

Welcome back!

A guide for teachers helping children and young people returning to school after a diagnosis of cancer



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This booklet was edited by members of the CCLG Publications Committee comprising multiprofessional experts in the field of children's cancers.

It was originally written by Isobel Larcombe, Prof Christine Eiser, Dr Helena Davies and Dr Mary Gerrard and was previously published in 2007 by Cancer Research UK in collaboration with CCLG.

The quotes in this publication are personal views and do not necessarily represent the view of CCLG.

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Thank you to all those who have contributed to this booklet.

Thanks to Team Olivia for supporting the publication of this booklet. Olivia is now in remission from Hodgkins Lymphoma which she was diagnosed with aged 13. Team Olivia raises funds for cancer charities for children.



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First published: April 2015 Next review date: April 2018

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CCLG_UK

Registered charity number 286669

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Getting back 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 normal school routine.

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 booklet 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.

Teachers play a vital part in the child's recovery.

About childhood cancer

Children's cancers are rare. Only 1 in every 600 children under 15 years of age develops a cancer, and these are quite different from those affecting adults. There are approximately 1,600 new cases of childhood cancer in the UK each year.

What is childhood cancer?

In general, cancer occurs when cells in the body become out of control and multiply. They stop working properly and, as their numbers increase, they form a lump or tumour. When cancer cells break away and spread to other parts of the body they may produce secondary tumours known as metastases. Leukaemia is a type of blood cancer which occurs when too many white cells are produced. • The causes of cancers in children and young people are not fully understood. While cancer in older adults can be affected by age and lifestyle factors such as smoking, this is not the case with cancer in children. Through research, we are learning more about cancer in children and are continuously improving treatments.

 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.

Is it possible to cure children with cancer?



Over 8 out of 10 children with cancer are now cured, compared with fewer than 3 in 10 over 40 years ago.

This success is the result of extensive research through clinical trials over many years and the foundation of a national network of specialist treatment centres, where care is given by a multidisciplinary team of experts. However, some children are left with long-term complications as a result of treatment called 'late effects'.

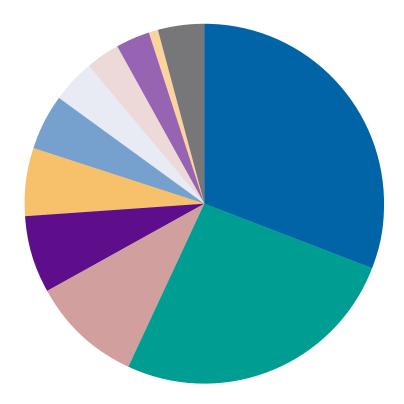
Doctors and researchers are seeking not only to improve survival rates, but also to ensure a normal future – physically and emotionally – for children who then become adults.

What are the different types of childhood cancer?

The most common types of childhood cancer are shown below.

Types of cancer in children

- Leukaemias 31%
- Brain and spinal tumours 26%
- Lymphomas 10%
- Soft tissue sarcomas 7%
- Neuroblastoma 6%
- Kidney tumours 5%
- Bone tumours 4%
- Germ cell tumours 3%
- Retinoblastoma 3%
- Liver tumours 2%
- Other 4%



Leukaemia

Nearly 1 in 3 children with cancer have leukaemia. This is a cancer of the blood cells and the bone marrow. There are different types of leukaemia approximately 80% of children with leukaemia have acute lymphoblastic leukaemia (ALL). The symptoms of leukaemia are lack of energy due to anaemia; susceptibility to infection; and abnormal bleeding and bruising.

Brain tumours

Brain tumours are the second most common cancer in children and approximately 1 in 4 childhood cancers involve the brain or spinal cord.

Symptoms vary widely and are caused by pressure on the brain or nerves by the growing tumour such as headaches, seizures, coordination, sight/ balance problems and hormonal problems.

Any disease of the brain or its treatment carries some risk of harming the physical and intellectual development of the child. Brain tumours can be difficult to treat and have wide-ranging implications for the child's learning, physical and social development (see page 22).

Lymphomas

These account for 10% of all childhood cancers and have been broadly divided into Hodgkin's lymphoma and non-Hodgkin's lymphoma. They affect the lymph nodes and lymphatic system, which are important in helping to fight infection.

Soft tissue sarcomas

These account for 7% of cancers in 0-14 year olds. The majority of these are rhabdomyosarcomas which arise in muscle cells. It occurs most frequently at around 3 years of age and can develop in the head, neck, chest or abdomen and limbs.

Bone tumours

These account for 4% of all childhood cancers. The two main kinds are osteosarcoma and Ewing's sarcoma, and both occur most frequently in teenagers.

Osteosarcoma is the most common type of bone cancer; usually arising in long bones (bones in the arms and legs). Ewing's sarcoma is rarer.

Germ cell tumours

These are very rare and can develop at any age. The most common places are the testicles, ovaries, base of the spine, brain, chest or abdomen.

The following three cancers account for 14% of all childhood cancers.

They occur mostly in children under 5.

Neuroblastoma is a cancer of nerve cells that most commonly develops in the back of the abdomen, in the adrenal glands above the kidneys, or at the back of the chest.

Wilms' tumour is the most common form of kidney cancer in children.

Retinoblastoma is a rare cancer found at the back of the eye. It can be hereditary or non-hereditary. The first sign of a retinoblastoma is often a white pupil that does not reflect the light. If the tumour is large it may cause a painful red eye.

Teenage and young adult cancers

Teenagers and young adults tend to get different types of cancers to children and adults with the most common ones being leukaemias, lymphomas and carcinomas, germ cell (ovarian and testicular) and brain and central nervous system (CNS) tumours.

Treatment and its impact How is childhood cancer treated?

All children and young people diagnosed with cancer are treated in specialist centres across the UK and Ireland. Often, some treatment can be given at a local hospital under the guidance of the nearest specialist centre. Treatments are based on nationallyand frequently internationally-approved treatment plans. This means that a child or young person with cancer will be treated in the same way wherever they live.

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



There are a number of different treatments available for childhood cancer. The type of treatment used depends on the particular cancer the child has.

Surgery

Many childhood cancers are treated with surgery which aims to remove the tumour during an operation. Usually, chemotherapy is given first to reduce the size of the tumour to make surgery easier.

Chemotherapy

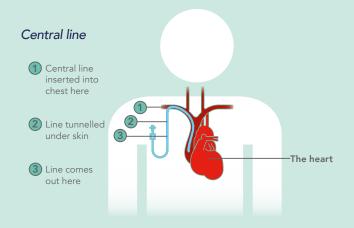
This is the use of drugs to kill cancer cells. The doctor may use a single drug or a combination. The drugs may be given by mouth but more usually by injection into the bloodstream (via the vein called IV). Chemotherapy is given in cycles: a treatment period followed by a recovery period, then another treatment period, and so on. Usually, children do not need to stay in the hospital for all treatment and can go home and back to school between cycles. Some drugs can be given in the outpatient clinic. Others require a short hospital stay.



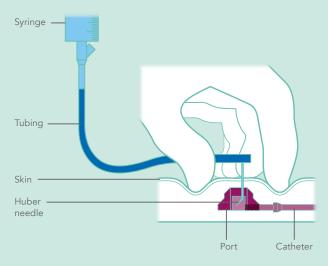
Fitted lines

A central line (sometimes referred to as a wiggly) may be fitted surgically. This functions as a longterm line into the vein which 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.

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.



Portacath



A child or young person with a central line may not be allowed to swim.

Contact sports such as rugby and judo should also be avoided.

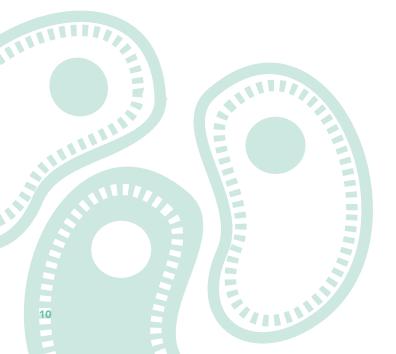
Illustrations on this page are reproduced with permission from Macmillan Cancer Support

Radiotherapy

Radiotherapy uses high-energy x-rays to destroy cancer cells. The radiation beams are very precisely aimed at the cancer. The child or young person lies still on a special table and a high-energy x-ray machine directs the rays at the site of the cancer. Some children are unable to stay still and may need to have a general anaesthetic each time that they receive their radiotherapy treatment.

Radiotherapy is painless and lasts just a few minutes. A course of radiotherapy may last for as long as six weeks, usually on a daily basis (Monday-Friday). Occasionally twice-daily radiotherapy is required.

Proton beam therapy is a special type of radiotherapy that can be used to treat some types of cancer. Currently, there are no machines in the UK able to deliver proton therapy to children, so this treatment is offered abroad if appropriate.



Stem cell transplants

These treatments are used for leukaemia but can be used for other cancers as well as other bone marrow disorders. There are two types of stem cell transplant – one where donor stem cells are used (allogeneic stem cell transplant) and the other where cells are taken from the patient (autologous stem cell transplant).

Allogeneic transplant

This treatment uses high doses of chemotherapy and sometimes radiotherapy to destroy the child's own bone marrow so that the donor stem cells can then start working in place of the child's. The cells are given back through a drip just like a blood transfusion. This is a complex treatment requiring times of isolation and children will be strictly monitored until their immune system recovers.

Autologous transplant

The child's stem cells are collected before this procedure and stored. High doses of chemotherapy are given to kill any potential cancer cells that remain and the stored stem cells are given back through a drip just like a blood transfusion. Again, the child will need time for their immune system to recover before they are able to return to school.

Immunotherapy

These drugs target specific cancer cells. They can attach themselves to a particular protein on the cancer cell which triggers the body's own immune system to attack and destroy the cancer cells. As they target cancer cells, other parts of the body are not affected and the side effects are usually mild. Immunotherapy is only suitable for certain types of cancer.

Targeted therapy

There are many new drugs being developed for children's cancer that work differently from the way chemotherapy works. These are often called biological agents or targeted drugs which work by blocking a specific gene or protein that cancer cells have.

What is the effect of treatment patterns on school?

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

Children and young people are often well enough to attend school between treatment sessions. When the cancer is under control, or in remission (no sign of cancer returning), children and young people usually feel well and rarely show any signs of the disease. Occasionally, cancer recurs after a period of remission and this is known as a relapse requiring further treatment. During some of 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 are not well enough to attend school. These will need support with education.

Sometimes, the child or young person will need to travel long distances for treatment at a specialist centre which may affect attendance.

Only after several years in remission is the child or young person usually considered to be cured of cancer.

What are the possible side effects of treatment that might affect school attendance?

Children will respond differently to treatment and will not necessarily experience all of the following side effects. Which side effects a child has will depend on the type of cancer and the treatment they receive.

Infection

Chemotherapy lowers the immune system and can result in children picking up infections more readily. This should not stop children going back to school as the main sources of infection during this period of time is from their own body and not other children's germs. It is perfectly safe for the majority of children to return to school and enjoy their usual activities.

Nausea and vomiting

The child or young person may feel sick for 24 hours or more after chemotherapy. Anti-sickness drugs usually control this side effect. Any nausea and vomiting should be resolved before the individual returns to school.

Fatigue

Some children or young people may seem listless and lethargic when they first return to school. They often tire easily and suffer lapses in concentration. Parents and teachers may decide that they should attend school for just a couple of hours or so at first. Fatigue can be greatly underestimated. It is more than just being a bit tired, and can affect mood as well as energy levels. It may be beneficial for the child to have short bursts at activities with regular changes in task and expectation. Being flexible with school attendance can be really helpful.

Drowsiness

Radiotherapy to the head is given to children or young people with brain tumours. Between five and eight 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.

Eating difficulties

Children receiving chemotherapy may find eating difficult at times. They may be ravenously hungry and can wake parents at night demanding food and may put on weight. At other times, they may be unable to eat and lose weight. Some children who require intense chemotherapy may need a PEG (percutaneous endoscopic gastrostomy) inserted. This is a tube surgically inserted through their abdominal wall into the stomach when they cannot eat or cannot eat enough to meet nutritional requirements.

Weak ankles, aches and pains

These can be caused by some of the chemotherapy drugs and result in difficulties in walking or climbing stairs, lack of coordination and concentration, or problems with handwriting. Children or young people may need a 'buddy' to offer to carry their school bag and help them get around the 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 on a flexible basis to act as a scribe.

Change in physical appearance

Treatment can cause an obvious gain or loss in weight, swelling or puffiness of the face, ulcers around the mouth, and total or partial hair loss. All these side effects should reverse once treatment is stopped. Some children may return to school with nasogastric feeding tubes in place which they may feel very selfconscious about and can be the focus of other children staring. Rarely, they may have had a limb amputated or have scars from surgery.

Altered bowel habits

It is quite common for children and young people to experience changes in their bowel habits. Both diarrhoea and constipation can occur as a consequence of chemotherapy and can cause the child or young person to experience abdominal pain.

Having a 'pass' for the toilet and access to a separate, more private toilet may help in this situation.

Long-term effects of treatment and follow-up care

As more children are cured of their cancer, longer term adverse effects of treatment may become apparent called 'late effects'. It is estimated that there are at least 35,000 people alive in the UK having been diagnosed with a childhood cancer and survived more than five years.

Chemotherapy and radiotherapy can have direct effects on the following:

 growth hormone production, bone and developing tissues, all of which may affect the final height of the child - growth hormone replacement therapy is now widely used

- infertility or may affect other organs
- increased risk of developing a second cancer
- can affect the brain and central nervous system and these effects may gradually emerge as learning difficulties. Although pupils score within the usual intelligence range, they may fall behind their classmates in tasks that require memory and fast mental processing skills. Radiotherapy can have an effect on the individual's learning ability, particularly if they were very young when they had their treatment.

Children and young people who have had treatment for brain tumours may require extra support in the classroom (see page 22).

Emotional effects

During and after treatment, some children or young people may feel anxious or worried, not only about a possible relapse and further treatment, but also about what the future holds for them. As a result, they may:

- lose self-confidence
- become more emotional or tearful
- may express their frustrations through anti-social behaviour or tantrums
- may become more dependent on parents
- some drugs, particularly steroids, may make individuals more emotional and brain tumours can also have this effect
- children will miss time from school and this can leave young people feeling 'left out' and isolated.

At the end of treatment, children are often expected to be 'back to normal' but, in reality, they may remain at a considerable disadvantage. At this point, most children look forward to returning to their classroom's familiarity and normality but, in practice, this is the time that they can feel the most different from their peers. They have the dawning realisation that their experience has changed them.

Many require a lifetime of medical surveillance to check for recurrence of the disease, and late effects on their health caused by the cancer or its treatment.

"

I lost touch with a lot of my friends, and the effects of the illness and the treatment were a huge blow to my confidence. I put on a lot of weight and felt really selfconscious. Twice I tried to start college, but had to give up as I found it too hard to cope.

David, 16

Returning to school

Children and young people are encouraged to return to school as soon as possible. Through preparation and planning, this process can be made much easier to ensure a smooth transition back into school life for both the child and the teacher.

To help plan, teachers need to be aware of some of the main issues before the child returns to school:

- importance of confidentiality and communication
- importance of keeping up to date with work either at hospital or home
- understanding the main worries of a child or young person returning to school, both emotionally and physically.

A school visit is usually arranged. This will be offered by your pupil's nurse specialist, their local children's community nurse or CLIC Sargent social worker. Here, a pupil's diagnosis and treatment is discussed with realistic expectations of how much the pupil can be expected in school. Appointments at the hospital for either treatment or review will almost always fall in school time, so these absences need to be factored into support.

Alison, paediatric oncology clinical nurse specialist

While 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. Long absences can have enormous implications for educational progress, as well as relationships with friends.

Being in hospital and receiving treatment can be a very lonely and traumatic experience. So it is not surprising that most pupils are keen to get back to the familiar routine of school as soon as possible, helping them to rebuild their confidence and adjust to normal life.

However, some children, especially teenagers, may dread going back to school. This may be because of temporary or permanent changes in their appearance. They may worry that they have missed a lot of work, or that being away will have affected their relationships with their friends.



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 like she'd never been away!!

Jo, mum of Olivia (age 13)

Most children and young people will return to school after their initial course of treatment. Once the initial diagnosis has been made, parents and teachers need to work together to promote an appropriate learning environment for the child.

Initially, many children will return to school on a parttime basis. Returning to school needs to be planned and the child's clinical nurse specialist (CNS) or 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 examinations, should be considered early, and practical arrangements put in place.

It is important that teachers alert the pupil's medical team if the pupil is absent from school.



Learning in hospital or at home

Most children's cancer hospitals have education departments that can support the child while they are in hospital. It's even possible for children to take exams in hospital if necessary. Teaching staff at the hospital will contact you to make sure the young person can continue their schooling whenever they feel well enough.

Home tuition is helpful for some children who are not in hospital but are too ill to attend school. It can help the child catch up on missed work and prepare them for their return. But children are still encouraged to attend school now and then mainly for social reasons.

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

Being flexible is very important as plans may be made for a return to school and then the child has an unexpected period in hospital or home tuition may be set up only for parents and the child to decide they would rather attend school. Sometimes home tuition can run alongside part-time attendance in school.

Communication between the hospital, home tutor and school is key to ensuring education is appropriate.



Communication and confidentiality

With parents/carers

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 of the disease.

The child's nurse specialist and hospital teacher will, with the parents' permission, contact the school and liaise with the headteacher, special educational needs coordinators (SENCos) and classroom teachers.

A diagnosis of cancer is personal information and confidential to that child and their family. 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 informal meeting with the family to enable them to voice any concerns and allows you to ask some simple questions:

- ask how they would like information shared with other staff members and pupils eg. assembly, classroom talk or not at all
- ask what information they would like to be shared at every stage eg. 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.



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.

Older children are better able to understand what is happening and indeed 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 for the headteacher to disseminate the information correctly to the relevant staff. Not every member of staff needs to know every detail but a brief overview to inform dinner staff or supply teachers in line with the wishes of the family is beneficial. 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.

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



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 young person. It can be very hard for the pupil to field questions from their classmates such as "What is wrong with you?" or ""Why are you off school?". Simple and correct information is always better than inaccurate rumours outside of the classroom.

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.

"

The chance to do some schoolwork in hospital is not only important academically but can also distract the child from their situation. Carrying out the same work as their peers can help them to feel in tune with what their friends are doing.

Tracey, Hospital Teacher

School friends may find the CCLG leaflet entitled: 'I have a friend who has cancer' useful.



Teaching siblings of a child who has cancer

A cancer diagnosis can cause strong and often conflicting feelings in siblings of the child or young person. 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 for their sibling's illness or that they are not doing enough to help. Many brothers and sisters keep their feelings bottled up inside to avoid worrying their parents.

Often, the place where siblings may show how they feel is at school. They may:

- withdraw and become very quiet
- feel ill with psychsomatic symptoms such as aches and pains or ignore genuine ones to avoid worrying their parents
- become disruptive in class
- cry easily
- become frustrated and have outbursts of anger
- fall behind in class work
- get lower marks than usual
- start missing school
- become rebellious towards teachers
- have arguments and fights with friends and other children in their class

It is important that all teachers in school are aware of pupils who have a brother or sister with cancer, so that 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 CNS, keyworker or social worker would liaise with the sibling's 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.

Emergencies

In preparation for the pupil returning to school, the clinical nurse specialist or the pupil's key worker will often help draw up a care plan. This should offer guidance on how to respond to potential problems. The child or young person is at risk of infection so more absences can occur if a child has a high temperature and needs to go to hospital for assessment. Other concerns may include nose bleeds, central lines being pulled or vomiting up a nasogastric tube.

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.

Measles, chicken pox and shingles

As chemotherapy suppresses the immune system, chicken pox and measles are especially dangerous to children being treated for cancer. Schools will be asked to be vigilant and inform the child's parents immediately if an outbreak occurs. It is important for schools to 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.



An example of a letter sent to all parents regarding measles, chicken pox and shingles.

> 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 (age 7)

Dear Parents

Measles, chicken pox and shingles

Please may we ask for your co-operation in an important matter.

One of our pupils is receiving medical treatment for cancer which puts them at risk if they are exposed to measles, chicken pox or shingles.

Please let us know immediately if your child is suspected of having measles.

Our pupil is also at risk from chicken pox and would need to be given an injection within three days of contact. If your child is suspected of having chicken pox, you should let us know.

It is also important that you let us know if there is shingles in your household.

Your child is not at any risk whatsoever from this situation. However, the health and wellbeing of our pupil who is at risk, does depend on the co-operation of all other parents and we hope you can help us.

With many thanks.

Yours sincerely

Head Teacher

Brain tumours and educational support

Children with cancer can have long absences from school therefore it is inevitable that their literacy and mathematical skills can fall behind others of the same age. However, children and young people with brain tumours may also have difficulties in a number of other areas and these children might benefit from being assessed for an EHC plan.

Specific issues for the child with a brain tumour might include:

- balance and coordination problems
- social functioning eg. ability to make friends, reading social cues, socially inappropriate behaviour
- hormonal imbalance and growth problems
- speech and communication eg. slurred speech, difficulties in comprehension and expression
- vision
- hearing
- memory
- concentration and attention
- learning problems
- behavioural problems such as anger are rare but need careful assessment.

All of the above can affect daily classroom tasks such as writing and taking part in PE as well as social integration with school friends. Allowances for this should be made when planning homework, lessons, revision and taking exams. See page 39 for further resources.

Education, Health and Care Plans (EHC)

An EHC plan looks at all of the child's needs across education, health and social care. It ensures the child receives the right amount of support by engaging all professionals involved in the child's care as well as parents, carers and young people themselves. The plan can start from a child's birth and continue onto further education and training, for some young people until they are 25 years old. They replace the previous Statements of Educational Needs and were introduced in September 2014.

The EHC plans do not relate to all children with a diagnosis of cancer but those with special educational needs. An assessment will need to be requested by the school, hospital or parents and is carried out by the local authority. For more information, please visit the **GOV.UK** website.



What are the main worries for children and teenagers with cancer returning to school?

Going back to school can be daunting for the child. They may lack confidence and motivation while also coping with low energy levels after treatment. They will have a variety of worries and emotional issues.

Physical appearance

Children and young people can feel very self-conscious about their looks, especially their hair loss, or if they have put on or lost a lot of weight. Wearing a wig, hat or bandana can help. Some children and young people may not want classmates to know if they are wearing a wig and it is important teachers are sensitive to this.

Changes in appearance can be a source of extreme anxiety, even to the extent that a child wants to withdraw from school until their confidence in their appearance returns. It is important that teachers recognise if a child is anxious about this, and gives 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.

All the other girls were busy shaving their legs and I was waiting for my hair to grow back! I think it may have been this lack of 'keeping up' that made my female friends less keen on me

Kat, adult survivor of cancer

Falling behind with 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. Most children will welcome school work to relieve the boredom. This can be planned and co-ordinated by the child's class teacher. The pupil's clinical nurse specialist can help the teacher with understanding the health needs.

Young people with important exams to sit such as GCSEs may have letters to support applications for special consideration provided by their hospital consultant for the examining board. These need to be given to the school's examination officer in good time prior to the exams starting. Hospitals can arrange for exams to be taken while in hospital and occasionally exams can be invigilated at home.

A school meeting is very useful where the child's nurse specialist or local children's community nurse can come into school to discuss the child's treatment and education.

> I had to take some of my GCSE exams at home because I was immunosuppressed. I remember my Physics teacher ringing me up on the day of the exam, giving me a pep talk and checking if I had any last minute questions. They really went above and beyond the call of duty for me.

Beth, survivor (age 17)

"

Some don't engage with their peer group, one of the worries is about changes in their appearance; they may have lost confidence and feel worried about talking to their friends about their illness. Going through something like this is very isolating for families.

Sam, CLIC Sargent social worker



Physical limitations

This may restrict them from taking an active part in sports and other activities and can make them feel frustrated and left out. Tiredness can also be a problem after treatment.

Teachers can make up for this by setting special, 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 have problems coordinating eye movement, so it is important to find the best place in the classroom for them. They may also suffer short-term memory loss, which usually improves after a while.

Mobility

Following 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 a major obstacle and ramps may be helpful for a child in a wheelchair, but be too steep for those with physical problems. Children may be vulnerable to being pushed over or knocked by others so consideration of children's safety in the playground needs to be discussed.

Most children are able to do PE although for some, participation may be problematic. Nonetheless 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.

Bullying

Changes in physical appearance may induce a fear of being teased or bullied, which increases an individual's reluctance to return to school. Preparing the classmates for the individual's return can help provide a reassuring and caring environment and promote peer support.

Bullying by older or younger children can be a problem and should be firmly dealt with immediately. The pupil's nurse specialist, social worker, youth workers and educators can all provide advice and support with managing bullying issues. Some of these professionals can come into schools and provide class or assembly discussions to help other pupils understand the issues.

It is important that schools have a strong antibullying policy in place which is strictly enforced.

Ben had some fantastic friends who always looked after him, and 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 (age 7)

Fear

Children may know they are very ill and be afraid that they could die, but may be too scared to talk to their parents or teachers. They may want to avoid causing further distress. Sometimes an independent counsellor or psychologist can help relieve anxiety and ease communication about very difficult issues between members of a family.

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 rather negative changes are not typical of all children as some seem to become more grown up and appear emotionally stronger than previously.

Friends may find it hard to cope with changes. Like adults, friends may be uncertain what to say to the sick child. 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.

"

It was really hard knowing a friend as close as Liv was going through something so horrible. We were all behind her no matter what. However, a book like this would have helped us to understand how she felt and what she was going through.

Katie, school friend of Olivia

School friends may find the CCLG leaflet entitled: 'I have a friend who has cancer' useful.



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

Frequently asked questions by teac

How much should I expect from my pupil in relation to schoolwork?

This is one of the most difficult questions for teachers. As a general rule, you should expect the same academic standards as before. However, children and young people with a brain tumour may experience difficulties in a number of areas (see page 22) 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 your 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 would then take their child to their local hospital for medical review.

What about discipline?

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 the child...

...still go on school trips?

It is important to include the child in as many class functions as possible (such as 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. It is valuable for children to have these experiences with the rest of their class and this will involve working closely with parents. Children become very dependent on their parents when they are ill, and may be anxious about going on a trip by themselves.

...still do PE?

Yes, unless the doctor has advised otherwise. Most children enjoy physical activity, and those with cancer 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. Some pupils may need to have short rests during the day.

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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 (age 16)

Who else should know about the child's illness?

All teachers at the school, including supply teachers, should know and be aware of important issues for the child or young person.

It is also a good idea to explain the cancer in simple unemotional terms to the rest of the class, before the pupil returns to school. This can lessen the chances of teasing.

But remember always ask the parents before informing anyone at the school and with older children give them the choice on this themselves.

How can home tuition be arranged?

If a child or young person is unable to attend school because of their health then home tuition may be arranged for a short period of time, through liaison with the hospital teacher. The hospital teacher is advised by the child's medical team if home tuition is appropriate and will communicate this to the school. Schools should be able to refer to the service providing home tuition within their local authority and liaise closely with the home teacher to provide current appropriate work for the pupil.

Regular reviews with the pupil can be helpful to monitor progress, or any difficulties with class work or homework. This is especially helpful where pupils have had a long absence from school. Some pupils may find it hard to 'seek out' a staff member so a regular slot, if agreed with the pupil, can help.

Pastoral care

It is important to identify one member of staff in whom the child or young person can confide, who will have the time to listen and give support when needed. Some schools find that the most practical person for this is a non-academic member of staff as they may be more available during the school day if they are needed. This person can develop a nurturing relationship with



the pupil as soon as they attend school during their treatment even if the visit is purely a social one. Your local authority will able to provide their education policy on children and young people with medical needs.

What about special diets?

Some children or young people may have a poor appetite, while others often feel ravenously hungry. Changes in appetite are likely to affect the individual's weight and shape. These problems may be related to the disease itself, or be temporary side effects of treatment. For some children and young people particular foods may be restricted during treatment. The child or young person's key worker will be able to inform you about these. Discuss any concerns that you have about diet with the parents.

Retaking a school year

Retaking a school year is discouraged as it is deemed more beneficial in terms of social integration and overall wellbeing for the child to remain 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.

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 (age 16)

Paediatric Oncology Clinical Nurse Specialist/Specialist Nurses

Based in all children's principal treatment centres and children's community nursing teams, these specialist nurses liaise with GPs and other members of the primary health care team and with schools and nurseries. With parental consent, they can provide information on individual children and young people, allaying anxieties and answering questions, not only on the sick child but also on siblings. They can also provide help and guidance, if asked, on how schools can prepare classmates for the pupil's return to school.

CLIC Sargent social workers

Specialist social workers provide financial, emotional and practical support for children, young people and their families during treatment and are based within principal treatment centres. Social workers will liaise when necessary to ensure children and young people retain links with their school or college so disruption to their education and friendships is minimised.

What happens if the child cannot be cured?

If a child or young person becomes terminally ill, a health professional (nurse specialist or social worker) will contact the school and discuss how best to prepare and support the pupils and staff. Some local authorities have a bereavement specialist on the 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, they may want to continue to engage with school.

What support can I get from professionals?

Some hospital education services provide sessions for professionals involved with the education of children with cancer.

The CCLG leaflet entitled: 'Bereavement: Sources of help and support' has a useful section on how schools can help when a pupil has died from cancer.



How can I help my pupil?

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



After diagnosis

Keep in touch with the parents

- Keep in regular contact with the child's parents and listen to what the parents have to say about their fears and concerns. Discuss any worries or potential problems the child or young person might have on returning to school. Be aware that this situation is new for parents and they may not be able to answer many questions.
- Ask the parents how much the child or young person knows about the cancer and how much information they would like you to pass on to others at the school. It might help to point out that all members of staff should know about the illness, and that classmates can be a great source of support when the child returns.
- Ensure that any automatically generated texts or phone calls about absence are stopped as these can be both irritating and upsetting for families.

• Keep the child and family up to date with what is happening in school and any special events that are coming up if the child is well enough to take part. If the school has a newsletter, make sure the family receives it together with any other letters that might be of interest to them. This helps to keep the child and family included.

Keep in touch with the child

- Visit the child in hospital and later at home, and perhaps bring along one or two classmates, if the child or young person agrees.
- Some schools have set up skype for children to keep in touch with their class and it may be a good idea to regularly remind children to keep in contact with their friend after the initial absence. Regular messaging apps, social media, text messages, letters and cards are a good means of keeping in touch and will help the individual feel part of the class and be keen to get back to school again.

Keep in touch with the hospital school or home tutor

- Regularly communicate with the hospital school and/ or home tutor and ensure suitable school work is sent to them and that you are up to date with the child's academic progress.
- Discuss the basic medical facts about your pupil with your pupil's nurse specialist or hospital teacher. It is common policy for teachers to be contacted directly by a member of the hospital team shortly after diagnosis. If you are the teacher liaising with the parents, try to become familiar with the treatments given and their effects on school performance.
- It is important to be vigilant about children's reactions at this point as any problems need to be dealt with promptly. Teaching assistants might be in a better position to monitor reactions and listen to what children are saying amongst themselves after any discussion. Be aware that pupils may have experience of cancer in their home lives that may have had a negative outcome.

Preparing the class

- Continue to call the child's name on the register to help classmates to remember that their friend is still included in the class.
- Keep a child's seat and tray in class. In September, when classes change, offer visits to the new classroom and an opportunity to meet the new teacher. Be especially thoughtful around transitions to secondary school or to a new key stage.
- Sensitively prepare the class for the physical and emotional changes in the child or young person and suggest ways to be helpful. It might be a good idea to explore the possibility of arranging a school assembly for myth-busting purposes and to increase awareness.

You may find CLIC Sargent's practical pack entitled 'Cancer and school life' helpful when talking to the class



Looking after the child at school

Keep school life as normal as possible

- The child should continue to be in the same classroom as other peers and to continue to do normal activities where possible. Separating a child from their class and friends results in alienation and isolation.
- Identify a key person at school who the child can see on a regular basis to review progress and discuss any worries.
- The child's condition should only be explained to the rest of the class with the parental or young person permission.
- Ensure all staff know special arrangements that are in place for the child so there are no misunderstandings or embarrassments for the child.

Practical issues

- Check that the child will have easy access to classrooms, toilets, the dining room and playground. If necessary, try to arrange for the child to leave the class five minutes early to avoid the rush.
- If the child has to remain inside during breaks and lunchtimes, organise any extra supervision that may be needed.
- Explore the possibility of allowing the child to leave five minutes earlier to avoid the 'corridor crush' in between lessons and at the end of the day. This may be more appropriate at secondary school.

What to look out for

- Try to recognise if the child is having problems with mobility, fatigue, lack of concentration or other effects of their illness or treatment.
- Keep a watchful eye on interactions in the playground and strictly enforce any anti-bullying rules.
- Have discussions about appropriate behaviour, assertiveness and role play in the context of PSHE or Citizenship classes.

Be flexible

- Be flexible about work; be supportive and encouraging. Most children and young people who have been in hospital are very keen to catch up. If possible, arrange a catch-up session with a teacher or tutor where possible.
- Be flexible about visits to the toilet, snacking, wearing a hat and so on.
- Consider a phased return transition with flexible or fewer hours as children and teenagers return to school.

If the child is tired

- If the child has concentration lapses, break the work down into small chunks and use lots of visual aids and practical tasks.
- Consider ways of dealing with fatigue such as offering quiet 'time out' areas such as the library, frequent rests and reducing the timetable.
- If a child needs some time out during the school day, ensure they know who and where to go to. A 'plan b' is also useful for days that arrangements need to change or when designated staff are absent.

Looking after brothers and sisters

- Support brothers and sisters of the child with cancer. It is usually a good idea to encourage children to talk about their brother or sister who has cancer, but be aware that they may be struggling with the situation themselves and may not want to constantly talk about it.
- Be vigilant to any difficulties such as homework not completed, things forgotten and being very tired.
 When siblings move school, ensure that the new school is fully aware of the situation even if the sibling with cancer has returned to school.

Use lots of praise and encouragement to motivate and engage the child back into school life. This will go a long way to building their confidence and enabling them to reach their goals! 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, adult survivor of cancer

Further information

Medical terms explained

Alopecia Loss of hair

Anaemia

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

Anaesthetic

Drug which stops feeling, especially pain. A general anaesthetic makes you unconscious. A local anaesthetic stops feeling in one part of the body.

Anorexia Lack or loss of appetite

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.

Catheter

Tube that is passed into the body to drain fluid

Central line (Hickman line, Port-a-cath) Long plastic tube that is inserted into a large vein near the heart under anaesthetic. Central lines are used to take blood samples and give drugs.

Central nervous system Consists of the brain and spinal cord

Cerebellum Part of the brain that controls balance and complex actions

Cerebral hemispheres

Together the two cerebral hemispheres form the cerebrum. The right hemisphere controls the muscles of the left side of the body, and the left hemisphere controls the right side of the body, and is also involved in emotion and language.

Cerebrospinal fluid

The fluids produced within the brain that circulates around the brain and spinal cord

Chemotherapy Treatment using one or more anti-cancer drugs

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

Hydrocephalus

An increased accumulation of cerebrospinal fluid in and around the brain. It can be caused by a brain tumour and is relieved by a simple surgical procedure called a shunt.

Immunity

Resisting infection. The body activates the immune response when it is invaded by bacteria or viruses. Once the body has been exposed to a disease, it remembers it. If the disease should invade again, the immune system can react very quickly and keep the disease at bay 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

Magnetic resonance imaging (MRI) scan Uses magnetic waves rather than radiation to produce a picture for diagnosis and monitoring treatment

Malignant Cancerous

Meninges Thin membranes that protect the brain and spinal cord

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

Paediatric oncology CNS Paediatric oncology clinical nurse specialist. Visits schools, updates teachers and talks to classes.

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 Pyrexia An elevated body temperature

Radiotherapy The use of radiation to treat the cancer

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

SENCo A school's special educational needs co-ordinator

Shunt

A shunt is a long, thin tube placed in to the brain and then threaded under the skin to another part of the body - usually the abdomen (tummy). It works like a drainpipe, carrying excess fluid away from the brain.

Tumour

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

Ultrasound scan

The use of ultrasound waves to produce a picture for diagnosis and for monitoring treatment

Useful organisations

Children's Cancer & Leukaemia Group (CCLG)

www.cclg.org.uk

CCLG members together with other professionals are responsible for organising cancer treatment for children in the UK and are dedicated to improving best practice and outcomes. We support research and also provide accredited information for patients and families.

CLIC Sargent

www.clicsargent.org.uk Tel: 0300 330 0803 Provides practical support and advice for children and young people affected by childhood cancer and their families and offers accredited information for patients.

Macmillan Cancer Support

www.macmillan.org.uk 0808 808 00 00 Provides practical, medical and financial support to anyone who is affected by cancer.

Cancer Research UK

www.cancerhelp.org.uk Tel: 0808 800 4040 Information on all cancer types and a key funder of research into cancer.

Child Bereavement UK

www.childbereavement.org.uk Tel: 01494 568900 Offers support and information for schools when a child dies.

Child Brain Injury Trust

www.childbraininjurytrust.org.uk Tel: 01869 341075 Provides advice for children who are affected by a brain injury.

Childhood Eye Cancer Trust

www.chect.org.uk Tel: 020 7377 5578 Information and advice for families affected by childhood eye cancer retinoblastoma.

Leukaemia and Lymphoma Research

www.beatingbloodcancers.org.uk Tel: 0207 405 0101 Aims to improve the lives of patients with all types of blood cancer.

Neuroblastoma Society

www.nsoc.co.uk Tel: 020 8940 4353 Raises funds for research into the disease and offers support and information for anyone affected by neuroblastoma.

Sarcoma UK

www.sarcoma.org.uk Main charity in UK dealing with all types of sarcoma.

Teenage Cancer Trust

www.teenagecancertrust.org Raise funds and supports teenagers fighting cancer.

The Brain Tumour Charity

www.thebraintumourcharity.org Tel: 0808 800 0004 Dedicated to saving lives through research, information, awareness and policy.

Useful resources about childhood cancer

For teachers

Cancer and school life pack (published by CLIC Sargent, 2014) Helping brothers and sisters (published by CCLG, 2014) 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, 2006) Bereavement: Sources of help and support (published by CCLG, 2015)

For children and young people

There is a comprehensive range of free publications available for children and young people with cancer and their families from a number of Information Standard accredited organisations. These may help when explaining childhood cancer during class.

Children's Cancer & Leukaemia Group

(www.cclg.org.uk)
An award-winning accredited publisher of information
booklets on childhood cancer. Titles include:
My brother or sister has cancer (younger children)
When your brother or sister gets cancer (older children)
Ben's stem cell transplant (younger children)
I have a friend who has cancer (school friends aged 10-16 years old)

CLIC Sargent

(www.clicsargent.org.uk) Mary has a brain tumour Joe has leukaemia Lucy has a tumour Tom has lymphoma

All booklets are free and can be downloaded or ordered online.



Children's Cancer and Leukaemia Group is a leading children's cancer charity and the UK and Ireland's professional association for those involved in the treatment and care of children with cancer. Each week in the UK and Ireland, more than 30 children are diagnosed. Two out of ten children will not survive their disease.

We bring together childhood cancer professionals to ensure all children receive the best possible treatment and care. We fund and support research into childhood cancers, and we help young patients and their families with our expert, high quality and award-winning information resources.

If you have any comments on this booklet, please contact us at the address below.

CCLG publications on a variety of topics related to children's cancer are available to order or download free of charge from our website.

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Registered Charity number: 286669