



Children's  
Cancer and  
Leukaemia  
Group

the EXPERTS  
in CHILDHOOD  
CANCER

# A school's guide to supporting a pupil with cancer

Information and support for teachers and staff helping  
children and young people with cancer at school



[www.cclg.org.uk](http://www.cclg.org.uk)



This edition was reviewed and edited by the CCLG information team in conjunction with the CCLG Information Advisory Group comprising parents, survivors and multiprofessional experts in the field of children's cancer.

With thanks to all those who have contributed to this booklet. The quotes in this publication are from pupils, teachers and medical staff. They are personal views and do not necessarily represent the view of CCLG. CCLG makes 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 in this publication. Information in this publication should be used to supplement appropriate professional or other advice specific to your circumstances.

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## About this guide

Going to school is vital for children with cancer. School helps them to feel 'normal' and reduces the isolation and loneliness which many children with cancer face.

Teachers have a really important role to play in encouraging the child's integration back into a school routine. But cancer is a scary word for many and it is completely normal for teachers and others working at the school to feel upset – not just for the awful situation facing the pupil and their family, but also for the impact on the rest of the class and school community.

As a teacher, you may feel daunted about what to expect and worried about not having the confidence or expertise to deal with the child returning to school.

This guide aims to lessen some of the worries you may have by giving simple practical information and advice on a variety of issues faced by the child and their family, and some ideas on how to help them within a school setting.

Teachers play a vital part in the child's recovery



Having a child with cancer in your class, is one situation that you don't think will ever happen to you as a teacher.

**Bob, primary school teacher**

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# About childhood cancer

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Around 1,650 children (0-14 year olds) and 2,100 young people (15-24 year olds) in the UK are diagnosed with cancer every year (compared with 375,000 of adult cases). The most common types of childhood cancer are leukaemia (a type of blood cancer) and brain tumours. Other cancer types include lymphomas, sarcomas and tumours in parts of the body such as liver, kidney, bone and eye.

**Cancers are not infectious.** You cannot catch them from other people and there is no risk of someone with cancer passing the disease to others.

### Are children's cancers the same as adult cancers?

No. Common cancers in adults such as breast, prostate, lung and bowel cancers are partly caused by older age, environmental and lifestyle factors such as obesity, drinking too much alcohol and smoking. These cancers are very rarely seen in children.

Some children's cancers come from cells left over from when the baby was still developing in the very earliest stages of pregnancy. These cancers are not seen in adults.

Some cancers found in children are also seen in adults, such as leukaemia. However, even when the diagnosis is the same, the diseases often behave differently in people of different ages.

### How is childhood cancer treated?

All children and young people diagnosed with cancer are treated in one of 21 specialist paediatric oncology centres across the UK.

While some treatment can be given at a local hospital under the guidance of the nearest specialist centre, many families may need to travel long distances depending on where they live.

Treatments are based on national guidelines which means that a child or young person with cancer will be treated in the same way wherever they live in the UK.

Many healthcare professionals are involved in the child's care including doctors, nurses, dietitians, play specialists, psychologists and others.

Over 84% of children with cancer are now cured and there is ongoing research into finding better and kinder treatments.

## Treatment options include:

**Surgery** – to remove the tumour if needed.

**Chemotherapy (or chemo)** – the use of drugs to kill cancer cells, usually by injection into the bloodstream via a central line (sometimes referred to as a ‘wiggly’) which is surgically fitted to the child’s chest. It is securely attached so should not fall out and cause problems at school (see page 40).

**Radiotherapy** – the use of high-energy x-rays to destroy cancer cells. The child or young person lies still on the radiology machine while radiation beams are precisely aimed at the tumour.

**Immunotherapy** – these treatments target specific cancer cells by triggering the body’s own immune system to attack and destroy the cancer cells. Side effects may be less as healthy cells may not be affected by the treatment.

**Targeted therapy** – a type of precision medicine that targets the biological changes within cancer cells to stop them from growing, dividing, and spreading.

**Stem cell transplant** – this treatment is used to restore blood-forming cells in the patient’s body when they are destroyed by high doses of treatment. Stem cells from a donor may need to be used. Patients need to stay in hospital in isolation for a period of time.

All of the above treatments may be used on their own or in various combinations. Treatments can last a number of weeks, months and, even years.

Children may also have a number of different side effects such as hair loss, feeling sick, vomiting and pain although some of these can be managed with medication.

## What happens when treatment has finished?

If treatment is successful, the child will have a lifelong follow-up plan involving regular check-ups in hospital over many years. This is to make sure there are no signs of the cancer coming back (called ‘relapse’) and also to look for any long-term effects that might happen as a result of the cancer and its treatment later in life (called ‘late effects’). These late effects can affect various things including heart, lungs and kidney function, growth, fertility and they may be at a higher risk of developing a second cancer in the future.



## Will your pupil be cured?

This is a hard question to answer. This is because there are so many factors to consider which are unique to your pupil: how the cancer is behaving in their body, and how their body reacts to the cancer and its treatment. Statistics are useful but they cannot say what will happen to an individual child.

## What happens if treatment is unsuccessful?

Cancer can sometimes come back after treatment has finished. This is called 'relapse' and the child will usually receive additional treatment. Some children who have relapsed will still be cured of their cancer.

If a pupil sadly becomes terminally ill, the child's nurse specialist or keyworker will contact the school and discuss how best to prepare and support pupils and staff. Some local authorities have a bereavement specialist on their educational psychology team or there may be a bereavement counsellor at the hospital who is available to talk to school staff and children.

Hospices can also provide support and advice for school staff and pupils. Even when a child is terminally ill, the child may still want to continue to engage with school.

### School resources for when a pupil becomes terminally ill

#### **Cruse Bereavement Care**

[www.cruse.org.uk/get-help/for-schools](http://www.cruse.org.uk/get-help/for-schools)

#### **Child Bereavement UK**

[www.childbereavementuk.org/listing/category/schools-further-education](http://www.childbereavementuk.org/listing/category/schools-further-education)



# How cancer treatment affects school attendance

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Once treatment starts, the child will be absent from school a lot because of hospital admissions, treatment cycles and the impact of side effects. Long absences can cause a drop in literacy and mathematical skills causing pupils to sometimes fall behind others of the same age. Teachers can help to minimise this impact by supporting the child in their learning.

## During treatment

Treatment cycles for different cancers vary. Some children may spend long periods of time in hospital for their treatment, while others may only be seen on an out-patient basis. This will vary according to the type of cancer and treatment used.

During this time, the child or young person may wish to attend school and may feel well enough to do so. However, some children may be at home between treatments and not well enough to attend school. These children will need support through home tutoring or through a hospital school.

Once treatment has finished, the child will still need to attend regular follow-up clinic visits at the hospital for the next few years to check for any signs of the cancer coming back. These visits will monitor how their body is coping with having had cancer and its treatment, and will require further absences from school.


## Possible side effects

Children will respond differently to treatment and will not necessarily experience all of the following side effects as it will depend on their type of cancer and the treatment they receive.

## Being immunosuppressed

Some chemotherapy lowers the immune system meaning that children undergoing treatment have a higher risk of picking up infections. As the child's immune system is less able to fight back, they can become ill which sometimes means further assessment in hospital.

The risk of infection should not stop children going to school. Children whose blood levels are in a safe enough range will be advised to return to school and enjoy their usual activities. However, many parents will worry about the risk of infection which may result in them keeping their child at home.



Appointments at the hospital will almost always fall in school time, so these absences need to be factored into support.

**Alison, clinical  
nurse specialist**

### Feeling sick or vomiting

After chemotherapy, a child may feel sick for 24 hours or more although anti-sickness drugs usually control this side effect. Any nausea and vomiting should be resolved before the child returns to school.

### Having fatigue

Some children or young people may seem listless and lethargic when they first return to school, and often tire easily and suffer lapses in concentration. Parents and teachers may decide that the child should attend school for just a couple of hours or so at first. Fatigue is greatly underestimated. It is more than just being a bit tired, and can affect mood as well as energy levels. It can also last a long time over many months, even years. Being flexible with expectations and school attendance can be really helpful.

### Feeling drowsy

Radiotherapy to the head area is given to children or young people with brain tumours. Between 5-8 weeks after this treatment, children or young people may go through a period of extreme sleepiness or drowsiness that can last for a week or two. This may mean that they are unable to attend school.

### Eating too much or too little

Children receiving chemotherapy may find eating difficult at times and may lose weight. In contrast, if a child is taking steroids as part of their treatment, they may be ravenously hungry all of the time and crave food even throughout the night.

### Weak ankles and muscle aches and pains

These symptoms can be caused by some chemotherapy drugs and result in difficulties with walking or climbing stairs, lack of coordination and concentration, or problems with handwriting. Children or young people may need a 'buddy' to help carry their school bag and to get around school, or they may find it easier to have an arrangement where they don't have a bag at all and leave their belongings in a locker or work on a tablet in class. It may be necessary for the child to receive additional support with handwriting such as laptop/speaking technology or a scribe.

It was hard to complete full days at school as my energy levels were always low, especially on chemo and steroid week.

**Orla, 14**

I had to take some of my GCSE exams at home because I was immunosuppressed. I remember my physics teacher ringing me up, checking if I had any last minute questions. They really went above and beyond for me.

**Beth, 16**

### Changes in physical appearance

Cancer treatments can temporarily cause a number of different side effects that can be upsetting to the child and also make them feel self-conscious:

- losing their hair, including eyebrows and eyelashes
- gaining weight if taking steroids – this happens quite quickly and causes swelling or puffiness in the face
- losing weight through being sick and changes in taste – sometimes, a child may return to school with a feeding tube in their nose
- skin changes such as dryness, spots, ulcers around the mouth or scars from surgery
- losing a part of the body through amputation as a result of bone cancer or eye removal due to eye cancer
- using a wheelchair – this may be from tiredness or as a result of cancer and its treatment

### Changes in bowel habits


Both diarrhoea and constipation are a side effect of chemotherapy and can cause abdominal pain. This means that the child may need to go to the toilet more frequently than others in the class.

### Emotional effects

Children can feel less self-confident, more emotional or tearful, may express their frustrations through anti-social behaviour or tantrums, may become more dependent on parents, and feel 'left out' and isolated from school and their friendships.

Home life can also become more difficult as normal routines turn upside down and parents can struggle to cope with the needs of the whole family.

It is difficult to know how a child or young person will respond to a life-altering diagnosis like cancer, but there is support available within the child's medical team to ensure good emotional health and wellbeing during treatment and beyond.



Having a 'pass' for the toilet and access to a separate, more private toilet will help

# Understanding worries of children and teenagers with cancer returning to school

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Most pupils are keen to get back to the familiar routine of school as soon as possible. This helps them to rebuild their confidence, see their friends and adjust to normal life.

Depending on age, some children and teenagers may dread going to school. They may feel that they look different, have missed lots of school work, lack confidence and motivation while also trying to cope with low energy levels after treatment. Teenagers may also be trying to cope with adolescence such as hormones and mood swings.

Having cancer can be lonely and traumatic, and there can be a dawning realisation that their cancer experience has changed them. This section explores some of the main worries facing children and teenagers with cancer on returning to school.

### Looking different

Children and, in particular, teenagers can feel very self-conscious so any change in how they look to others can be a huge source of anxiety, even to the extent of not wanting to go to school. Losing their hair and weight changes can hugely affect their body image. Wearing a wig, hat or bandana can help lessen the impact although some children and young people may not want classmates to know if they are wearing a wig, and teachers (including supply teachers) need to be sensitive to this.

It is important that teachers recognise if a child is anxious about how they look, and give them

appropriate support; if not, it can mark the start of longer term withdrawal, poor attendance after treatment finishes, low educational attainment and long-term social isolation.

I lost touch with a lot of friends, and the illness was a huge blow to my confidence. I put on weight and felt self-conscious. I tried to start college, but had to give up twice as I couldn't cope.

**David, 16**

Other girls were shaving their legs and I was waiting for my hair to grow back! I think this lack of 'keeping up' made my female friends less keen on me.

**Kat, 13**

I found it hard going to school as I was worried about losing my hair. I tried wearing scarves and hats to make me feel more confident, but I was still conscious about what my friends would think of me.

**Orla, 14**

## Falling behind with school work

This is a major worry for most children and young people with cancer, especially those who have been away for long periods. It is very important that children are given a structured programme of school work as soon as they can cope, both in hospital and while at home. Many children will welcome school work to lessen feelings of boredom and to keep their mind stimulated.

## Having physical limitations

Particular drugs can cause the child or young person to have weak ankles and muscles. This may restrict them from taking an active part in sports such as football or gymnastics, and can make them feel frustrated and left out. Extreme tiredness can also be a problem after treatment. Teachers can make up for this by setting less active tasks for the child or young person instead. Most children and young people know their own limitations and will participate as much as they can.

Children and young people with brain tumours may experience additional problems so it is important to find the best support in the classroom for them.

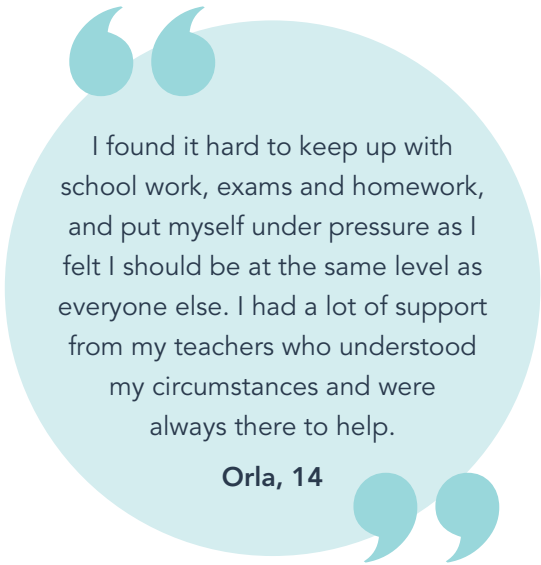
## Difficulty moving around

Following a diagnosis or removal of a tumour, some children and young people may have difficulty with balance or may be confined to a wheelchair. Stairs can be an obstacle and ramps may be helpful for a child in a wheelchair but are too steep for those with physical issues. The child may be vulnerable to being

pushed over or knocked by others so consideration of the child's safety in the playground and when moving around the school needs to be discussed.

## Feeling scared and anxious

Depending on the child's age, they may know they are ill and be afraid that they could die. After treatment has finished, they may be scared that the cancer will come back needing yet more treatment. But they may be too worried to talk to their parents or they may want to avoid causing further distress. A child may confide in a staff member at school about how they are feeling. In some cases, a referral to a counsellor or psychologist can help relieve the child's anxiety and ease communication within the family. The child's keyworker can give further advice on this situation.



I found it hard to keep up with school work, exams and homework, and put myself under pressure as I felt I should be at the same level as everyone else. I had a lot of support from my teachers who understood my circumstances and were always there to help.

**Orla, 14**

## Fear of being bullied

Changes in physical appearance may induce a fear of being teased or bullied, which increases a child's reluctance to go to school. Preparing the classmates for the individual's return can help provide a reassuring and caring environment, and promote peer support. Bullying can be a problem and should be dealt with immediately. The pupil's nurse specialist, social worker, youth workers and educators can all provide advice and support with managing issues of bullying. Some professionals can come into schools and provide class or assembly discussions to help other pupils understand these issues.

**It is important that schools have a policy in place to prevent and address bullying and cyberbullying behaviour.** Children with SEN, disabilities and appearance-related differences can be disproportionately impacted by bullying and so additional pastoral support may be needed in these circumstances.



Going back to school after months of hospital stays can be incredibly scary. There is an endless list of worries a pupil may have: fitting in with classmates, being away from mum and dad, keeping up in lessons and even just worries about getting up for school at 7am!

**Karen, hospital learning mentor**

The most difficult time for me was finishing treatment. I was diagnosed with anxiety which made me feel negative about school. My efforts to catch up and the pressure I put on myself to gain good exam results did nothing to help stress and anxiety. I suffered from panic attacks in class and felt confused as to why this was happening. After a couple of months, I had learnt to control my anxiety but still have low days!

**Orla, 14**



## Losing friendships

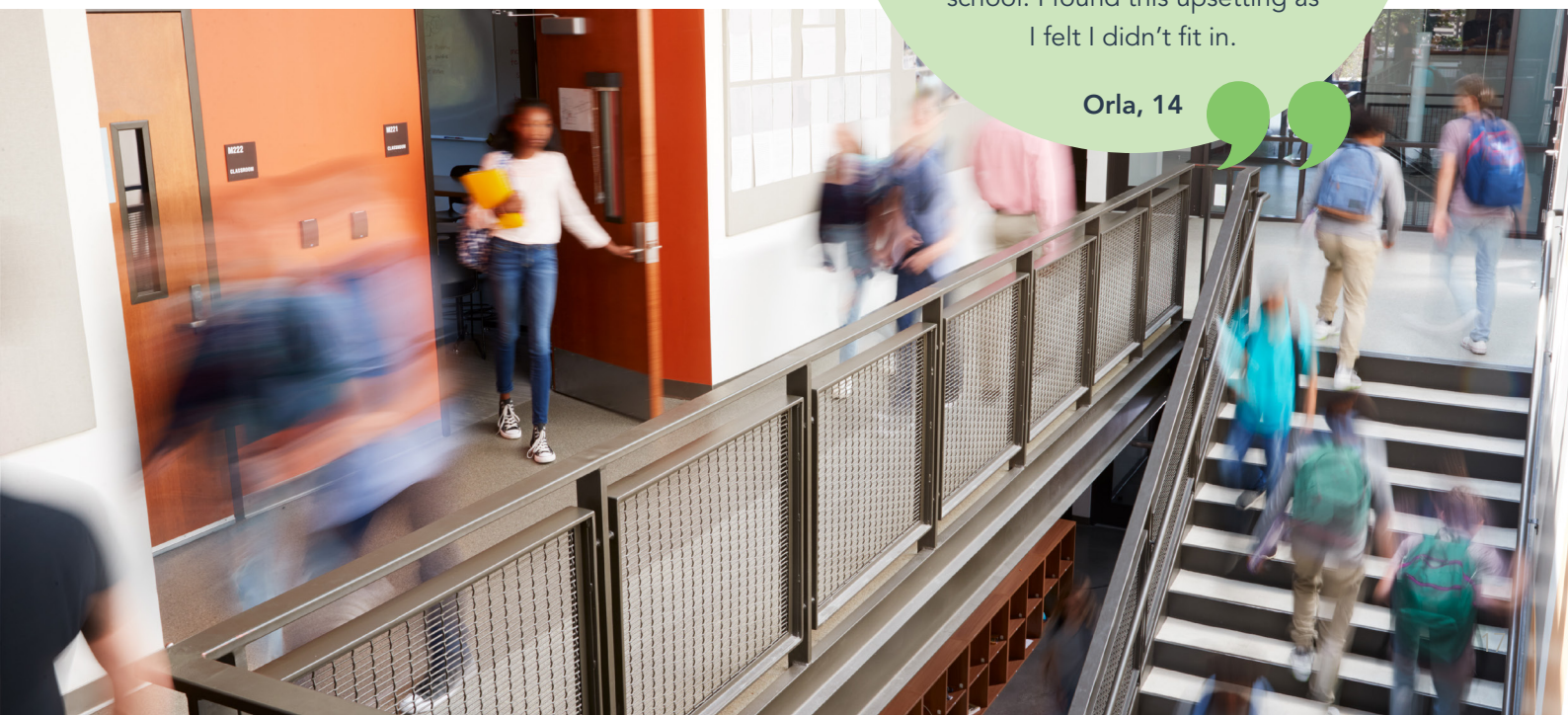
When pupils miss a lot of school, they may find it difficult to 'fit' back in with their peers straight away as the dynamics of a peer group may have changed while the child was away from school. On returning to school, the child may have changed – they may be moody, become more easily upset or seem more withdrawn. These changes are not typical of all children as some children can feel more mature and emotionally stronger because of their cancer experience.

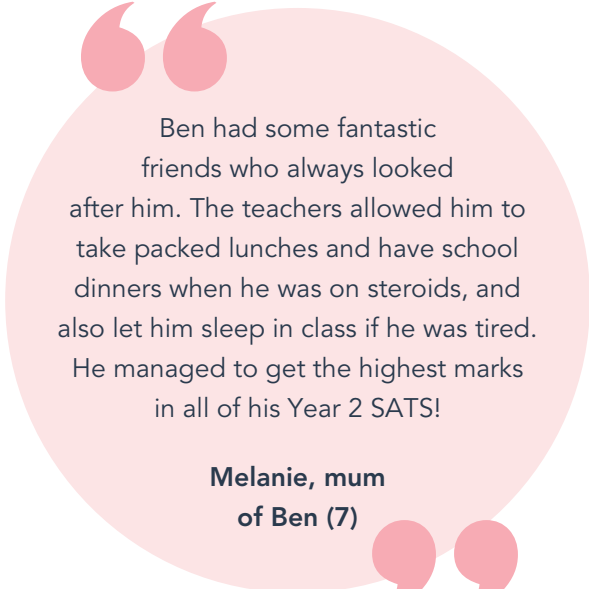
Friends may also find it hard to cope with changes. Like adults, friends may find it hard to know what to say. Yet research has shown that friends are very important in helping the child or young person fit back into school life. They can provide practical

help (carrying books between lessons), emotional help (listening to the child's fears), and social help (answering questions from others and providing some protection from bullying or teasing). It is important to encourage a number of children in these activities, as the responsibility may be too great for one child alone.

I found myself changing friendship groups at school as some people found my illness hard to understand and didn't know what to say. I had support from some close friends but was often left out from parties and meet-ups, mostly because of my absence from school. I found this upsetting as I felt I didn't fit in.

Orla, 14





Ben had some fantastic friends who always looked after him. The teachers allowed him to take packed lunches and have school dinners when he was on steroids, and also let him sleep in class if he was tired. He managed to get the highest marks in all of his Year 2 SATS!

**Melanie, mum  
of Ben (7)**



# Helping children back into school

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Getting back to school is vital for children and young people with cancer. They are encouraged to return to school as soon as possible and many will return after their initial course of treatment. School helps them to feel 'normal', rebuild their confidence and reduce the isolation and loneliness that many children with cancer face.

The process of returning to school can be made much easier through planning and preparation to ensure a smooth transition back into school life for both your pupil and the school.

Communication between the family, school and hospital is key in making sure a child's attendance at school is kept up and their education and social needs are met.

## Preparing and planning after diagnosis

As soon as a school hears the news that one of its pupils has been diagnosed with cancer, it is a good idea to start thinking about the best way of communicating with all concerned and to understand family wishes surrounding confidential information. This needs to be done in a sensitive and compassionate way.

Schools are often dependent on parents for information, however, it is important to realise that this is an extremely stressful and traumatic time for the parents themselves and they may be unable to understand all of the implications such as school attendance while undergoing treatment.

Before a child is due to come back to school, the child's keyworker (usually a clinical nurse specialist or hospital social worker) will contact and liaise with the school and coordinate an individual health care plan for the child returning to school with the parents' permission. This gives full details of the child's diagnosis, treatment, potential side effects and how they might impact the child as well as suggestions on how the school can help.

A planned meeting will normally take place with the family, keyworker, hospital teacher, SENCo and class teacher before a child returns so that everyone has a chance to ask questions and helps to alleviate any worries that a school might have. The keyworker can also help prepare classmates or the whole school before a pupil returns.

The care plan is flexible and is updated by the hospital as the child's needs change over time. Schools can contact the keyworker or hospital teacher if there are any concerns or need advice.

Some hospital services offer a 'Teacher Day' for school staff to attend to help find out more information or meet other teachers who also have a pupil with cancer.

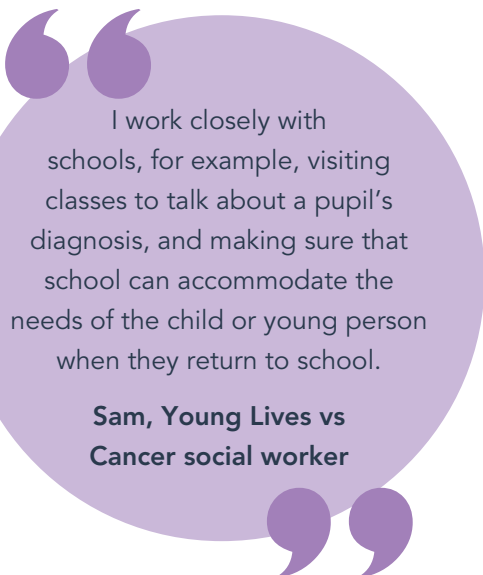
The following sections cover the main issues that teachers need to consider after a cancer diagnosis

## Communicating and sharing confidential information

A diagnosis of cancer is personal information and confidential to that child and their family. It is important to share information in accordance with the family's wishes. However, no school can guarantee total confidentiality as other school staff may need to know certain aspects and indeed there may be other parents and children at the school who already have some information.

It is good practice to establish open lines of communication from the beginning and set up a private meeting with the family to enable them to voice any concerns. Some simple questions to ask:

- ask **how they would like information shared** with other staff members and pupils – assembly, classroom talk or not at all
- ask **what information they would like to be shared** at every stage – full diagnosis or general terminology such as 'poorly'
- **check regularly** how the parents and pupils feel about sharing information as this can change over time
- identify any **religious or cultural customs** which may affect how the family and school deal with diagnosis
- ask **how much the child or young person (as well as brothers and sisters) knows** about the disease to avoid giving contradictory answers to the child and others



I work closely with schools, for example, visiting classes to talk about a pupil's diagnosis, and making sure that school can accommodate the needs of the child or young person when they return to school.

**Sam, Young Lives vs  
Cancer social worker**

### With the child

It can be difficult to know how to talk to children about their illness. It is important that they can trust adults to tell them the truth. Most doctors recommend that children with cancer are told honestly about their illness. They often don't wish to be treated differently or given special attention and may just want to carry on as normal.

Older children are better able to understand what is happening and have the right to be heard and involved in any choices or decisions. Once doctors feel a child is competent, they will involve them in discussions about their treatment and will usually

include them in decisions. The best approach is to be optimistic, and to answer any questions truthfully, but sensitively.

### **With other school staff**

Once the school has discussed with the family about who should be informed about what, it is important to share the information correctly to the relevant staff.

Not every member of staff needs to know every detail but it is important to share a brief overview to inform all teachers, dinnertime staff or supply teachers in line with the wishes of the family. This allows for flexibility such as toilet visits, attendance and wearing hats or bandanas, and also allows them to be aware of the needs of siblings. It is also important that any new staff are made aware too.

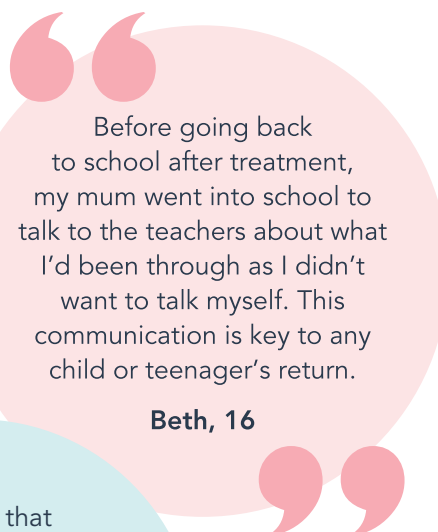
When informing school staff, be aware that some may have their own experiences or connection with cancer which requires sensitivity.

### **With school friends**

The child's diagnosis should only be explained to the rest of the class and other pupils with the permission of the parents and/or pupil.

It can be very hard for the pupil to answer questions from their classmates such as "What is wrong with you?" or "Why are you off school?" so it can be a good idea to explain what cancer is to classmates before the pupil returns to school to avoid teasing. Simple and correct information is always better than inaccurate rumours outside of the classroom.

Teachers can support school friends by allowing them to talk about their feelings and worries as well as reassuring them that cancer is not contagious. It is also a good idea to actively engage them by asking them how they can help their friend while they are in hospital and how they can be a good friend when they come back.



Before going back to school after treatment, my mum went into school to talk to the teachers about what I'd been through as I didn't want to talk myself. This communication is key to any child or teenager's return.

**Beth, 16**



I believe that communication is critical in making the transition from months of treatment back into the classroom.

**Deirdre, mum  
of Talia**

## While your pupil is absent from school

Many children miss a lot of time from school after diagnosis. Hospital appointments and admissions for treatment or infection can be frequent and can happen suddenly. Long absences can have huge implications for educational progress, as well as relationships with friends. Once the initial diagnosis has been made, parents and teachers need to work together to promote an appropriate learning environment for the child. It is important to make sure the child keeps up to date with schoolwork as much as possible while not attending school.

“ We had circle times in class and various children shared some of their stories, commonly about grandparents. I was waiting for the question ‘Will Owen die?’. It was one I prepared for. I knew I couldn’t lie to them as it was a possibility. My answer was to say that sometimes people can die from cancer but Owen was having medicine so he would hopefully get better. No child asked this question – they treated it like he had a tummy bug or cold.

**Bob, primary school teacher**”

## Hospital schools

Most children’s hospitals have education departments that can support the child while they are staying in hospital. Their main purpose is to help keep children’s minds active while in hospital and to help them keep up with their school work as much as possible. It’s even possible for children to take exams in hospital if necessary. Teaching staff at the hospital will liaise with you so that school work for the pupil can be in line with their peers.

“ It was hard being off school for so long but the teachers at the hospital were incredible for keeping my passion for learning going.

**Vicky, adult survivor of cancer**”

## Home tuition

Home tuition is helpful for a short time if a child feels too ill to attend school, for example, after a stem cell transplant when they may be immunosuppressed for a period of time. It can help the child catch up on missed work and prepare them for their return but they are still encouraged to attend school now and then mainly for social reasons. This is arranged through the hospital school and your pupil’s hospital team. Schools should be able to refer to their local authority service to liaise with the home tutor about appropriate work for the child. Sometimes home tuition can run alongside part-time attendance in school.

## Teacher tips

**It is important to be vigilant** about children's reactions so that problems can be dealt with promptly. Teaching assistants might be more able to monitor reactions and listen to what children are saying amongst themselves. Be aware that pupils may have experience of cancer in their home lives that may have had a negative outcome.

### Keep in touch with your pupil

- **Visit the child in hospital and at home**, and perhaps bring along one or two classmates, if the child or young person agrees.
- **Consider video calls** and regularly **remind children to keep in contact** with their friend. Messaging apps, social media, letters and cards will help the child feel included and keen to get back to school.
- **Regularly communicate with the hospital school and/or home tutor** about the work set and to keep up-to-date with the child's academic progress. Remote home learning tools and resources may be helpful.
- **Offer an opportunity to meet new teachers and visit new classrooms** when changes occur. Be especially thoughtful around transition to secondary school or a new key stage.

### Keep in touch with parents

- **Keep in regular contact** with the family and listen to their fears and concerns. Discuss any worries or potential problems. Be aware this situation is new for parents and they may not be able to answer many questions.
- **Discuss the basic medical facts** with your pupil's nurse specialist or hospital teacher. If you are liaising with the parents, try to become familiar with the treatments given and their effects on school performance.
- **Stop any automatically generated texts or phone calls about absence** as these can be both irritating and upsetting for families.
- **Keep the family up-to-date** with what is happening in school. Make sure the family receives school newsletters or information to help them feel included.

### Preparing the class

- **Continue to call the child's name on the register** and keep their place in class such as seat, tray, peg, locker to help classmates remember their friend is still included.
- **Sensitively prepare the class for physical and emotional changes** in the child or young person and suggest ways to be helpful. Consider having a school assembly for myth-busting and to increase awareness.



# Looking after your pupil at school

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There are lots of ways you can help your pupil cope with coming to school after a cancer diagnosis. Above all, try to establish normality and set achievable goals, even for children with a poor outlook.

Initially, many children will return to school on a part-time basis. Your pupil's keyworker will advise on expected attendance as pupils may need designated catch-up time and tuition phased in. It is important that decisions are made about what to tell other pupils and how much the child can be expected to achieve when they first start back. Problems that might be anticipated, including the need for extra time in exams, should be considered early, and practical arrangements put in place.

### Arranging pastoral care

It is a good idea to identify one member of school staff that the pupil can talk to and confide in, and who will have the time to listen and give support when needed. This can be a teacher or a non-academic member of staff, who may have more availability during the school day if they are needed. This person can develop a nurturing and supportive relationship with the pupil as soon as they attend school.

### Protecting your pupil's health

Cancer is not infectious, and children or young people returning to school after cancer do not present any health risk whatsoever to others. However, children undergoing treatment do have certain health requirements which need to be taken into account by school staff.

The thought of returning to school after 3 months of treatment was one of the most difficult things for Olivia. The school and our specialist nurse helped enormously by speaking to the students, giving them advice on how to handle her return. Within a week of being back, Olivia said she felt that she'd never been away!

**Jo, mum of  
Olivia**

We had a postcard system and each day a child in the class would write a message to Owen and enclose a picture or piece of work they had done. When Owen was well enough, he would do the same back – receiving these letters was very exciting.

**Bob, primary  
school teacher**

## In case of emergencies

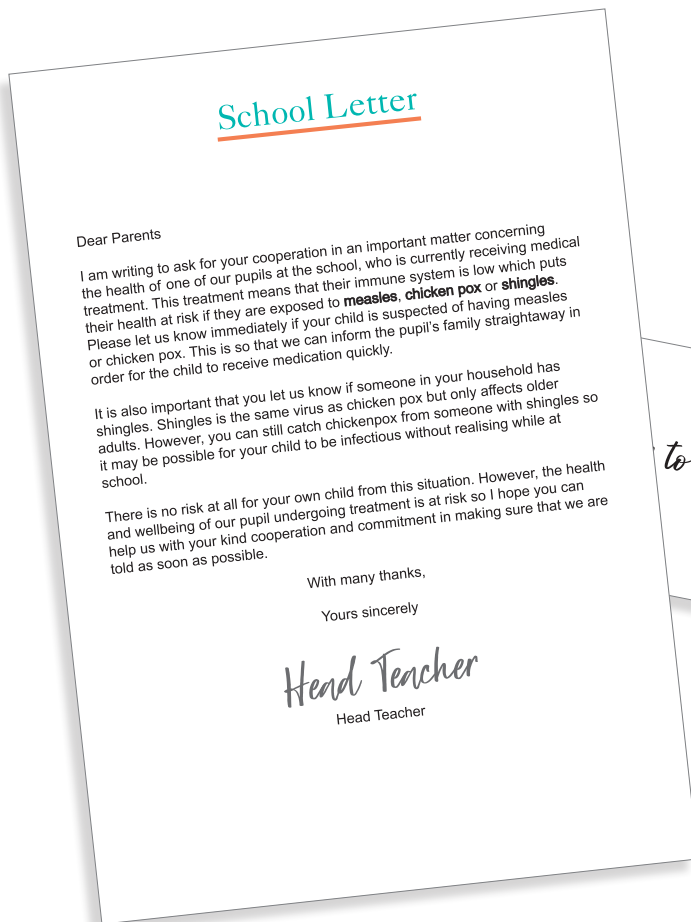
The pupil's hospital team should offer a care plan and guidance on how to respond to potential problems when a child goes to school whilst on treatment. A pupil receiving chemotherapy has a higher risk of infection, causing more absences if they need to go to hospital for assessment due to a sudden fever or high temperature. Other concerns may include nose bleeds or central lines being accidentally pulled.

## Immunisations

It is usually recommended that the child or young person should not be immunised while he or she is receiving treatment for cancer; or for six months afterwards (12-18 months after a stem cell transplant.). The only vaccine generally recommended is the flu vaccine in the autumn term. However, they may not be able to have the nasal vaccine at school.

## Chicken pox, shingles and measles

As chemotherapy suppresses the immune system, chicken pox and measles are especially dangerous to children being treated for cancer. Schools need to be vigilant and inform the child's parents immediately if an outbreak occurs. It is advised that schools send a letter to parents of all children at the school, informing them of the importance of alerting the school if their child has chicken pox or measles.



*to Parents*



Ben returned to school within a few months of diagnosis and I was kept informed of any illnesses going around. I feel it was important for him to be just like the other kids.

**Melanie, mum  
of Ben (7)**

## Educational support

Children who are having or who have had treatment for cancer may experience difficulties in a number of areas and require additional educational support. It may be beneficial to work with the school SENCo to plan and ensure the right support is in place. This is particularly true of children with brain tumours depending on exactly where the tumour is and how it is treated. Specific difficulties might include:

- balance and coordination issues
- social functioning such as ability to make friends, reading social cues, inappropriate behaviour
- hormonal imbalance and growth issues
- speech and communication such as slurred speech, difficulties in comprehension and expression
- vision and/or hearing issues
- memory issues
- concentration and attention issues
- learning issues
- behavioural issues such as anger
- irritability, mood swings or low mood
- reduced mobility
- anxiety

All of the above can affect daily classroom tasks such as writing, and taking part in PE as well as social integration. Allowances for this should be made when planning homework, lessons, revision and taking exams. An assessment for an EHC plan may be needed and the pupil's keyworker can help with this.

## Education, Health and Care Plan (EHC) assessment

Sometimes, a pupil may benefit from having an assessment for an education, health and care (EHC) plan. These are for children and young people aged up to 25 who need more support than is available through special educational needs. EHC plans identify educational, health and social needs and set out the additional support to meet those needs.

The EHC plans are not needed by most children with a diagnosis of cancer but can help those with special educational needs. The school, hospital or parents can request an assessment to be carried out by the local authority. For more information, please visit [www.gov.uk/children-with-special-educational-needs](http://www.gov.uk/children-with-special-educational-needs)

### Specialist information and support for teachers supporting a pupil with a brain tumour

#### The Brain Tumour Charity

[www.thebraintumourcharity.org/living-with-a-brain-tumour/get-support/children-and-families-service/education-resources/](http://www.thebraintumourcharity.org/living-with-a-brain-tumour/get-support/children-and-families-service/education-resources/)

#### The Children's Trust Brain Injury Hub

[www.thechildrenstrust.org.uk/brain-injury-information/info-and-advice/return-to-education](http://www.thechildrenstrust.org.uk/brain-injury-information/info-and-advice/return-to-education)

### Returning to school: A teacher's guide for pupils with brain tumours

(The Royal Marsden and Cerebra, 2018)



Flexible part-time timetables can be arranged, whilst visits into school to meet with peers over social break-times are extremely useful.

**Lynda, secondary school teacher**

After four months, Owen returned to a more stable timetable at school. His hair started to grow back and normality started to return. Allowances were made for tiredness and a quiet area was always available for a little rest.

**Bob, primary school teacher**

## Common questions asked by teachers

### How much should I expect from my pupil?

As a general rule, you should expect the same academic standards as before. However, children and young people may experience difficulties in a number of areas (see page 28) and these pupils may benefit from extra support.

Remember to make allowances for any work missed while the child or young person was absent. Check with the hospital or home teacher to see what work was done and the child's working levels, as these will be different due to time out of school and their medical condition. Once back at school, the pupil should be encouraged to achieve his or her full potential.

### Will I have to take my pupil's temperature or do anything else medical?

It is not the school's responsibility to monitor a pupil's temperature, or do anything medical. If the pupil appears hot, or you are concerned in any way, phone the family whose responsibility it is. They will then take their child to the hospital for assessment.

### What about discipline?

It is important that discipline should be the same whether a child has cancer or not. Some children and young people may complain of tiredness to

avoid activities they do not want to do. Remember that a pupil who has recently been ill may be more emotional, react negatively to criticism or be more prone to tears.

### Can my pupil still go on school trips?

It is important to include the child in as many class functions as possible (e.g. assemblies, parties, performances) throughout their treatment period. The acceptance of these invitations will be decided by the child and parent, considering levels of stamina and wellbeing at the time. Trips are an important part of the school experience and it is valuable for children to have these experiences with the rest of their class which will involve working closely with parents. Be aware that children can become very dependent on their parents when they are ill, and may be anxious about going on a trip by themselves.

### Can my pupil still do PE?

Yes, unless the doctor has advised otherwise such as in the case of swimming and contact sports. Most children enjoy physical activity, and don't want to feel left out or different from the rest of the class. They should be encouraged to do as much as they can cope with comfortably. They may get tired more easily, so allow them to set their own limits and to stop when they are ready. Be aware that some children may not know their limits, so checking in with them regularly will be beneficial. Some pupils may need to have short

rests during the day. It is important for all pupils to feel part of the lesson. For example, it may be possible for children to participate in part of the lesson with an adult helper; or they may be able to take a less active role, such as being an umpire. Physiotherapists involved with the pupil's care at the hospital are an excellent source of advice in these circumstances.

### What about special diets?

Some children or young people may have a poor appetite, while others often feel ravenously hungry. These problems may be related to the disease itself or temporary side effects of treatment. For some patients, particular foods may be restricted during treatment. The child or young person's key worker will be able to inform you about these.

If the child is receiving steroids and has an increased appetite, it is advised to allow small snacks to be eaten throughout the day if necessary.

### Will my pupil need to retake the school year?

This is not advised as it is more beneficial for the child in terms of social integration and overall wellbeing to stay in their peer group. However, if very large amounts of school time have been missed, then the child may need to repeat the year at school.

Be sensitive to the child or teenager's feelings around their diagnosis. I was perfectly comfortable talking about what I'd been through, but this is not the case for everyone. Irrespective of attitude, it's important once they're back at school to treat them the same as their peers

**Beth, survivor (16)**

It is important that teachers talk to the pupil's medical team if the pupil is absent from school in case there needs to be further follow-up with the family at home.



## Teacher tips

**Use lots of encouragement to motivate the child back into school life.** This will build their confidence and enable them to reach their goals. Schools and teachers have an important part in making sure the child is well supported.

### What to look out for

- **Problems with mobility, fatigue, concentration** or other effects of their illness or treatment.
- **Interactions in the playground** – strictly enforce anti-bullying rules.
- **Lessons or discussions which include cancer, serious illness or death** – be sensitive and allow the pupil time to talk and/or leave the room.

### Preparing the class

- **Have class discussions** or role play about appropriate behaviour.
- **Explain special arrangements** that are in place.

### If the child is tired

- **Offer 'time out'**, ensure they know who and where to go to. A 'Plan B' is useful for when arrangements need to change.
- **Offer quiet 'time out' areas** such as the library, frequent rests and reducing the timetable.
- **Break the work down into small chunks** and use lots of visual aids and practical tasks.

### Keeping normal school life

- **The pupil should continue to be in the same classroom** as other peers and do normal activities where possible.
- **Identify a key person** who the pupil can see regularly to review progress and discuss worries.
- **Inform staff of special arrangements** so there are no misunderstandings or embarrassments.
- **Be flexible and supportive about work.** Most pupils are very keen to catch up. If appropriate, arrange catch-up sessions.

### Practical issues

- **Ensure easy access to all areas.** Consider the pupil leaving the class early to avoid the rush between lessons and at the end of the day.
- **Organise any extra supervision** that may be needed for breaks and lunchtime.
- **Encourage regular handwashing** for the whole class to help avoid the spread of germs.
- **Be flexible about rules** around visits to the toilet, snacking, wearing a hat and so on.
- **Consider a phased return** to school with flexible or fewer hours.



# Teaching siblings of a child with cancer

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A cancer diagnosis can cause strong, and often conflicting, feelings in siblings. They will experience huge disruption to normal routines and family life, and will feel a number of emotions.

They may feel jealous and resentful of the attention given to the sick child but also guilty in the belief that they are somehow responsible or that they are not doing enough to help. Many siblings keep their feelings bottled up to avoid worrying their parents. Often, the place where siblings may show how they feel is at school. They may:

- withdraw, become very quiet and cry easily
- feel ill with psychosomatic symptoms such as aches and pains or ignore genuine ones
- become disruptive in class and/or rebellious towards teachers
- become frustrated and have outbursts of anger
- start missing school, fall behind or get lower marks than usual
- have arguments and fights with friends and other children in their class
- have an increased level of general anxiety

It is important that all teachers in school are aware of pupils who have a brother or sister with cancer, so they can deal with any behavioural problems firmly, but with sensitivity and understanding. Older siblings may react in different ways with challenging behaviour needing extra support. If there are siblings at another school, the nurse specialist, keyworker or social worker would liaise with the sibling's school.

### Teacher tips

- **Encourage children to talk about their sibling** who has cancer, but be aware that they may not want to always talk about it.
- **Be sensitive to any issues** such as homework not completed, things forgotten and tiredness. When siblings move school, ensure that the new school is fully aware of the situation.
- **Having a sibling diagnosed with a serious illness is traumatic.** The feelings of stress and anxiety outlined in the next section (pages 36-37) can also apply to brothers and sisters.
- **Be sensitive about lessons or discussions** which include cancer, serious illness or death – allow siblings to talk and/or leave the room.

I did everything I could to help make things better at home. I cooked the tea, cleaned and helped out with homework. I found it hard to sleep, I was always worrying and I didn't eat much at school as I just had too many things to think about.

Ellen, 13

# Future needs of your pupil

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Having cancer is a scary and traumatic experience. Children are often expected to be 'back to normal' after treatment but, in reality, they may remain at a considerable disadvantage through coping with both physical and emotional issues as they try and process what has happened to them.

Feelings of stress and anxiety can happen at any time in the future and can be a part of the child's normal adjustment process. Events such as changing schools or taking exams can trigger these feelings even years later. Visits to hospital for check-ups and follow-up care may also bring worries to the surface. Children may also feel that these appointments highlight differences to other children.


Research shows that children and young people who have been diagnosed and treated for cancer (even when diagnosed at a very young age) may be at an increased risk of developing post-traumatic stress disorder (PTSD). Symptoms include anxiety, anger, flashbacks and low mood.

These feelings can result in further absences from school and isolation from friends, however, psychological help and support is available via the child's hospital team or GP. The effects of having been treated for cancer are often lifelong with two out of three survivors having an issue or 'late-effect' related to their treatment. These issues can occur at any point and could affect heart, lung or kidney function, fertility, growth and development amongst others. Be aware that appointments will continue long after treatment finishes and support to cope with these effects may be required both physically and emotionally.

### Teacher tips

It is important to gain updated permission from the parents and/or pupil for communication plans in the future.

- **School staff members can change over time** so make new staff aware. This is still important even if a long time has passed since diagnosis.
- **Inform teachers, form tutors, head of year and pastoral care teams** for each new school year of the pupil's medical history so that support can continue.
- **Contact parents to discuss transition plans** and to ask permission to pass on any necessary details to new schools or colleges. Liaise with new schools to ensure care continues.



“ “ Joe, 12, had leukaemia when he was 8 years old. His parents noticed he was becoming anxious and thought it was related to leaving primary school. He had a panic attack at school and was anxious and tearful when returning for hospital appointments. After having psychological support, Joe felt less anxious about attending school and was able to sleep better.

**Dr Amandeep Samrai, clinical child psychologist**” “



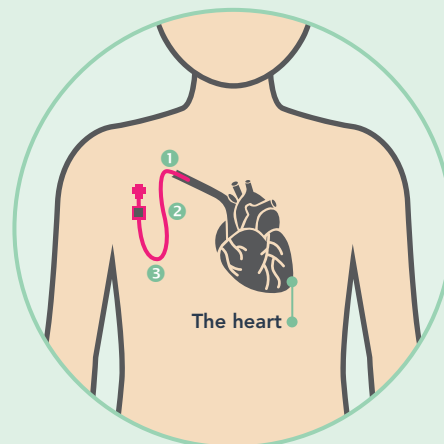
# Further information

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## Fitted lines explained

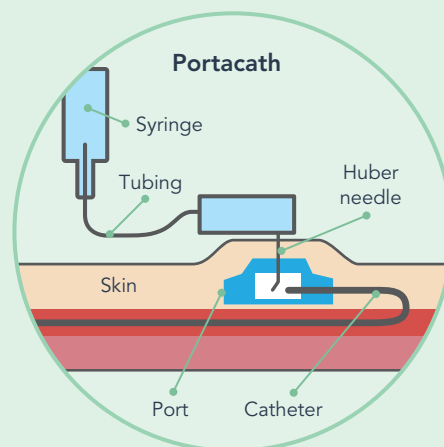
A **central line** (sometimes referred to as a wiggly) is a long plastic tube that is inserted into a large vein near the collarbone under anaesthetic. This allows drugs to be injected and blood samples to be taken without a needle. The line can be seen taped to the child or young person's chest and is normally covered by clothing. It is securely attached, should not fall out and should not cause any problems at school.

**A child or young person with a central line should not go swimming. Contact sports are usually not advised, but you should discuss with your pupil's medical team.**



- 1 Central line inserted into chest here
- 2 Line tunnelled under skin
- 3 Line comes out here

An alternative device is a **portacath**, which is implanted under the skin usually in the chest. This has the advantage that swimming and sports are less of a problem but the device has to be accessed with a needle each time it is used.





## Glossary of medical terms

**Anemia:** Low haemoglobin, or low red blood cell count. A blood transfusion may be required.

**Benign:** Not cancerous.

**Biopsy:** Removal of a small piece of tissue for examination, to establish a diagnosis.

**Blood count:** The number of cells of different types contained in a sample of blood.

**Bone marrow:** The substance at the centre of the long bones that makes blood cells.

**Brain stem:** Connects the brain to the spinal cord. Is involved in bodily functions such as breathing, blood pressure and heart rate.

**Central nervous system:** Consists of the brain and spinal cord.

**CT or CAT scan:** X-ray procedure in which a computer is used to produce a three-dimensional image. Used for diagnosis and for monitoring the effects of treatment.

**Febrile:** Having a temperature.

**Growth hormone replacement therapy (GHRT):** Growth hormone is a chemical made by the pituitary gland in the brain. It controls physical growth in children. GHRT involves giving extra growth hormone to children who lack it, in order to enable them to grow normally.

**Haematology:** The study of blood.

**Immunosuppressive:** Lowering the body's ability to fight infection.

**Intravenous:** Into a vein, for example, when drugs are given directly through a drip.

**Lumbar puncture:** Insertion of a needle into the spinal canal to remove fluid and/or give drugs.

**Lymphatic system:** A network of tubes and nodes (glands) which filter body fluid and help to fight infection.

**Lymphocytes:** White blood cells that fight infection.

**Malignant:** Cancerous.

**Metastases:** Cancer that has spread from the place where it started (also known as secondary cancer).

**Nasal tube:** (Nasogastric or NG tube) A feeding tube that goes from the nose to the stomach.

**Neutropenic:** Having less than the normal number of neutrophils in the blood.

**Neutrophil:** A type of white blood cell which fights infection.

**Oncology:** The study and treatment of cancer.

**Oncologist:** A doctor who specialises in the treatment of cancer.

**Paediatrician:** A doctor who specialises in the care and treatment of children.

**Paediatric oncologist:** A doctor who specialises in the care and treatment of children with cancer.

**Platelets:** Blood cells concerned with clotting of blood.

**Primary:** Original site of cancer.

**Prognosis:** The outlook or expected outcome of a disease and its treatment.

**Prosthesis:** An artificial replacement of, for example, a bone or an eye.

**Relapse:** The return of symptoms of a disease after a period of good health; re-occurrence of a tumour after treatment.

**Remission:** A period of good health when there is no longer any visible cancer.

**Tumour:** An abnormal lump of tissue formed by a collection of cells. It may be benign or malignant.

## Help and support

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

[www.cclg.org.uk](http://www.cclg.org.uk)

Publishes a variety of free resources to order or download, including story books and animations for young children. These may help when explaining childhood cancer during class.

### **Young Lives vs Cancer**

[www.younglivesvscancer.org.uk](http://www.younglivesvscancer.org.uk)

Helpline: 0300 330 0803

Provides practical support and advice for children and young people affected by cancer and their families.

### **Macmillan Cancer Support**

[www.macmillan.org.uk](http://www.macmillan.org.uk)

Helpline: 0808 808 00 00

Provides practical and emotional support to anyone affected by cancer.

### **Teenage Cancer Trust**

[www.teenagecancertrust.org.uk](http://www.teenagecancertrust.org.uk)

Provides practical and emotional support for every young person affected by cancer.

## Useful resources for teachers

- Cancer and school life pack (published by Young Lives vs Cancer, 2017)
- Supporting brothers and sisters (published by CCLG, 2020)
- Supporting children with cancer in school (published by the Royal Marsden, 2019)
- Pupils with cancer: A guide for teachers (published by the Royal Marsden, 2008)
- Returning to school: A teacher's guide for pupils with brain tumours (published by the Royal Marsden, 2018)
- [www.thebraintumourcharity.org/living-with-a-brain-tumour/get-support/children-and-families-service/education-resources/](http://www.thebraintumourcharity.org/living-with-a-brain-tumour/get-support/children-and-families-service/education-resources/)
- [www.thechildrenstrust.org.uk/brain-injury-information/info-and-advice/return-to-education](http://www.thechildrenstrust.org.uk/brain-injury-information/info-and-advice/return-to-education)

Thank you for reading this booklet and we hope it answers your questions. If you need any further information, please talk to your pupil's medical team at the hospital who will be happy to help.

Since my treatment finished, I have been to university, graduated with a first and trained as a teacher – all the goals I wanted to reach! I wouldn't take back having cancer. I've learned how strong I am and have become even more determined to succeed!

**Kelly, survivor of childhood cancer and teacher**

Dear cancer,  
I beat you aged eight and today I got my PhD in cancer research.

**Vicky, survivor of childhood cancer and cancer research scientist**

My diagnosis coincided with my first year of GCSEs but I decided not to take a year out. My teachers were instrumental in constantly liaising with myself and my hospital school teachers to keep me up to date with school work.

**Beth, survivor (16)**

Every child will handle their return to school in a different way, but if the right level of support has been offered throughout the treatment and recovery journey, the child will quickly settle and feel quite comfortable back in the school environment.

It is amazing to witness a young person who has faced one of the hardest challenges of any person's lifetime, quietly return to school and become an inspiration to the whole community.

**Lynda, secondary school teacher**



## 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 contact us at [publications@cclg.org.uk](mailto:publications@cclg.org.uk).

Our work is funded by donations. If you would like to help, text '**CCLG**' to **70085** to donate **£3**. You may be charged for one text message at your network's standard or charity rate. CCLG (registered charity numbers 1182637 and SC049948) will receive 100% of your donation.

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Leicester LE1 7GB

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

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