It is estimated that a UK General Practice with an average list size will diagnose cancer in a child or young person every 1.8 years[91].

Types of Cancer in Children and Young People

Childhood cancers:

There are 76 distinct types of childhood cancer. They are broadly grouped into cancers affecting the blood and those that cause solid tumours. There are clear differences between most childhood and adult tumours, reflecting different biology. Many childhood tumours are of 'embryonal' origin or other 'high grade' malignancies, whilst carcinomas are uncommon. Childhood malignancies can progress very rapidly and a delay of even a few days may be associated with substantial clinical deterioration. Conversely, some childhood tumours can present in a more indolent way, including Hodgkin Lymphoma, and some low-grade intracranial tumours - malignancy cannot therefore be excluded solely based on a long history.

The main types of childhood cancer are leukaemia, brain and spinal tumours, lymphoma, soft tissue sarcomas, neuroblastoma, renal tumours, bone tumours, germ cell tumours, retinoblastomas, other carcinomas and melanomas, and liver tumours.

Leukaemia:

This is the most common type of childhood cancer, accounting for approximately one third of all cancers in children[87]. It is a cancer of the white blood cells – white blood cell production and maturation gets out of control and the cells continue to divide.

Brain and central nervous system tumours:

These are the most common solid tumours in childhood. In Scotland, they account for 26% of all cancers and 51% of deaths in children aged 0 to 14[87]. They are often identified later than other childhood cancers due to their varied and often initially subtle symptoms.

Lymphoma:

This is the third most common type of childhood cancer. It accounts for around 9% of childhood cancer diagnoses in Scotland (2012-2021)[87] and is split into two main groups: Hodgkin's Lymphoma and Non-Hodgkin's Lymphoma.

Soft tissue sarcoma:

The most common soft tissue sarcoma is rhabdomyosarcoma. Other types include fibrosarcomas, schwannomas and primitive neuroectodermal tumours.

Neuroblastoma:

This is a solid cancer that develops from cells called neuroblasts. They can occur anywhere in the body but usually start in the adrenal glands or in nerve tissue that runs alongside the spinal cord. In some cases, neuroblastoma can spread to other places in the body such as the bone marrow, lymph nodes, bone, liver and skin.

Renal tumours:

These arise from the kidney and are more common in younger children. Wilm's tumours may be associated with underlying genetic conditions.

Bone tumours:

The most common types are Osteosarcoma and Ewing's Sarcoma. Osteosarcoma can present at any age but has a peak incidence in the second and third decade of life[94]. Most common sites are the femur, tibia and humerus. Ewing's Sarcoma has a peak incidence between the ages of 10 and 15 years and rarely occurs under the age of five. Most common sites are the pelvis, femur, tibia, fibula, rib and humerus.

Germ cell tumours:

Germ cell tumours are growths that form from reproductive cells. They can develop at any age and usually originate in the ovaries or testes (gonadal germ cell tumours), but they can sometimes occur in other parts of the body as well (extragonadal germ cell tumours). Sites where extragonadal germ cell tumours most commonly occur are at the bottom of the spine (sacrococcygeal), the brain, chest and abdomen. There are several types of germ cell tumours including germinomas, yolk-sac tumours, embryonal carcinomas and teratomas.

Retinoblastoma:

This is a rare cancer of the retina. It is most common in very young children and infants, with the average age of diagnosis being around four months old. It can occur in just one eye or both. Approximately 40% of cases are inherited.

Liver tumours:

There are two main types of liver tumours - hepatoblastoma and hepatocellular carcinoma. Hepatoblastoma most commonly affects children under the age of five. Hepatocellular carcinoma is less common and affects older children.

Other:

Histiocytoses and Rhabdoid tumours are rare cancers of childhood.

Young people's cancer:

Cancer is more commonly seen in young people than children, with a mixture of late presenting childhood cancers and early presenting adult cancers.

The main types of cancer in young people are:

- Lymphoma
- Carcinomas (cervical, melanoma, thyroid cancer)
- Germ cell tumours (testicular or ovarian)
- Brain tumours
- Bone cancers
- Soft tissue sarcoma
- Leukaemia

Assessment for Suspected Cancer in Children and Young People

Children:

Studies show that children with cancer may attend multiple consultations before diagnosis. However, it is important to recognise that frequent attendance is common in this age group and usually reflects benign or self-limiting conditions rather than serious pathology.

An unwell child may be unwilling to comply with examination or may disguise their impairment. Developmental regression is a significant finding and lack of evidence of normality may need to be escalated for investigation.

It is essential for clinicians to balance vigilance with the broader context of frequent attendance. A child should be examined if there is concern about cancer even if they look well, and clinicians should ask how many times they have been seen by a healthcare professional or have sought advice for the problem.

The following features raise suspicion for a childhood cancer:

- Attendance across any pathway (e.g. A&E, NHS 111, GP) **three or more** times
- Change in attendance rates e.g. a family that usually attend infrequently suddenly attending frequently
- Unusual or persistent symptoms (see good practice), that do not respond to simple interventions e.g. antibiotics, laxatives, or a short course of steroids
- Parents or carers have persistent concerns, even if symptoms are more likely to have a benign cause

Young people:

Young people most commonly attend their GP for infection, psychological support or contraceptive advice. A presentation with symptoms which are unexpected within this age group should lead to focused clinical examination, even if they appear otherwise well.

Symptoms due to cancer in young people can be misattributed, for example:

- Pain following sport, gym or muscle strain
- Fatigue due to social life, academic pressures, studying for exams, jobs while at university, anxiety, or mental health problems

Certain conditions, such as Neuro-Developmental Difference (NDD), can affect a young person's ability to manage medical consultations, including describing symptoms, being compliant with a physical examination or the stress of the environment.

As with children, repeat presentation, including to other professionals (e.g. A&E, AHPs) should be considered a warning sign of a possible cancer.

It may be appropriate to organise urgent tests in primary care if a young person is well and there are single clinical features of concern. Examples include:

- A full blood count (FBC) if there is pallor, bruising, petechiae, infection, lymphadenopathy or generalised bone pain.
- USS for a soft tissue mass
- X-ray for unexplained localised bone pain

A referral to secondary care must not be delayed by waiting for test results if investigations are being arranged for a young person in which there is significant concern about cancer. Repeated attempts at tests (e.g. bloods) should also not delay a referral for assessment.

Urgent Suspicion of Cancer (USC) Referral

Children:

In most cases the first contact for children with suspected cancer is general paediatrics. This may take the form of a phone call for emergency and very urgent concerns. Local guidelines should be followed as referral pathways differ across Scotland.

Young people:

The referral pathway may be more complex for young people with suspected cancer. The person may need clear guidance to understand different appointments, to avoid missed scans/failed attendances. For some young people, consideration should be given to sharing information with parents/guardians. Adult guidelines should be followed, where appropriate, bearing in mind that the more common cancer types seen in this age group are different to those in older adults.

Clinical features that can be associated with cancer in children and young people:

While many CYP cancers present with non-specific symptoms, the majority of CYP presenting with these symptoms will not have cancer. The guidance aims to support clinicians in identifying those at higher risk while avoiding unnecessary investigations.

The following table is not an exhaustive list of clinical features – it is important to remember that children and young people can present atypically.[91-93]

Cancer type	Associated symptoms	
Leukaemia	■ fever ■ recurrent or persistent infection ■ pallor ■ fatigue ■ generalised bone pain and/or limp	■ hepatosplenomegaly ■ lymphadenopathy ■ bleeding ■ petechiae ■ any of the features found in NHL (see below)

Cancer type	Associated symptoms
Lymphoma: Hodgkin's	■ lymphadenopathy typically progressing over weeks-months ■ fever ■ sweats (drenching and at night) ■ pruritus ■ weight loss ■ breathlessness
Lymphoma: Non-Hodgkin's (NHL)	■ lymphadenopathy (particularly cervical) ■ splenomegaly ■ abdominal distension ■ sweats ■ fever ■ pruritus ■ weight loss ■ breathlessness
Lymphoma (either type)	Lymphoma can present with a mediastinal mass (see good practice) causing: ■ airway compromise – wheeze, stridor, orthopnoea ■ superior vena cava obstruction – breathing difficulty with facial swelling
Brain tumour	See – **Better Safe Than Tumour** – for age specific symptoms ■ persistent/recurrent headache ■ persistent/recurrent vomiting ■ behaviour change, confusion, or lethargy ■ developmental regression or reduced school performance ■ seizures ■ loss of balance ■ papilloedema ■ head tilt, wry neck, or stiff neck ■ focal neurological deficit ■ abnormal eye movements ■ new squint ■ blurred or loss of vision ■ co-ordination or walking issues ■ increasing head circumference crossing the centiles ■ delayed or arrested puberty
Neuroblastoma	■ abdominal mass, ■ unexplained neurological symptoms ■ hypertension ■ periorbital bruising ■ Horner's syndrome ■ skin lesions in infants ('blueberry muffin' appearance) ■ systemic symptoms (bone pain, pallor, bruising, fever, fatigue, irritability, lymphadenopathy)

Cancer type	Associated symptoms	
Renal tumours (nephroblastoma)	■ palpable abdominal mass (can be painful), ■ haematuria (can be visible or persistent non-visible)	■ hypertension ■ associated fever
Soft tissue sarcoma	■ soft tissue mass anywhere on the body (firm/hard, tethered, non-tender, enlarging) ■ proptosis ■ nasal or ear obstruction or discharge (persistent or recurrent, bloody/purulent) ■ urinary retention	■ scrotal swelling, vaginal discharge (blood stained) ■ back pain, lower limb pain or weakness (see good practice for malignant spinal cord compression) ■ can be associated with enlarged draining lymph nodes and weight loss
Bone tumours	■ persistent localised bone pain (pain can be at rest) ■ bony mass or swelling ■ spontaneous or minor trauma fracture	■ back pain including a painful scoliosis ■ unexplained limp ■ can cause malaise and fever
Liver tumours	■ hepatomegaly ■ abdominal pain	■ systemic upset (fever, fatigue, loss of appetite) ■ rarely jaundice
Retinoblastoma	■ white or absent pupillary red reflex	■ new onset squint
Germ cell tumours	■ scrotal swelling (testis) ■ abdominal mass (ovary) ■ neurological symptoms (CNS involvement)	■ can be associated with gynaecomastia, virilisation, and/or precocious puberty
Germ cell tumours (continued)	Germ cell tumours can present with a mediastinal mass (see good practice) causing: ■ airway compromise – wheeze, stridor, orthopnoea; ■ superior vena cava obstruction – breathing difficulty with facial swelling	
Langerhans cell histiocytosis	■ Bone (pain, swelling, multiple lesions on X-ray and can be lytic) ■ posterior pituitary features (polydipsia/polyuria)	■ skin (rash, which is unusual, fluctuant, persistent, can look like eczema unresponsive to treatment, severe cradle cap, persistent/recurrent otitis externa, anal excoriation)
Haemophagocytic lymphohistiocystosis	■ systemic upset ■ fever ■ splenomegaly	■ pallor ■ fatigue ■ bruising and/or bleeding

Good Practice Points

Persistent symptoms:

For this guideline, 'persistent' indicates the continuation of specified symptoms and/or signs beyond a period that would normally be associated with self-limiting problems. This should take into account what the parent/carer/young person considers unusually persistent for them and the child's baseline and overall clinical picture. The precise period will vary depending on the severity or combination of symptoms/associated features, as assessed by the health professional.

Lymphadenopathy:

Lymph nodes in the neck that are under 2 cm in longest dimension may be reactive and can commonly be felt in slim young people. Other reassuring features could include a recent infection, masses which are reducing in size and those which are very tender. Neck nodes which are 2 cm or larger, nodes palpable in supraclavicular fossae, axillae and large nodes in the groin merit further assessment and consideration of cancer. If there is associated splenomegaly, night sweats, weight loss, bone pain, unexplained respiratory symptoms, or limp then this is concerning regardless of the size of nodes and should prompt a USC referral. It is important to note that rapidly enlarging malignant nodes can be tender and/or uncomfortable and so do not fit the classic "painless lymphadenopathy" scenario.

Emergency referral:

The following clinical scenarios are emergencies and must be referred immediately to secondary care:

- **Malignant Spinal Cord Compression** is a severe, often irreversible complication of para- or intra-spinal pathology. It is rare in paediatrics but not in children with cancer
- Mediastinal involvement with cancer (most frequently lymphoma or germ cell tumours) causing airway compromise (wheezing, orthopnoea, stridor) or superior vena cava compression (breathing difficulties, distended neck veins, facial swelling)

Thyroid cancer:

For the assessment of suspected thyroid cancer in children and young people, please see the **Head and Neck and Thyroid Cancers Guideline**.

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Any enquiries regarding this publication should be sent to us at

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Edinburgh
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