



The Royal Marsden
NHS Foundation Trust



Specialist Schools
and Academies Trust
EXCELLENCE AND DIVERSITY

Education and cancer

A guide for teachers



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The Royal Marsden was the world's first cancer hospital. Today with our academic partner, The Institute of Cancer Research, we form the largest comprehensive cancer centre in Europe treating over 40,000 patients a year from across the UK and abroad. A pioneer in cancer diagnostics, treatment and research we are committed to providing our patients with the best cancer care anywhere in the world.

The Specialist Schools and Academies Trust

works to give practical support to the transformation of secondary education in England by building and enabling a world-class network of innovative, high performing secondary schools in partnership with business and the wider community.

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Education and cancer

A guide for teachers

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Foreword

This publication has been developed in a partnership between the Children and Young People Unit at The Royal Marsden NHS Foundation Trust and the Specialist Schools and Academies Trust.

Both organisations are passionately committed to the welfare and education of all children and share a conviction that the recommendations and examples of good practice in this resource will benefit and inspire all pupils with cancer and their teachers in secondary schools and colleges.

As the leading UK specialist cancer centre, The Royal Marsden is keen to share good models of patient support and clinical practice. Some have already been adopted by treatment centres and schools where a pupil has cancer. This guide is intended to complement outreach service to schools on behalf of young patients, by enabling teachers to support pupils, and the school community, more effectively during and after treatment for cancer.

The Royal Marsden is indebted to the patients, families and teachers who have responded to its research and shared their stories.

The Specialist Schools and Academies Trust is delighted to extend its academic alliances and its community partnerships to include this collaborative project with The Royal Marsden. As part of its work, the SSAT seeks to develop networks in education that support schools and teachers in their efforts to ensure that every learner receives the high quality education that all young people deserve. Its commitment to the Every Child Matters agenda and to multi-agency working make this partnership with The Royal Marsden Hospital a most welcome step forward.

Elizabeth Reid
Chief Executive,
Specialist Schools
and Academies Trust

Bette Petersen Broyd
The Royal Marsden
NHS Foundation Trust

Audience

Teachers and leaders in schools wishing to work effectively and sensitively with pupils who undergo treatment for cancer.

Aims

- To enable teachers to respond to a pupil's needs with empathy, confidence and success
- To address issues relating to the pupil with cancer, parents, siblings, classmates, subject teachers and support staff
- To update teachers on the facts about cancer in children and young people, their treatment patterns, side-effects, quality of life and long term outlook
- To provide insights into specific problems associated with treatment for cancer and to equip teachers with practical strategies
- To suggest a strong framework of support for a pupil with cancer by disseminating good practice among colleagues and teaching pupils how they can help a fellow classmate with a serious illness
- To show how meeting the needs of a sick or recovering pupil can support a successful return to education and eventual achievement of their potential

01

Introduction

How to use this guide

Teachers

This guide is specifically aimed at teachers in secondary schools and colleges. However, many of the suggested strategies are easily adapted to the primary school context, and we hope that teachers will extract and adapt the sections they find useful.

We trust that the teacher identified as the link person for a pupil with cancer will disseminate our recommendations and ensure that all colleagues are informed of how best to meet the pupil's needs. This should of course comply with the family's wishes on confidentiality.

Sections of specific relevance to a pupil's situation can be photocopied or distributed electronically to individual subject teachers. We propose that this information forms part of a teacher's insight into how best to include a pupil both socially and academically and to aid the differentiation in lesson planning.

The 'Checklist for schools' section found on pages 96–97 of this publication, is a prompt for teachers to ensure that they have considered and, where appropriate, acted on guidance about how best to support a pupil with cancer.

We encourage teachers and support staff to share information widely but safely.

Health professionals

We suggest that the 'Pupil details' form, found on page 94 of this publication, is filled in by a health professional to ensure the information about the diagnosis and treatment of a pupil is correct and informative.

See chapter 6 – Information and support, found on page 86.

This guide is available as a downloadable pdf from www.royalmarsden.nhs.uk/RMH/patients/forchildren or from www.schoolsnetwork.org.uk/academies

A separate publication for pupils diagnosed with a brain tumour is also available.



Aims

A diagnosis of cancer is devastating for any child or young person and their family. The usual routines of school and family life are turned upside down and the future can seem impossible to contemplate as it holds so many fears and uncertainties.

The teachers and fellow classmates of a recently diagnosed pupil are likely to feel a similar sense of shock and disbelief. Most are unlikely to have had any experience of cancer in someone of school age and may initially suspect the worst. This can lead to a feeling of powerlessness and a notion, usually misguided, that the family should be respectfully left alone to deal with their misfortune.

School represents normal life to most children and young adults. It offers opportunities to socialise, to engage with their peers and to benefit from the rewards and stimulations of learning and being a part of a greater community. Keeping these vital aspects of a pupil's normal life alive can greatly reduce their feeling of isolation and loneliness during their illness and time in hospital. It can also act as an aid to recovery for the young person to feel included and to have clear academic goals which reaffirm a belief in a fulfilling future.

This publication aims to guide teachers faced with the task of supporting a pupil while absent from school with a serious illness and during the difficult time afterwards. It explains some aspects of what the pupil may be going through both medically and psychologically. It also offers some practical strategies for ensuring a swift and supportive reintegration to school life after a long or debilitating absence. Suggestions are included for how teachers can provide sustained and targeted support for pupils who face extended treatments, devastating long term side-effects or an uncertain future.

A multidisciplinary group of experienced professionals at the Royal Marsden Hospital have carried out research into the educational experience of patients during and after treatment. Its recommendations are based on interviews with pupils and their parents/carers and teachers, on questionnaires and lesson observations and on ongoing supportive outreach work to schools, and on liaison with other UK treatment centres.

Many teachers will recognise methods and processes they already use successfully in class. However, the authors hope this collection of strategies and ideas will encourage teachers to use their creativity and empathy to provide just the right combination of help and targeted support that their pupils will need in order to reintegrate into school life and to reach their full potential.

01

Some facts about cancer

A diagnosis of cancer in a child or young person of school age is relatively rare. Each year some 2000 children and young people are diagnosed with cancer in the UK. About 1000 new cases are in the secondary school age group, 11 to 18. This number remains relatively constant from year to year and means that there is about a 1 in 600 chance of a pupil being diagnosed and treated for cancer.

The types of cancer that affect children and young people are generally very different from those found in adults. Different cancers have different biology, they occur in different parts of the body and they respond differently to treatment. Consequently the treatment and cure rates also vary. Children's cure rates are much higher than those for adults, even for cancers that may appear similar.

For teachers it is very important to stress these differences when speaking to their class about cancer. Many pupils will know of an adult who has had cancer and perhaps died from it. They may make a false assumption that if someone they know with a particular cancer had a poor outcome it will inevitably be the same for their newly diagnosed classmate. Others may presume that a diagnosis of cancer is always linked to smoking.

Causes of cancer in children

The cause of most cancers remains unknown, although a small proportion of children are born with an increased risk. In general cancer occurs when a cell in the body becomes out of control and begins to multiply. These cells stop working properly and as their numbers increase they form a lump or tumour. If the cancer cells break away and spread to other parts of the body they may produce secondary tumours known as metastases. When the cancer arises in a white blood cell, this is called leukaemia or lymphoma.



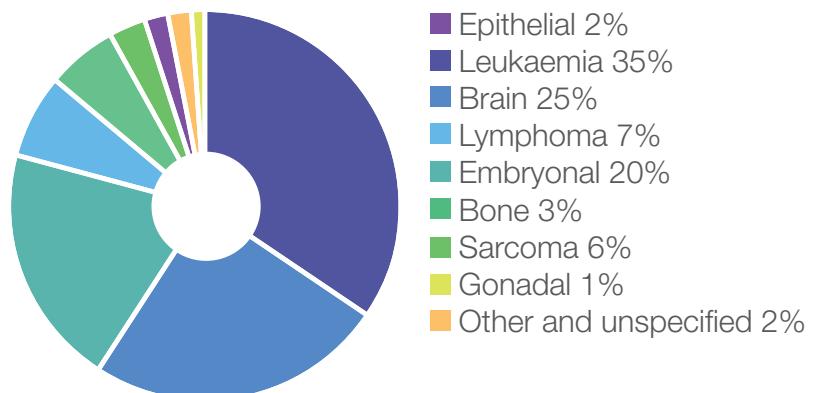
Dispel assumptions

Teachers may need to explain to their class that cancer is not infectious and that being near someone with cancer is in no way dangerous to them. However, it can be life threatening for the pupil being treated for cancer to be near anyone with measles, chicken pox or shingles if they become infected.

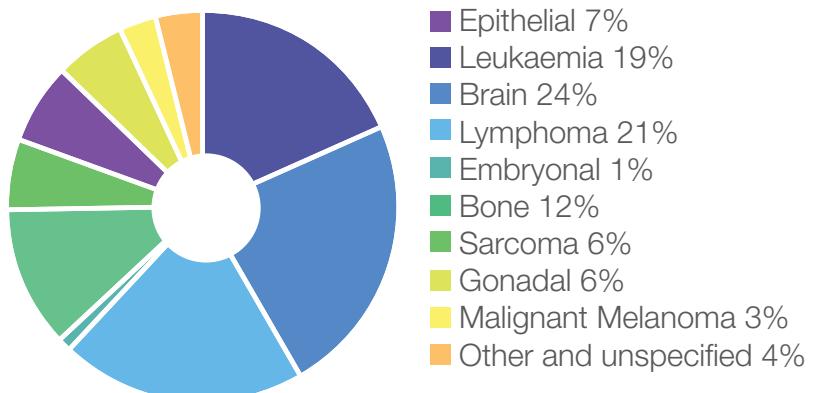
Cancers are not infectious. In children and young people, as in adults, they are unlikely to be inherited. It is exceptionally rare for several children in any one family to develop cancer. Neither parent nor anyone else is to blame because of what they did or did not do. There has been extensive research into the potential impact of environmental risk factors but they have failed to show any clear cut evidence of a link. This is unlike adult cancers, where for instance smoking is a proven risk factor.

The types of cancer that affect children and young people are generally very different from those found in adults.

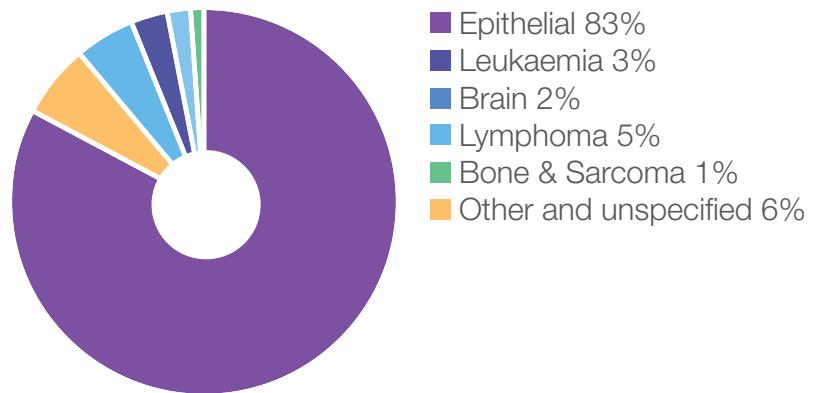
Cancer incidence in children 0–9 years



Cancer incidence in children 10–17 years



Cancer incidence in adults



01

Outlook

The incidence of cancer in children and young people is relatively stable. Some cancers show a small increase, of approximately 1% per year. However, the number of cancer survivors has increased dramatically due to the substantial improvement in cure rates over the past 40 years caused by advances in research and treatment. These days, children and young people have a cure rate of over 70% overall compared with less than 30% in the 1960s. Some individual cancers have a cure rate of more than 90%, although some others have a much poorer prognosis.

With increased cure rates, the long term effects of treatment are ever more important. Issues relating to long term survival must be addressed so the individual pupil's needs can be met as they return to education. The aim is to fulfill their potential with the expectation of a full and normal lifespan.



Be encouraging

Teachers may want to impress on their pupils that just because someone has been diagnosed with cancer does not stop them from being the person they are.

'Back in the 1950s a diagnosis of cancer was a virtual death sentence. Now the overall cure rates in children and adolescents are about 75% and rising.'

Consultant in children's oncology



The role of the teacher

As a teacher there is a great deal that you can do to help and support your pupil with cancer and the family, both during treatment and in the months and years to follow. It can be difficult to gauge the appropriate level of contact and how much support is needed and welcomed by the family. Their views and your perception of the situation are likely to be constantly shifting according to the stage of the illness, the severity of the treatment and the pupil's overall prognosis.

The school should ensure good, open lines of communication with the family at all times in order to determine how the school can support the pupil's education and ensure overall social and academic inclusion. It should have a policy outlining the approach to pupils with medical needs.

Work from school

One of the first and most important tasks is to establish an appropriate flow of work for the pupil to get on with when they are feeling well enough. As pupils are likely to be in and out of hospitals with periods of recovery at home it is advisable to pass the work directly on to the pupil and parents/carers. In some cases the work can be supported by the hospital school or a home tuition service, in which case close liaison between all parties is needed.

Help from school

In many homes and hospitals pupils will be able to connect to a wireless network. This enables work to be shared directly between the school and the pupil, hospital teacher or home tutor. Some schools find it useful to provide the pupil with a school laptop for the duration of their illness.

Provision of work is in line with official guidance: '**All pupils should continue to have access to as much education as their medical condition allows so that they are able to maintain the momentum of their education and to keep up with their studies.**' (Department for Children, Schools and Families: *Access to education for children and young people with medical needs*, 2003)

The following pages outline the host of different ways in which the teacher can support the welfare of a pupil after diagnosis and treatment for cancer.

02

When first diagnosed

Keeping in touch

When a pupil is diagnosed with cancer, the school's first task is to think about the best way to communicate with the family, other pupils and the teachers. The class teacher will need to take the lead from the pupil and parents on how much contact they would welcome and how wide a circle of teachers and pupils they feel should be informed.

Immediately after diagnosis the family is usually in severe shock. They may not want to share much information with the school while they are still trying to come to terms with the initial trauma. However, many families find that once the treatment has started and they have adjusted to the overwhelming situation, they may welcome the opportunity to share information and be receptive to contact from teachers and pupils. It is crucial that a teacher is named as the liaison person with the family in order to ensure ease of communication. This should minimise the need to repeat information and so lessen the burden on the family. Families usually welcome the school showing concern for the pupil's wellbeing.

Other pupils can do a great deal to make sure their friend still feels part of the school community:

- Send get well cards and letters – individually or as a class – at regular intervals
- Send texts, emails or social network messages
- Send photographs or make a video diary
- Visit the patient – small groups are best. Check first if it is acceptable to the family and the hospital
- Continue inviting them to activities and parties; they may be able to pop in for a little while – if not, perhaps next time

Pupils may need to be reminded that if they do not get a response to a card or text it does not mean that their gesture was not welcome. They should continue to include and support their absent friend, who is probably delighted to receive their messages but too ill or preoccupied to respond.



Teachers could:

- Continue to call the name on the register – it helps the class to remember their friend and often sparks off impromptu updates
- Send circular letters home – keep the family informed and included
- Support the siblings
- Keep in regular contact with the parents and bring teachers and pupils up to date (if agreed by the family)
- Sensitively communicate changes to the sick pupil's appearance or behaviour, where appropriate
- Arrange for suitable work to be sent to the family, hospital school or home tutor

'The teachers have been fantastic, flexible and so accommodating.'

Leon's mum

'It upset me that some teachers did not seem to know my situation. I had to keep explaining things – the last thing I wanted to do!'

Mark, age 12

02

A member of staff at the treatment centre or a community nurse may, with parental permission, get in touch with teachers to discuss the following:

- **Treatment plan:** an outline of the treatment plan with suggestions as to when the pupil may feel able to do some work or attend school, either full time or part time
- **Attendance:** encouraging the school to welcome the pupil whenever they feel well enough and it is medically safe to do so – as advised by a medical practitioner. This could result in a temporary ‘come and go as you please’ policy. The educational welfare officer should be notified about the nature of the absence
- **School rules:** allowing rules to be relaxed temporarily for the pupil so that he or she feels able to attend school. This could include: allowing hats, wigs, caps and bandannas; leaving class when in need of rest, medication or toilet; drinking water or snacking in class; staying inside during breaks (with a friend to keep them company); moving between classes when the corridors are empty
- **School work:** patients are encouraged to keep up with their school work as much as they feel able. It is useful to send them work in their favourite or key subjects. This gives the pupil a chance to keep up and feel included. Many patients will have access to a hospital school and to the internet. The patients will need to have the work made available to them early on, so they can work whenever able to. Delays can lead to patients feeling rejected or unimportant. They need to know that everyone has confidence in their future
- **Exams:** access arrangements and special consideration in exams may need to be discussed with the pupil, parents, examinations officer and hospital teachers or home tutors
- **Home tuition:** it is best to apply as early as possible if home tuition is recommended by the pupil’s consultant
- **Measles and chicken pox:** these can be life threatening to someone whose immune system is suppressed during treatment. It is strongly advised that schools should check for the need to send out a letter to all families whose children mix with the sick pupil. The letter should ask them to inform the school immediately if they suspect anyone of having either chicken pox or measles.

See page 93 for a proforma letter schools can adapt to their needs.

- **Support:** some pupils may need learning support when they first return to school. This should be discussed with the family and hospital staff
- **Contact:** professionals at the treatment centre can help you with questions or issues of concern – within confidentiality rules. If it is difficult to obtain the family’s permission it is possible to ask generic questions that do not require discussion of a pupil’s particular situation

Communication with the family

Open lines of communication with the family are an essential part of good educational practice. Parents are the experts on how their children function at home and so have insights into some of the strengths or internal struggles that may be masked at school. Parents can be invaluable allies to teachers in helping the pupils to meet their needs and realise their potential, both educationally and socially.

It is important that the parents and teachers align their expectations of the pupil. After diagnosis and treatment for a serious illness, there is a clear need to protect and accommodate the changing needs of a sick child. However, those needs will have to be updated regularly in light of how the treatment progresses. Either party could otherwise end up having inappropriate expectations, overcompensating a capable pupil or disregarding genuine need.

Both parents and teachers may be reluctant to share their concerns and observations frankly for fear of appearing demanding, anxious or inappropriate. The pupil may also be very reluctant to communicate openly about their illness or difficulties. They usually want to be treated 'normally' and to avoid any potentially stigmatising effects of illness.



'Mr Field rang us every Monday for an update. It was good of him and very reassuring. We could chat about all our concerns and worries.' Tim's parents

02

When having a talk with the family:

- Privacy and a comfortable environment are essential
- Sit with rather than across from the family – it is less formal and confrontational
- Include the young person as much as possible – both with direct and non-verbal communication
- Accommodate the family's stress and trauma by hearing them out (and having tissues within reach)
- Establish if and how the family would like information to filter through to other members of staff and pupils
- Follow up with regular communication which helps both parties to feel in the loop. Most families welcome regular phone calls or meetings at a predetermined time
- Find out if the family would like staff from the treatment centre or community nursing team to help in informing staff or pupils. Their experience may make them better equipped to field questions and offer practical strategies or solutions
- Religion, culture and customs may all influence how the family deal with their trauma and express themselves. Different ways of coping all deserve respect
- Arrange for a sympathetic interpreter if the family speak little or no English

Confidentiality

Every pupil has the right to expect their school to provide a safe and secure environment. This includes ensuring that sensitive or personal information is kept confidential and the pupil's best interest is maintained. However, teachers cannot offer or guarantee absolute confidentiality: they may have to share information with other teachers who need to know.

Where information appears to be widely known it should not be assumed that it is appropriate to share or discuss this information with anyone other than the teachers of the pupil concerned.

Families may initially feel very protective about what information is given to whom. They often change their opinions of this as treatment progresses, so teachers should check regularly how the pupil and the parents feel about sharing news.

It can be very hard for the pupil, or their siblings, to have to field questions from their peers – questions which would have been answered, or never asked, if information was given freely in the first place. Clear and correct information is always preferable to incorrect or harmful rumours that may circulate outside the classroom.

Patients should be encouraged to rehearse how to reply to frequently asked questions such as, 'What is wrong with you? Why are you off school? Can I catch it? Are you going to die?'



Professionals speaking to staff or pupils

Some families choose to ask a nurse or teacher from the treatment centre or community team to visit the school to talk to groups of teachers and/or pupils. This can be very helpful for all concerned as it provides an opportunity to understand more about what the pupil is going through and how to help or be more supportive. It can be valuable education, instructive and thought provoking. It takes away from the pupil's teacher the burden of having to handle a difficult and potentially emotive subject.

Health professionals are clearly bound by their professional codes of conduct to maintain confidentiality. In the classroom they are also bound by the school policies on confidentiality.

Disseminate information

Be aware that confidentiality issues can sometimes conflict with the need for sound and practical advice to those involved with teaching and supporting the pupil.

In one school the pupil and the special educational needs coordinator (Senco) discussed the best way to disseminate information and updates. They produced an information sheet with a well chosen photograph of the pupil, outlining some of the most important issues. It included a brief explanation of what the pupil had been through so far and what the future treatment plans and side-effects were likely to be. With the family's permission this information was distributed to the pupil's teachers and posted on the staff room notice board. It was used as a template for subsequent updates.

In a different case, the mother of a pupil with complicated and lengthy treatment for cancer took it upon herself to write brief updates after significant visits to the treatment centre. She made copies and passed them to the school Senco. The mother continued this process over several years and was very frustrated that the school offered little sympathy or practical help. When one day she finally confronted the school about their lack of support it was discovered that the regular updates had all been filed away by the Senco – without having been disseminated to staff. The Senco had incorrectly deemed the details to be confidential.

'The teachers and my mates kept in constant contact. Phone calls, letters, visits and email. They were brilliant!' Jerome, age 14

02

Liaison between teachers

Once the school has a clear indication from the family about who should be informed, and about what, it is vital to disseminate the information appropriately. It is not essential for every member of staff to have all or the same information except in respect of situations where the school rules are being compromised to accommodate the pupil. So if a pupil has been allowed to wear a cap during the months it takes for hair to regrow it is important that the support assistant and dinner staff are also in the picture.

Teachers

Individual subject teachers should expect to provide the pupil with a work programme for their subject and appropriate supporting material. Online support from a teacher can be very helpful and motivating for the pupil.

All teachers will need to know what has been agreed with the family in terms of:

- Uniform
- Leaving the classroom
- Attendance
- Expectations
- Homework and coursework deadlines
- Seating plans
- In-class support
- Drinking and snacking
- Taking part in PE and practical lessons
- Discipline



'The school visit from hospital staff was brilliant. In just a short time the major points were explained and the school really understood what I needed and how they could help. It saved me a lot of potential grief.' Martin, age 15

Pupil card

It is useful to give the pupil a card explaining their situation, which they can easily show to any member of staff who challenges the pupil; it saves having to repeat explanations.

Symptoms

Teachers may sometimes need to know which symptoms and side-effects are to be expected and which should cause concern. Some pupils may become particularly anxious before an important appointment at the treatment centre. How the pupil feels able to cope may fluctuate greatly from day to day. The school needs to agree the best way to communicate such concerns internally.

Maintain expectations of behaviour and discipline

Most pupils prefer to be treated like everyone else and have their temporary special needs accommodated discreetly. Some pupils may be tempted to exploit their situation and get used to being the centre of attention and concern. They may find readjusting to school routine particularly difficult and be genuinely sensitive and emotional or prone to tears and tantrums.

Siblings

Ensure staff teaching siblings are included in the information being disseminated and advised about how best to support them.

See section on siblings, page 22.

Support

Staff may have had their own traumatic experiences of cancer and so news of a newly diagnosed pupil may bring up raw emotions for them. Such feelings should be recognised and accommodated. Some teachers may feel intensely uncomfortable talking about illness and the fear of dying. They should be supported as much as possible and feel able to draw on the experience of other teachers, treatment centre staff or outside agencies. Identified support options and contact details should be available for all staff.

Cultural awareness

There may be potential misunderstandings or conflicts due to diverse values, beliefs, customs or cultures in the school population. Awareness of such differences is essential. In some cultures illness, and in particular cancer, is taboo or a source of shame for the family. This will affect how information is shared.

Teasing and bullying

Teachers should have strategies for dealing with teasing or bullying. Policies may need to be updated or discussed.

02





'I clearly remember the day the school secretary walked into our class with a message for Miss Johnson. They both looked in my direction with sad faces and their heads slanted in sympathy, a look I have come to resent with a passion! My stomach immediately tied into a knot and my mouth felt dry with fear. All I could think was that my brother had died and that my parents were too busy and upset to tell me. I was trembling with pure terror when Miss walked towards me. She bent down and whispered, 'Your neighbour rang to say that she will collect you half an hour later, same place.' I had a hard time holding back the tears of relief!'

Sharon's sister, age 11

02

What do I tell the pupils?

Most children and young people desire more than anything to fit in and to be like everyone else. Being diagnosed with and treated for cancer immediately sets them apart from their peers – who may have no knowledge or experience of the trauma their friend is going through. Some genuinely prefer to keep the experience of cancer to themselves, while others breathe a huge sigh of relief when the barrier to understanding their situation is broken down.

Having established just how much and how far the family wants the information to spread, the teacher will need to discuss with the pupil and the family the best way to go about sharing the news. A variety of problems and potential areas of concern can be prevented with good preparation of the peer group.

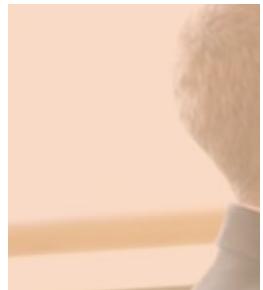
The pupil needs to decide with their teacher if they want the information to be given to the teachers only, the class, year group or entire school. They may prefer to be absent when the talk takes place. Others are keen to be right in there and field questions, show off their scars and tubes and dazzle their friends with their newly acquired medical knowledge.

It can be very helpful and entirely appropriate to include the school nurse, professionals from the treatment centre or community nursing team or a parent. Pupils may gain lots of factual information and usually have lots of questions to ask. Some worry if cancer is catching, others that it always ends tragically. Such issues need addressing properly.

As the teacher you may also want to offer all pupils advice on how to be a good friend in what is, for most of them, an unfamiliar situation.

Being a good friend

- Understand that mood swings are likely and try not to take them personally
- If a friend snaps, ‘I don’t want to talk about it!’ it usually means just then – not forever
- If your friend is absent, keep in touch. Send them a text, a card or an email. Arrange brief visits
- Even though they may sometimes feel too poorly to do the actual work they may still like to feel included and be informed of school gossip
- Invite them to the same parties and get-togethers you would normally do. One day they may feel well enough to turn up for half an hour. If not, they may do so next time – if invited
- Never stop supporting your friend. They may temporarily seem quiet and boring – but they still need your friendship
- Stand up for your friend if others make insensitive comments. Report name-calling to staff. Do not tolerate any teasing or bullying
- Many patients find the loss of hair acutely distressing. Try to be supportive – compliment their choice of hat, cap or bandanna
- If your friend is feeling particularly weak or tired, offer to carry their bags for them
- Be willing to escort your friend to the medical room or school office



- Allow your friend to photocopy your notes to help them catch up with work. They have often missed a lot of work and laborious copying by hand can be tiring
- If a teacher unfamiliar with the situation begins to hassle your friend for wearing a cap or leaving the room, explain the situation so your friend does not have to do it – yet again!
- Be prepared to include your friend in PE, games or drama as much as they feel able. It is better to take part just a little than to sit on the side
- Take care not to bump in to or wrestle with your friend. They may have needles and lines inserted under the skin, or they may just be feeling delicate

In return for being a good friend pupils should expect to be kept informed of progress and be given opportunities for talking about how they feel about the situation. They need to be reassured that cancer in young people is rare, not contagious and usually has a good outcome.

'A nurse and a teacher from the hospital came to talk to all the staff and later on they spoke to Adam's form. They were bombarded with questions from his classmates. We all learnt such a lot and found it much easier to deal with the situation.'
Mrs Bowden, head of year 8

'Penny just stood up in front of the class and told them she had bone cancer. She then explained about therapy and operations in a very open and matter of fact way. Very impressive!'
Mr Goodwin, head of year 7

02

Siblings

The brother or sister of someone diagnosed with cancer suddenly experiences great disturbance in their life. They have to face up to the vulnerability of their family unit and may feel acutely anxious. They may experience emotional turmoil including an uncomfortable mix of worry, resentment and guilt.

Families with a very ill child often have to make huge changes to their lives with very little time to plan. One or both parents may spend a great deal of time with the sick child, often far away from home in specialist treatment centres. The parental attention and presence at home is suddenly altered and daily routines disrupted.

Teachers should all be aware that the siblings of a seriously ill child are likely to experience adjustment problems and may need sympathetic handling, including time and space to talk. If the family agrees, it may be appropriate to talk to the entire class about the situation, as siblings are often bombarded in the playground by questions which they find distressing or to which they do not have appropriate answers. Friends can be very understanding, but may need to be shown how they can be supportive. If they are in the same school, it may be sensible to include teachers or groups of pupils from the sibling's class in any talks given to the sick pupil's class.

Frightening fantasies about their sick brother or sister are more likely to take hold if the pupil is not kept informed of events at the treatment centre. Not being able to visit their sibling and see for themselves what is happening can create additional anxiety. Parents may be in a real dilemma about what is best for all their children in this situation. Good feedback and communication between teachers and parents can allay fears.

Take note

Teachers may find that the pupil who has a sibling with cancer fails to bring in items to school, wears inappropriate uniform or is unable to complete homework simply because they are being cared for by a changing succession of relatives or neighbours, sometimes away from home.

Some points to be aware of:

- The stress experienced by a sibling may manifest itself in any number of ways: anxiety, low mood (as opposed to clinical depression), angry outbursts, resentment or poor learning ability through reduced concentration and attention
- The pupil may experience psychosomatic symptoms such as aches and pains, imagining they also are ill or, conversely, ignore genuine symptoms in order not to worry their already overburdened parents
- Rumours about illness can quickly gather momentum in school. This can be hurtful, cause panic or isolate pupils. The best way to prevent or deal with rumours is to answer questions honestly and create empathy
- Feelings of guilt can be strong and debilitating. The sibling pupil may feel the illness is somehow their fault, they may feel guilty for being healthy or they may have unsettled issues with their brother or sister

Siblinks is an organisation offering support for brothers and sisters, website: www.siblinks.org



School staff can help by:

- Channelling attention towards the pupil's interests and giving the parents feedback about their child's achievements
- Helping the pupil to keep a positive outlook

If ultimately the treatment fails, the patient may die. If this happens, the sibling is likely to be in a whirlpool of emotions, needing sensitive support for a long time. The sibling's needs for support and understanding must be considered before any general announcements in class or in assembly are made, and before future memorial ceremonies.

'We told the headteacher that our daughter would be having treatment for cancer for at least a year. We explained that we wanted her to feel as normal as possible and to attend school whenever she could. We talked about all the special arrangements the school could make. There was only one way to ensure that everyone knew the situation and that was to tell the staff everything at the next staff meeting. He didn't. When challenged he mumbled something about confidentiality and protecting vulnerable individuals. NOT informing the staff left our daughter very vulnerable indeed!' *Chantelle's mum*

02

Sibling letter

Proforma letter which can be adapted and sent to teachers

Dear Name of Teacher

Re: Name of pupil

This is to inform you that _____ has a brother/sister named _____ aged _____ who is currently having treatment for _____.

The parents have given their permission for us to draw your attention to the fact that _____ is likely to be experiencing stress and worry as a direct result of the fact that this family is facing a serious diagnosis and possibly extensive and debilitating treatment.

It might be useful to keep an eye on _____ over the coming weeks and months in case the trauma of the sibling's illness affects _____'s performance and well being. You may wish to give _____ an opportunity to talk about the situation on a regular basis with someone they trust. It might be prudent to have additional contact details for carers in case at some points the parents are staying at the hospital with their sick child.

During this time, particularly where your pupil is cared for away from the family home, there may be understandable reasons why _____ might turn up at school with incorrect uniform, incomplete homework or missing equipment. Please inform relevant subject teachers sensitively and discuss appropriate discipline strategies. If your pupil is due to sit public exams you may wish to speak to the examinations officer about how appropriate it would be to inform the examinations board by forwarding a letter from the patient's consultant.

For more information about strategies for siblings:
www.royalmarsden.nhs.uk (for patients/for children/returning to school/cancer)

If you have any questions or concerns please get in touch with me and/or the parents.

Yours sincerely,

Teacher/Head of year/Head of house

Home tuition

The primary aim of educating children and young people with extensive medical needs is to minimise the disruption to normal schooling. This is essential for the future development of the pupil and for their ability eventually to become fully functioning productive members of school and society.

The medical team will discuss realistic educational expectations with the family and give a guideline as to when the child is able to return to school – whether full time or part time. While the child or young person is in hospital they often have access to a hospital school. However, more and more treatments given to patients are managed on an outpatient basis, which may result in a pupil being at home for lengthy periods.

It can be very helpful for parents if early on the school establishes the likely need for home tuition and contacts the Local Authority (LA) with a view to setting it up. Treatment centre staff can arrange for a letter in support of home tuition from the pupil's hospital consultant.

The Local Authority is responsible for ensuring that pupils:

- Are not at home without access to education for more than 15 working days
- Have access to education from the start, if it is clear that they will be away from school for long and recurring periods
- Receive an education of similar quality to that available in school
- Get a minimum entitlement of five hours teaching per week if they are educated at home because of illness, as long as their health permits it

We recommend

If a pupil is receiving home tuition they should still be able to make visits to school now and then. This is likely to be mainly for social reasons and is important for their future successful reintegration into school. As such visits do not directly influence academic learning, they should not jeopardise the home tuition arrangements.

'My home tutor was completely mad and set me all sorts of weird little tasks to do each day. Strangely I enjoyed those visits – and I did really well in my exams.'
Matt, age 18

This may mean arranging access to home teaching, a hospital school or an integrated hospital/home education service.

Local authorities should have a senior officer in charge of overseeing the arrangements. They should also have a written policy setting out how they will go about meeting their responsibilities. Early liaison between parents, school, children's services and the treatment centre is important.

Further information:
Access to education for children and young people with medical needs,
Department for Children, Schools and Families
www.dcsf.gov.uk

03

Getting back to school

'When Lucy was still on treatment and making incredibly slow progress we saw a little light in her eyes when we encouraged her to make some brief visits to school. She was not able to do that much but it really gave her a flavour of what normal life could once again be like. It took her away from the endless focus on illness and treatment.' *Lucy's mum*

Welcome back

Returning to school can be daunting after prolonged absence or debilitating illness. The pupil may feel socially isolated or that catching up is an impossible academic mountain to be climbed. Confidence and motivation may be at rock bottom and energy levels non-existent. Their sense of self and their place in the world may have shifted and physical and psychological changes taken hold. They may, in so many ways, face an uncertain future.

To help as much as possible and to stimulate a positive outcome it is important that the school is always welcoming. The pupil should be encouraged to attend school as soon as it is medically safe to do so, even if on a very part time basis. Perhaps just a few hours or half a day a week is appropriate to start with. Readjusting to school routine can be hard. If at first they are attending school only intermittently and for social reasons, with no academic demands made, then so be it – that ultimately may be in their best interest. Sympathetic understanding of their limited initial energy should eventually lead to increased confidence, recovery and full social and academic reintegration.

Some pupils harbour a fear of relapse which can undermine every aspect of their lives. Such worries may need to be addressed and discussed with parents or professionals. They may persist even years after treatment has been successfully completed.



Some strategies:

- Arrange for regular progress meetings with the pupil or parents – at home or school – and be prepared to be flexible about approaches and expectations
- Think creatively about what can be done to accommodate the pupil – temporarily or permanently. This might include adapting access to classrooms, adjusting the timetable, allowing the pupil to stay inside during breaks or leave classrooms early to avoid the crush in the corridors
- Create an atmosphere of support where potential issues can be readily discussed and sorted before they turn into problems
- In the early stages after returning to school the pupil may be more at ease if they can sit next to trusted friends in class – this could be incorporated into teacher directed seating plans
- Allow the pupil to attend school as they feel able. This could initially mean having lunch at school to socialise with friends and then staying on for one or two lessons a couple of days a week
- Anxieties about returning to school may escalate to ‘school refusal’ or ‘school phobia’, which may require specialist advice. The treatment centre will have experience of this and it may be helpful to speak to the child and adolescent psychologist, psychiatrist, social worker, hospital teacher or outreach nurse

‘The first day back at school after my diagnosis was dreadful. Crossing the school threshold was such an effort.’ Olly, age 15

‘I found the return to school the most difficult part of my daughter’s illness.’ Sophie’s mum

03

Hair loss and self image

Some young people experience great difficulty in coming to terms with changes to their physical appearance. How they perceive themselves may alter once cancer has become a part of their lives. For most, the issues are temporary. Others, however, have to adjust to a permanent shift in how they see themselves and how they feel they appear to others.

Learning to live with lasting scars or amputations is hard for anyone. While in the middle of establishing themselves as individuals the diagnosis of cancer and a changed body image can seriously undermine the entire process.

A change in weight, changes to the skin texture or needing to wear a hat or scarf can be extremely difficult to accept. Some have additional issues if they have lines sticking out of their body which restrict their freedom to move and to feel part of the group.

Young people already seem preoccupied with their weight, appearance or dress to an excessive extent. They are already on heightened alert in terms of what is considered acceptable within their group and what is not. For all these reasons a changed body image can be one of the toughest aspects of cancer treatment that your pupil has to face.

Hair loss

As a side-effect from the treatment hair may become weak and fall out. Chemotherapy drugs also cause other body hair to fall out such as eyebrows, eyelashes, underarm and pubic hair. Usually the hair will grow back once the treatment finishes, but the treatment can drag on for many months. However, if the hair roots have been destroyed by radiotherapy the hair loss is likely to be permanent. This might mean that there are bald patches rather than an overall bald appearance.

Hair loss is particularly traumatic for young people to come to terms with because their hairstyles are such an integral part of their self image and the youth culture they aspire to or identify with. Through their hair and clothes young people assert their independence and individuality. To have sudden baldness forced upon one can almost become the most distressing aspect of a young person's illness.

Your pupil may experience a sense of shame and social isolation which may drive them to avoid school despite doctors recommending a part or full time return. It is clearly of the utmost importance that teachers understand the stigma the pupil feels as a result of hair loss, and go out of their way to accommodate individual requests to wear a wig, hat, cap or bandanna.

Boys are just as affected as girls and refusal to go to school affects both sexes. For pupils refusing to go to school because of their hair loss it is important to have regular strategy meetings to enable a graded and supported return to school. When the hair eventually does grow back it may be of a different colour or texture. For boys in particular it can be a sensitive issue to have developed curly hair.



Strategies for support:

- Allow the pupil to wear a cap, hat or bandanna in class even if this goes against normal school rules. On sunny days outdoors it is essential for health reasons
- Inform all members of staff about the temporary exemption from school rules for this person. Check that the pupil is happy for the information to be posted on the notice board or circulated via email to all staff – including dinner ladies
- Inform the class in advance of any changes in appearance – if the pupil agrees. They may prefer their teacher or someone from the treatment centre to do the talking, but some would like to be there and field questions themselves. If the class are told exactly why the changes have occurred and their empathy is engaged they will usually accept the situation with good will and not try to bend the rules to their own advantage
- Wigs can be expensive but are usually provided free by the NHS. They are not always comfortable and peers need to be sympathetic to their friend who may prefer not to wear it

Changes in body weight

Significant increases or losses in weight can be hard to adjust to because it is yet another blow to the pupil's self esteem and body image.

Some pupils may have a feeding tube inserted through their nose so they can have liquid feeds or medication administered during the night as they sleep. While some feel too poorly to go to school during such a time others may be keen to attend, even if only part time. The tube's existence and function should ideally be explained to classmates.

'My school arranged a mufti day where everyone wore a silly hat or wig, including the teachers. They raised lots of money for charity and I felt ok about wearing my cap after that.' *Ling, age 11*

'People at school called me "lesbian" because my hair was so short. Others said I could not have been very ill since I survived!' *Janice, age 13*

Gaining weight from treatment is less common but may well be associated with the medicines prescribed (particularly steroids) or with hormone imbalances as a side-effect from treatment. Your pupil may need to eat or drink regularly, so it may be appropriate to waive the rules to allow this.

Skin changes

Some people experience flaky, itchy, sore or red skin as a result of cancer treatment. Usually such changes are temporary but after some treatment, especially allogeneic stem cell transplants, they may become chronic. Sometimes skin may weep, peel or change colour and become patchy or dry. In such circumstances contact sports or boisterous play in the playground may be inadvisable. In summer extra sun protection may be needed during outdoor games and sports.

03

Teasing and bullying

As every teacher knows, teasing and bullying can be a huge problem for children and young people. Research shows that rates of reported bullying are up to three times higher in pupils treated for cancer compared with their healthy peers. The bullies are usually other pupils, but some teachers or support staff are also known to make unkind comments.

Bullying can of course take various forms: physical, verbal and emotional (including teasing, name calling, ridiculing and humiliating, spreading rumours about someone or excluding them from a group). Cyber bullying involves sending nasty or unkind photos and texts via mobile phones or being abusive or threatening in emails or on social networking websites.

What are the effects of bullying?

Someone being bullied is likely to display physical and emotional symptoms such as feeling sad or depressed, scared, shy or isolated and having low self-esteem leading to poorer academic performance. They may also experience headaches and tummy aches, have difficulty sleeping, have a disrupted eating pattern or engage in self harm or worse.



'I'm bullied all the time – I've just become used to it. It toughens you up!' Simon, age 12

'Sadly we had to move our son to a different school. He had no academic support and was being bullied. The new school was fantastic and very supportive in every way'
Abdul's dad

Signs to look for:

- Feeling ill in the morning or not wanting to go to school
- Trouble falling asleep at night or early morning waking
- Being worried about the journey to and from school
- Having torn clothes or damaged books
- Possessions (including money) going missing
- Unexplained cuts and bruises
- Deteriorating school performance
- Changes in behaviour – showing more aggression, being unreasonable or becoming shy and withdrawn
- Finding creative excuses for not attending school

Tackling bullying: some suggestions

- Create an atmosphere where bullying is not tolerated, which is made explicit to all pupils and staff
- Gently keep probing if you suspect bullying
- Take seriously all information about or signs of bullying
- Speak to the parents, other teachers and fellow pupils, if appropriate
- Inform the class/peer groups and teachers of the cancer and its treatment (with pupil/family permission)
- Teach coping strategies such as preparing an effective response, avoiding eye contact, standing tall or ignoring taunts
- Change routines, seating plans or playground rules
- Provide more supervision and ensure the pupil knows who to talk to confidentially

An open forum

At The Royal Marsden we strongly recommend that the school provides as much opportunity to inform and discuss the situation as the pupil and their family will allow.

Inviting outside agencies, professionals from the treatment centre, community nurses or survivors to speak to classes and offering them an opportunity to ask questions can often dispel any animosity caused by ignorance. Once the topic is thoroughly aired and explained it can significantly reduce the number of inappropriate or insensitive questions the pupil with cancer is expected to field.

- Keep a diary of events and incidents – encourage the pupil to do the same
- Set up a peer support programme
- Provide a post box for pupils to write anonymously about concerns
- Reassure the bullied it is not their fault and not to blame themselves
- If detected report cyber bullying to the website administrators, internet service provider or mobile phone provider
- Contact police if the threats are serious and illegal

Preventing bullying

Bullies often pick on the people they see as different, don't understand or have no experience of. Cancer in children and young people is, thankfully, rare so few young people have any real understanding of what a fellow student with cancer is going through, why they seem different and what the treatment involves. Myths about cancer or fears born of insufficient knowledge can breed an atmosphere of scorn, fear and hostility.

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'Mrs Smith is the kind of teacher who just makes life so much easier. She anticipated Simon's problems and reassured him that 'special consideration' was not the same as cheating. Simon really needed that extra time and the school provided it without once making him feel that he was a drain on the system. The other pupils did not always know how Simon was helped. He was so grateful not to have to stand out from the group once again.'

Simon's mum





03

Falling behind with work

Being out of step with their peers is upsetting for a young person. For some it is all important to keep up – with the youth culture, friendships and academic work.

Before the pupil returns to school it is vital to ensure that setbacks to learning are minimised. If the work provided by individual subject teachers is relevant and stimulating, it is more likely that the pupil will tackle it during spurts of energy in hospital or at home. Good liaison between the teachers and the home tutor will provide continuity which will help the pupil.

Reducing the number of subjects

For pupils in secondary schools, particularly at key stage 4, it can be a huge relief if the number of exam subjects is reduced. Even though it may have been discussed and rejected early on in the treatment, it can still be the right solution and welcomed by the pupil if proposed at a later stage when the reality of the situation is clearer. If the pupil can cut out the subjects they find most difficult and arduous or those with least relevance to their future, it frees them up to spend more time and to channel their precious energy on the subjects that really matter to them. This is particularly helpful if the pupil is given strategies to ensure they catch up with work missed.



'Some teachers give me funny looks when I ask for missed homework. They seem to think I should concentrate on getting better. But my treatment for leukaemia is three years long!'

Alex, age 14

Repeating a year

For some the only realistic solution left after all others have been tried or discussed is to offer the pupil the opportunity of repeating a year. For some this is a totally abhorrent idea which they cannot entertain. Others will welcome it and breathe a sigh of relief that they have a second chance to perform academically even if it means forsaking their friends in the year group.

Coursework

Depending on the subject it may be possible to enter the pupil for exams which have a suitable amount of coursework. Some will find it easier to complete coursework at their own pace and as the course progresses. Others prefer to delay everything until they sit an exam. This should be discussed with the subject teacher and the examinations officer, both of whom will be familiar with the varying demands of different exam boards.

'Some teachers seem to think that if they put you into a lower group, that solves the problem of you having missed so much work!' Bianca, age 12

'Marked statistical deterioration in processing speed compared to pre-treatment. Some vocabulary and all musical knowledge seems completely lost.'

Educational psychologist's report on one young cancer patient

03

Tests and exams

Apprehension about exams is understandable. They can be a harsh statement of what the pupil can and cannot do in terms of the subject studied and consequently in terms of the future education and career choices that may be open or closed to them. If being treated for cancer means having to face lower results than might otherwise have been expected it can damage the pupil's morale.

An early discussion about possible options available to ease the worry about exams is important. For some pupils it may be sensible to reduce the number of exams they sit. Others may have to have the burden lifted altogether and delay all exams.

School strategies for public exams

- Reduce the number of exams taken
- Arrange for curriculum support or revision classes
- Arrange for 'transfer of candidate' if necessary (see page 37). Many treatment centres are recognised examination centres
- Apply for access arrangements or special consideration with the exam board – include a consultant's letter with medical reasons
- Make use of 'enhanced grading' where applicable

Teacher strategies for tests and exams

- Reassure the pupil about any allowances or special arrangements that can be made
- Encourage the pupil to see the test as a way of pinpointing what learning has been acquired and where gaps still exist
- For internal exams the pupil should only be tested on what has been learnt
- Check where coursework or timed essays can take the place of exams
- Provide the pupil with a list of the work they need to revise
- Help the pupil plan their revision
- Liaise with home tutors or hospital teachers about coursework
- Arrange for a quiet room, frequent breaks, drinks, food, and extra time if needed
- Make sure the candidate is familiar with any exam concessions such as a laptop. Working with a scribe – or being one – also needs practice

Access arrangements

Access arrangements cover the entire course and should be applied for well in advance. They are based on well established need but must still meet the requirements of the assessment. Someone with side-effects from cancer treatment should be eligible but will need a supporting letter from the consultant.

Access arrangements at the discretion of the examination centre:

- Up to 25% extra time
- Breaks for food and drink or for rests
- A separate room
- Transcript
- Prompter
- Bilingual dictionary (for candidates whose first language is not English, Irish or Welsh, and who arrived in Britain less than two years ago.) Dictionaries are not allowed in English or foreign language exams



Access arrangements requiring application to the awarding body:

- Additional time over 25%
- A reader or scribe
- Modified examination question papers
- Practical assistance
- Word processor
- Use of British sign language

Apply early for access arrangements. Consult the Joint Council for Qualifications (JCQ), which publishes Rules and guidance relating to candidates eligible for reasonable adjustments in examinations.

Special consideration

If a health crisis has occurred at the time of sitting the exam, over and above the long term illness, it is possible to apply for a marks allowance of up to 5%. This is usually granted in only exceptional cases. Being on treatment for cancer usually qualifies.

Enhanced grading

If a candidate has missed an exam or unit of work altogether, an adjustment to the final grade can be made as long as certain minimum requirements have been met. It is up to the school to provide proof of the candidate's ability under test conditions. Usually the minimum work required is 35% for GCSEs and 50% for A-levels. In cases where minimum requirements are not met, an exceptional circumstance award may still be made.

Transfer of candidate

The school enters the pupil for their exams but arrangements are made for them to sit the exams elsewhere, such as in hospital.

'The exams officer spoke to everyone about arrangements for Nick's exams. She organised a separate room and extra time and made sure the coursework counted towards enhanced grades. She was just lovely.'

Nick's mum

'I work harder than all my friends – I have a lot to prove!' *Shanice, age 17*

03

School transition

Starting in a new class or school can be exciting – and nerve-wracking. Someone being treated for cancer may find their natural ability to adapt to changing circumstances has altered. A different environment may seem overwhelming, particularly if there has been prolonged absence from school.

It is important that all relevant information shared between parents and the teacher, Senco or other relevant staff is passed on to the next teacher or school. For some pupils, the problems associated with education do not disappear as soon as treatment is completed. Difficulties may linger or increase or decrease with time. This is one reason why the situation should be reviewed regularly.

Strategies to reduce pupil anxiety during transition

- Desired seating plan accommodating special requirements
- Inform well in advance if possible and make early visits and introductions
- Share successful strategies used for supporting the pupil in class or between home and school
- Consider social/emotional needs when setting or streaming
- The new teacher should try to meet with the pupil and parents before the transfer and discuss any special considerations or needs
- Share relevant information with other staff ahead of time – such as levels of energy, need to wear a cap or hat, useful strategies and special circumstances
- Familiarise primary school pupils with secondary school features and vocabulary such as lockers, homework diaries and timetables

School action

For the reasons mentioned above, the authors strongly recommend that anyone treated for cancer is put on ‘school action’ of the SEN register as soon as they are diagnosed. This should ensure that an independent education plan (IEP) and additional support is made available and that the pupil’s situation and needs are regularly reviewed and planned for. Updates by parents or treatment centre professionals should help in this process.

Special educational needs

Some pupils go through treatment with only minor disruption to their education. Others find themselves disadvantaged for years, with debilitating treatment and huge gaps in their education. Clearly their needs are very different. Some will be able to return to school with minimal concessions apart from a little understanding. Others will need formalised special educational needs (SEN) support for a long time, perhaps for their entire school career.

Even if a pupil has been successfully treated for cancer and has gone into remission there are several reasons why there may still be genuine and long lasting problems with learning. Radiotherapy administered to the head and certain chemotherapy drugs such as methotrexate can seriously and progressively affect young people’s academic processing skills. Sadly, it is also the case that the younger the pupil receiving treatment the greater the problems may be at a later stage. Chronic problems, albeit in a minority of pupils, include chronic fatigue, psychological problems and attention and concentration difficulties.



Teachers in secondary schools may not be aware that a pupil was treated while at primary school for a type of cancer involving educationally debilitating treatment. They may therefore be unable to differentiate their teaching meaningfully. Inclusion on the SEN register should highlight such issues beyond the time a pupil is considered 'cured'.

Having baseline assessment results of the pupil to hand can be very useful for the Senco putting together a case for SEN support. It may not be practicable to carry this out when the pupil is newly diagnosed, but test scores and other evidence should be kept and compared wherever possible.

Preparation

An innovative member of the support team in a secondary school arranged a smooth transition for one young pupil being treated for cancer. Laura was invited into the school during the summer holidays before transfer in September. She became familiar with the school layout and helped produce an information document for the school staff. Laura chose a picture of herself for the information sheet and helped fill in what were successful strategies for meeting her needs according to categories such as:

- Special educational needs
- Mobility around school
- Socialisation and arrangements for lunch
- Desired seating plan accommodating special requirements
- Levels of energy/fatigue and strategies for coping
- Arrangements for use of a laptop computer
- Details about attendance and treatment commitments
- An outline of physical limitations and arrangements for PE

Laura, her parents and teacher update the document regularly. It has greater relevance and more details than an IEP drawn up by the Senco only. Laura feels she is being listened to, understands her situation better and has some influence on her education.

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'As a parent it is so hard to accept that your child is almost a different person after treatment for cancer. Schooling is no longer plain sailing with A-levels and university to cap it all. Instead we have struggled and battled to get the support Jerome deserves. It took us years of wrangling, pestering and writing to anyone we could think of, including our MP. We finally got some support, but when I think of the frustration it caused, the feeling of total abandonment and hopelessness, it almost makes me scream – again!'

Jerome's mum

The SEN Code of Practice: stages

School action

The Senco takes responsibility for the young person's needs, and any extra help needed is provided by the school from existing resources. An individual education plan (IEP) describes the pupil's difficulties and the strategies and provision suggested for meeting the identified targets and goals. Regular reviews of the IEP will allow any changes needed to be incorporated. The review should be at least twice a year and the parents and pupil should be able to contribute to the IEP content.

School action plus

For complex needs and poor progress the pupil should be placed on 'school action plus' of the SEN code of practice. Specialist staff from outside agencies may be involved in assessing the pupil and offering advice on how best to meet the pupil's needs.

The LA or health authority can help with input from specialist staff such as a speech and language therapist or educational psychologist. The parents are included or informed about these arrangements.

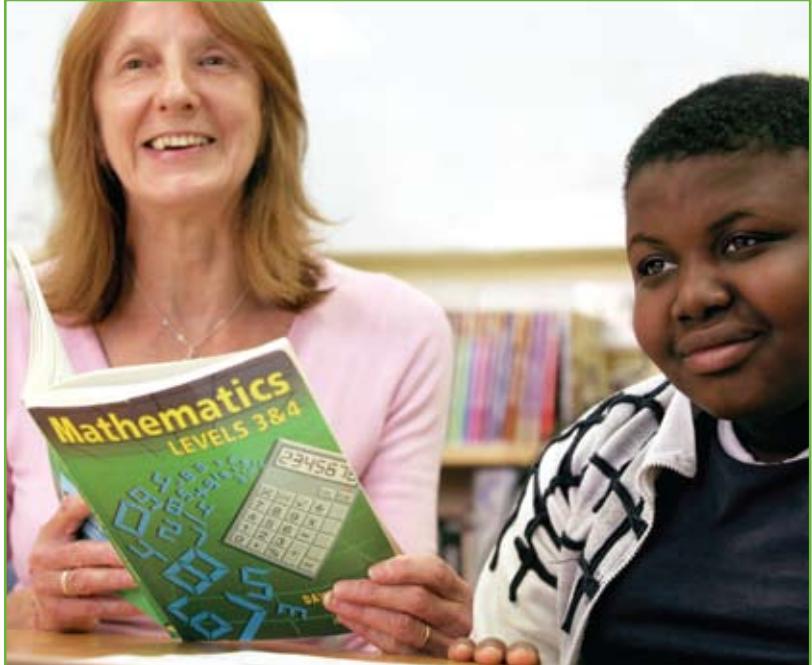
Full statement

A full statement of SEN is appropriate where a pupil requires additional support over and above what the school is able to provide. With parental consent the LA will make a statutory assessment of need and outline the special help and support required to meet them.

Parents can, in some cases, express a preference for their child to attend another school better suited to meet the needs of the child.

The statement supports the young person's education up to the age of 19 and is reviewed annually.

LAs should be informed as soon as a need is identified, even if the pupil is not yet back at school full time. The process of getting everything in place can be lengthy so it is in the pupil's best interest to make an early start.



'If only we had started this whole process sooner!' Senco

'I just want some action now – not more cocked heads and sympathetic lip service!'

Amanda's dad

'It is so helpful to have IEPs in place. We all welcome the opportunity to discuss things in detail at the review meetings.'

Louis' mum

03

Special educational support

The role of the learning support assistant (LSA) or teaching assistant (TA) is crucial in the sometimes complex process of bringing about a smooth return to school after a pupil's treatment for cancer. They need to be well informed about the pupil's needs and the sometimes rapidly changing circumstances which affect those needs.

Ideally the support assistant should be involved in the planning and review stages of the pupil's individual education plan (IEP). They need to be entirely comfortable with the overall aims and objectives and the strategies recommended to achieve these.

Some of the support assistant's work will involve adapting curriculum materials, perhaps to meet the needs of several pupils. They may work in class or in withdrawal lessons supporting one or several pupils. Sometimes they may create groups of pupils who support each other. A variety of situations is desirable as it can be too intensive for the pupil to be working 1:1 with an adult for much of the day.

Inevitably some pupils are reluctant to be singled out from their peers for special support and this can present additional problems.

'At long last I am happy that the support she is getting matches her needs – finally!' *Nalini's mum*

Issues to be aware of

- Reliance on a support assistant can have implications for the pupil's social isolation, welfare, independence and confidence
- Support assistants need to ensure that the help they offer still ensures that the pupil's work accurately reflects their ability
- The nature and amount of support should be recorded
- Whenever particular skills or knowledge are being assessed as part of class work the support assistant may need to withhold inappropriate help in order for the teacher to be able to assess the pupil fairly (see below)
- The support assistant is unlikely to have previous experience with cancer patients and should be given additional support and supervision

Support assistants should not:

- Allow pupils to take credit for work which is not their own
- Complete assessed written work for the pupil
- Carry out practical tasks being assessed
- Fail to inform the teacher of assistance given
- Write or draw anything the pupil has not told them to do
- Help inappropriately – which can be disabling by deskilling the pupil



Support assistants should:

- Discuss problems and offer constructive criticism
- Praise ideas and work well done – build up the pupil's confidence and independence
- Be patient – it is unrealistic for some pupils to work to the speed of the rest of the class
- Share the task of supporting a pupil. Working with the same person all the time may not be challenging enough; sharing support is likely to reduce dependency
- Share impressions of a pupil's personality and ability to cope as it can stimulate more varied opinions of the pupil – and more varied expectations
- Go on outings and residential trips with the pupil, if appropriate. The extra curricular learning and social interaction taking place away from school can be invaluable
- Question the need for 1:1 support if this makes the pupil more isolated from their peers. Social skills and general interaction may be the main focus in cases where the long term outlook for the pupil is poor
- Motor slowness can be a common problem and so the pupil may need help with recording homework tasks
- Help run homework clubs in order to provide a logical continuation of work covered in class

Additional support

Paul is receiving additional LSA support in most lessons, but the support differs according to the teaching styles and conditions in the class.

In chemistry lessons pupils are allowed to sit where they like. The practical lessons are noisy with a lot of chatting and moving around the class. Paul sits on the edge of the classroom with the support assistant 'buffering' him from the other pupils as the noise makes Paul feel overloaded. The support assistant runs a lesson, meant for Paul only, in parallel with the teacher. In effect he is isolated from the class.

In English, however, the teacher has a designated boy/girl seating plan informed by the Senco's analysis of individual pupils' needs. Paul sits in the centre of the class, surrounded by pupils. The support assistant moves around the class to help anyone while keeping a special eye out for Paul's needs. Paul is happier in his English lessons, he interacts appropriately with the teacher and his peers and feels an integral part of the class. He feels able to concentrate, to interact and to achieve.

04

Specific issues

Fatigue

The tiredness felt by someone treated for cancer can be very debilitating as it is often combined with general aches, feeling drowsy and being low in spirits. Pupils may suffer from mental and physical fatigue which can affect everything they do.

Tasks which previously involved little effort may be exhausting. They may be unable to attend school full time or do homework after a full day at school. Fatigue can compromise aspects of learning such as memory and concentration. The effects usually last about six months after treatment, but can be much longer.

Mental or cognitive fatigue or over-stimulation are less obvious than physical fatigue.

'I don't have to struggle around school. I just sign in and out at reception instead of going to the top floor for registration.'

Prashan, age 11

'Jane feels left out when her friends arrange to do things at the weekend and fail to include her because they assume she will be too tired.' *Jane's mum*

'We never realised just how long term is and how debilitating the tiredness would turn out to be.'

Mr Jones, form teacher



What might I see?

- The pupil may say they feel tired or use words such as 'fuzzy' or 'confused'
- Work may be slow or lacking
- Apathetic or apparently lazy behaviour
- Slurred speech or blurred vision
- Difficulty getting around school on time; arriving late for lessons
- Not interacting with peers
- Poor concentration, distractibility or difficulty remembering things
- Irritability or low mood

After radiotherapy

Somnolence syndrome may develop about six weeks after radiotherapy and may include periods of drowsiness, lethargy, loss of appetite and irritability.

'It is so frustrating that I cannot do what I used to!' *Lizzie, age 11*

'I've never known tiredness like this – it zaps you completely.'
Damilola, age 14

'I'm sure my friends think I'm boring because I don't want to join them. I just have to go to bed and rest.' *Jon, age 16*

04

Strategies

- Arrange short bursts of work with frequent rests
- Reduce expectations of homework and class work
- Help the pupil to prioritise work
- Make a note in the homework diary explaining why work may be late or incomplete
- Allow the pupil to leave the classroom five minutes early in order to get around more easily. They may need someone to help them carry their belongings
- Provide a coloured card for the pupil to indicate when they need time out – by actually leaving the classroom or just ‘switching off’ and putting their head down
- Modify time limits in tests and with homework and coursework
- Allow typed work if the handwriting is too unsteady or tiring for the pupil
- Provide handouts to save the pupil from listening and taking notes at the same time
- Reduce the timetable or the number of subjects studied
- Provide a calm and restful environment where the pupil can take time out
- Ask how they feel – even when they find it hard to articulate, they may benefit from discussing fears and worries

Time out

Stephen places a coloured card on his desk with ‘REST’ written on it whenever he needs to have a little time out. He sometimes just lies across his desk for a while. The teacher knows to leave him alone or offer that a friend takes him to the medical room for a lie down.

‘Games and PE would make him feel washed out for a day or two afterwards. Now he just takes part for 20 minutes. He is coping with shorter bursts and school is supportive.’ Temi’s dad

Chronic fatigue

A minority of pupils will have ongoing chronic fatigue which can be present for many years after treatment. These pupils need a programme of activity and rest similar to pupils with chronic fatigue syndrome (CFS) or myalgic encephalomyelitis (ME).

Further useful information available:

Great Ormond Street Hospital for Children
www.ich.ucl.ac.uk

Cancerbackup
www.cancerbackup.org.uk

A gradual increase in the timetable is recommended. The pupil should start with just one or two lessons and build it up according to ability. Mornings can be particularly difficult, so late morning or early afternoon starts may be best.

Mobility and physical education

Treatment for cancer can be physically debilitating and some pupils will have difficulty with mobility or become excessively tired. It is important to focus on what the pupil can do rather than what they cannot do.

Movement around school

When a pupil initially returns to school they may be quite unsteady and fearful of being pushed in the corridors during lesson changeover. During this limited period of time the pupil could perhaps be allowed to leave lessons five minutes early in order to be able to navigate the corridors while they are still empty and more safe. Some pupils might benefit from the company of a friend or support assistant to steady them or to carry their books. Homework should ideally be set earlier on in the lesson so that no pupils miss out on this information.

If a pupil is using crutches or a wheelchair, the timetable or room allocation may need to be changed while the pupil's mobility is compromised. At the same time, some pupils respond well to the expectation that they can cope. It is a delicate path to tread.



'The class teachers offered to swap classrooms so that Alex could remain on the ground floor. We originally planned for all year 7 classes to be on the same floor, but really all it means is that the rest of us get a bit of extra exercise running between classes – and Alex can join his friends and get on with his education.' Academy principal

04

Strategies

- Have procedures in place for the safe evacuation of a pupil with mobility problems
- Provide the pupil with a card allowing them to leave class early in order to navigate the corridors safely
- Arrange for buddies to accompany the pupil around school – and reward them for doing so
- Rearrange classrooms and seating plans to facilitate mobility

Central line

The pupil may be fitted with a central line or a shunt to drain away fluid. In such cases it is inadvisable for the pupil to take part in contact sports. However, they should still be included as much as possible in other more gentle and controlled activities.

See page 75 for examples of a central line or shunt.

Swimming

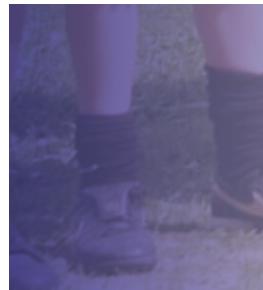
Swimming is not allowed while the pupil still has a Hickman line inserted. With a Port-a-Cath or a shunt, swimming should not be a problem. Re-introduction to swimming needs careful monitoring, though. A previously competent swimmer may have become slow and weak and will need to regain their confidence and ability to swim safely.

Warm-up and cool-down

It is good educational practice generally to take time to warm up and cool down before and after PE and sports as it significantly reduces the risks of strain and muscle injury. Pupils may benefit from being included in these sections of the lesson even if they cannot take an active part in the main activity, which may be too boisterous for them.



'Being sporty both in and out of school Barry fiercely resented any restrictions on his participation in sports and PE. Barry's teacher understood how important it was for him to be included. During football and rugby Barry would take part in all pre-match warm-ups and skills training. His role would switch to referee or scorekeeper during the actual games.' Barry's dad



Some strategies for inclusion in PE and sports

- Adapt the activity to meet the needs of the individual
- Allow participation at manageable speeds and appropriate levels
- Include pupils for both practical and social reasons
- Incorporate yoga techniques such as visualisation and relaxation
- Build up skills gradually – practise individual movements before putting them all together
- Liaise with the pupil's physiotherapist, if appropriate
- Create a 'can do' culture through creative and adapted activities providing motivation and offering choices
- Be aware that reluctance to take part and get changed in front of peers may be due to sensitivity about altered body image. Greater privacy may be required

Some pupils may use their recent illness as an excuse to avoid PE and games when they are in fact well enough to participate. This reluctance should be addressed carefully. It may be related to changes in the pupil's body image, hormones or confidence as a direct result of their treatment for cancer.

School trips and outings

Well planned and appropriate school trips have great educational and social benefits. It is regrettable if such trips are avoided because full participation seems difficult. Instead it might be possible to invite a parent or learning support assistant (LSA) along with the pupil. If involved in the planning and risk assessment early on, the LSA may be able to organise some alternative activities during the trip.

'I really miss not being able to swim.' Adam, age 11

'The playing fields are just too far away for Mark to walk there – someone takes and collects him so that he can still do the sports.'

Mark's dad

'After the amputation Neill's parents kept his bedroom upstairs and expected him to manage the stairs. They want us to have similar expectations at school – and Neill is thriving!'

Mr Wood, form teacher

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Taking medication, eating and drinking

Medication

Some pupils need to take regular medication at school. This can be accommodated in a variety of ways. The need for medication should never be an excuse for school or family to prevent the pupil from attending school unless the pupil's consultant has concerns about this. Depending on the age of the pupil and the support structures available in the school, the management of medication can be done by the pupil and/or a member of staff such as the school nurse, a teacher or a member of the office team or support staff.

A pupil on steroids may well be prone to mood swings and it may be prudent to inform the pupil's teachers so they can anticipate any problems.

Some treatment protocols for acute lymphoblastic leukaemia require the patient to take medication five days every month as part of their maintenance treatment, which can last several years.

Eating and drinking

As a direct consequence of cancer treatment, the pupil may need to drink regularly or eat small and frequent amounts. If the situation is explained to the teachers and classmates (with the pupil's and parents' permission), and the temporary nature of the arrangement made clear, it should not cause any real problems, even if other pupils may not eat and drink during lessons.



'My teacher allowed me to have a drink of water in class. When the others complained that they were also thirsty he let them bring in water, too. Mr Jones claims it is good for the brain! I am just glad we are all treated in the same way.' Peter, age 12

Academic performance and expectations

Serious illness and prolonged absence from school are likely to have an impact on the pupil's academic performance. There will be gaps in learning as well as a possible lack of energy, confidence and motivation. The expectations teachers have of a pupil may need to be revised. The number or types of subjects taken to exam level may need revising. Assessments may have to be delayed or adapted.

It might appear tempting to tell the pupil not to think about school at all. For some that will come as a huge relief, particularly if school is not the most cherished part of their life! Others, however, will worry greatly about falling behind, their future and how to catch up with the rest of their class. They may feel the exclusion from the school community and their social network as an additional trauma.

It is a difficult situation for a teacher to be in. If they send work to the pupil in an attempt to include them it can be seen as insensitive pressure at a time when they least need it – if they don't, it might be seen as if everyone has already given up on the pupil and do not believe they have a future.

Discuss with parents or professionals at the treatment centre what they recommend. The best compromise may be to select only the most relevant, stimulating or favourite subjects and to forward books, material and details to the parents so that the pupil can do some work when and if they feel up to it. If a folder of work follows the pupil in and out of hospital it will also give the teachers in the hospital school an idea of how best to help the pupil.

If work is available it may also provide a smooth transition to home tutoring if it becomes necessary.

'School thinks Simon is doing well – but we know that he is not performing to his original potential. Sadly, Simon is also acutely aware of this.' Simon's mum

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'Before her illness Sandra was in the top 2% 'gifted and talented' group. She has been put into lower groups because of her long absence but she still performs way above the group average.' *Mr Small, deputy headteacher*

Emotional and behavioural aspects

The diagnosis and treatment for cancer requires huge emotional adjustments for the pupil and their family. The physical changes alone are likely to make the pupil feel acutely sensitive. Additional changes such as mental fatigue and difficulty in keeping up with school work or memory difficulties add further stress. However, for some the most profound trauma is having to come face to face with their own mortality and living with the constant fear of a relapse.

Your pupil may well have anxieties when returning to school and feel that they no longer belong. While some come through with their self-confidence intact or even bolstered, many emerge with a fragile self esteem which needs thoughtful care and nurturing by teachers and pupils.

Pupils can present with a mixture of mature thinking and emotional/social immaturity. They may become less well developed socially and emotionally than their peers. This juxtaposition can be difficult for the pupil to handle and will need tact and discretion from staff.

It can be hard for a pupil to confront the fact that their performance on a number of levels – academic, social and athletic – may have deteriorated. Some may be inadvertently protected by a lack of understanding of any changes. Others will find each fresh realisation of a newly acquired limitation extremely disheartening. Something similar to a grieving process then occurs, until the gradual acceptance of a new identity. It can be a slow and painful process. Crucially the issues of expectations of their own performance, and those of parents and the school, need to be dealt with in a sensitive manner.

Monitor behaviour

In a child with a history of cancer it is important to alert the parents to any behaviour changes, in order to exclude a medical cause.

It is as well to tackle these problems proactively and perceptively, as anxieties about school can quickly escalate to school phobia.

What might I see in the classroom?

- Mood swings, melancholy, withdrawal, lack of enjoyment or motivation, tearfulness
- Anxiety, worry, depression and agitation about keeping up with work, choice of subjects, exams and the future
- An excessively perfectionist attitude or obsessive behaviour
- Emotional immaturity, over-dependence and clinginess
- Poor concentration and memory, restlessness, impulsive behaviour and academic underperformance
- Frustration, anger, irritability and aggression
- Impaired social skills or egocentricity and inflexibility
- Attention seeking behaviour
- Isolating behaviour such as withdrawal from social activity and interaction
- School phobia
- Psychosomatic symptoms, which may include complaints of headaches or abdominal pain



Some strategies to consider

- Did the pupil have pre-existing emotional or behavioural difficulties? These might be exacerbated by a serious life-threatening illness where the family stability is undermined
- Discuss your concerns with a member of staff at the treatment centre. They may be able to rule out or confirm a link to the medical condition or side-effects from treatment. Sometimes the behaviour is beyond the control of the pupil
- Offer counselling – perhaps with a professional school counsellor
- Lend a sympathetic ear or link the pupil with someone who understands
- If the pupil is at risk of self-harm, parents, and usually professionals, need to become involved

Good management of a pupil with behaviour problems may need careful assessment and diagnosis. Keep a behaviour diary (see below) and consult a psychologist or professional at the treatment centre or an educational psychologist from the Local Authority. They may be able to offer help through the child and adolescent mental health service (CAMHS).

'Mark often expects others to 'fix things' for him and so take away the responsibility from him. Paradoxically it makes him feel out of control, so he gets angry.'

Psychologist

'I'm glad I was in an all boys' school. There were some jokes and teasing but I much preferred that to the girls I know who are too sympathetic and feel sorry for me!' Nick, age 14

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Behaviour diary

- A behaviour diary should include frequency, intensity and duration
- Are there triggers such as time of day, particular lessons or pupils?
- How is the behaviour managed? Does it result in more attention or isolation?
- Is praise given to positive and appropriate behaviour?
- Is difficult or inappropriate behaviour ignored?
- Are triggers excluded or modified?
- Is there consistency and routine?
- Is calm behaviour being modelled by pupils and teachers?

Some important principles of good behaviour management

Good communication

Set aside time to really communicate with the pupil and listen to their concerns. A discussion with parents should clarify the extent to which the problems are exclusively school related. Conversations between members of staff should establish a fuller picture and ensure consistency in behaviour management.

Finding the right balance

It is understandable if teachers are sometimes unduly lenient or protective of a young person with cancer. However, it can unwittingly maintain or exacerbate behavioural problems. The pupil may need to be treated in the same way as their peers in most respects, but at the same time it is inappropriate to discipline a pupil for behaviour which is organic and beyond their control.



Get advice

Seek professional advice early on about problems. Good behaviour management, in these cases with expert input as appropriate, can stop problems becoming entrenched.

Perseverance and patience

Try to focus on a single problematic behaviour at a time. Apply the same strategy consistently and patiently. Indicate that it is the behaviour not the pupil that is unacceptable. Improvements should be noted and praised.

Individuality

As with other pupils, management strategies which work for one pupil with cancer will not necessarily work for another. Individual assessment is required.

Social issues and relationships

Treatment for cancer can keep a pupil out of their usual social loop for long periods. The protective environment of the hospital, with constant care by medical professionals, and increased dependence on parents may have additionally set your pupil apart from their peers at school. The profound experience of dealing with the diagnosis, treatment and life after cancer can be additionally isolating.

Good social reintegration into school is essential if the pupil is to get any sense of belonging. It can be crucial for their progress in all aspects of life and may prevent any incidents of teasing and bullying. As a teacher you may have to ensure that the pupil's social skills are relearned; extended absence from school can cause them to regress.

Social skills we may take for granted

- Understanding non-verbal communication such as body language, facial expressions and tone of voice
- Reading social cues
- Listening
- Taking turns and sharing
- Making and keeping friends
- Understanding jokes
- Controlling feeling and emotions
- Behaving appropriately for the circumstances

The other pupils in the class can in turn learn a great deal about acceptance, tolerance and inclusion by working alongside their friend being treated for cancer. This is in addition to the scientific, communication and organisation skills they may gain.

'The cards and letters I received during my illness meant so much to me at a time when I was really low. I know that some may feel "Why did I bother?" because I never got round to thanking them – but that does not mean that I did not appreciate them! One or two cards especially arrived just when I felt like giving up.' *George, age 17*

'I will always be grateful that my friends were there for me when I most needed them. I don't keep in touch with them anymore but that is because we have grown apart – perhaps because of my illness.' *Bianca, age 18*

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Many find it hard to use the right words when they meet a friend who has been diagnosed with cancer. Others try to avoid the situation altogether or feel that their one attempt to visit or send a card was 'rebuffed' because nobody was able to show their appreciation. This is probably because the pupil was too preoccupied at the time. Many pupils find they have lost contact with friends during treatment and have difficulty getting accepted back into the group.

The paradox of youth is clearly at play: each one strives to establish their independence and individuality while at the same time needing desperately to fit in and belong with their peer group.

After hospitalisation and a prolonged absence from school with intense closeness with parents and adults the social reintegration into school becomes crucial precisely because it can be so difficult. If schooling is recommended by doctors to the extent the pupil feels able, it should at all times be facilitated, even if this means their attendance is sporadic. It may be tempting for the school to suggest that the pupil should stay away until completely well again, but that may be for such a long time that it leads to a whole host of other problems, such as school phobia and lack of confidence.

Many patients experience a 'displacement' from their peers, which can be permanent. The trauma of dealing with a life threatening illness and debilitating treatment sets them apart from their peers who may seem preoccupied with trivial issues. They often feel different and that they have grown up rapidly and so, grown apart.



'We were never really able to establish if Martin was so reluctant to go to school for social or academic reasons. We suspect both.' Martin's parents

School refusal

School refusal or phobia

A reluctance to go to school is very common in children and young people after any absence connected to a serious or life changing illness. The reluctance may become entrenched and lead to school refusal or to phobia with its own debilitating symptoms.

Warning signs to look out for:

- Reluctance to attend school, including physical complaints such as abdominal pain, headache, sore throat
- Pupil presents with physical signs of anxiety such as racing heart, shaking, sweating, difficulties breathing, 'butterflies in the tummy', nausea

Speaking to the pupil and the family is essential and should precede speaking to outside agencies. However, it is important to exclude an underlying depression which may need treatment or referral. Treatment centres will often be able to give advice or provide psychological assessment and support. The local CAMHS and GP may also be able to offer support.

'My friends are kind and considerate, but they don't really want to hear about my illness. That's ok with me 'cos I don't want to talk about it much. It's hard for them to understand where I'm coming from. We have completely different views on life, how we think, what we consider acceptable or normal.' *John, age 15*

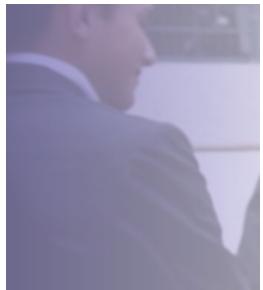
'Though Natalie is well liked and accepted she still feels quite isolated – an outsider.'

Mr Brown, form teacher

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Managing school related anxiety

- Discuss areas of concern with the parents and with the pupil
- Ensure parents are part of the solution by working with them to help them feel confident. Their involvement and encouragement are crucial
- Appoint a liaison/key worker to aid communication and help the pupil form a trusting relationship, gathering information and implementing strategies
- Discuss with the pupil what are the areas which cause most distress, eg bullying/no friends/feeling different/work too hard or easy/too many pupils/noise/too busy/don't know anybody/no confidence
- Suggest solutions or strategies for how the school plans to deal with bullying or academic difficulties
- Negotiate areas of change in school routine or procedures. Suggest times to come in for social reasons or to attend classes where they feel most confident
- Acknowledge how difficult it can be for the parent, and the pupil, to distinguish between symptoms of phobia and of actual illness and side-effects from treatment
- Inform other teachers appropriately so they know the strategies to use
- An early referral to the pupil's consultant or a psychologist may be helpful
- Initially attempt only small steps toward reintegration/attendance, gradually building up length of attendance
- Provide a timetable which clearly shows the negotiated attendance agreements
- Negotiate the help of one or two friends/buddies to stay with the pupil at breaks/lunch times/known stressful times
- Consolidate successes at each stage
- Modify usual practices – such as allowing parents on school premises to build up the pupil's confidence
- Draw up a stepped plan for a return to school and agree with all parties to keep to it as far as possible
- Reward success
- Manage distress calmly
- Consider using home tutors, who can help in the transition between home and school
- Have set meeting arrangements away from other pupils
- Share information with other teachers to ensure consistency
- Arrange a buddy or mentor if appropriate
- Readjust the timetable – allow part time attendance
- Start small, build up gradually and reward
- Identify a person or area where the pupil can go in times of stress or need
- Allow friends similar privileges, such as staying inside at break, to avoid social isolation
- Let the pupil know you understand their difficulties, but with both language and attitude/body language show that you expect them back at school as soon as appropriate and agreed
- Any plan of action should be implemented as soon as possible. The longer they are out of school the more difficult it is to get them back in



Maintain the familiar

When Felicity returned to her high achieving girls' grammar school after lengthy treatment she ended up showing classic signs of school phobia. She had previously been a star pupil with a small, close group of friends. She loved school and was keen to get back into class despite feeling nervous about being so frail and having no hair.

When she discovered that she had been placed in lower groups for most of her subjects, away from her friends, her world collapsed. Her already dented self esteem evaporated completely.

At the time when she needed her friends the most, they were in different sets or groups with little opportunity to associate. Feeling isolated, she withdrew herself more and more from school. She used excuses such as 'feeling poorly' or 'tired'. Considering what she had been through already it was hard for her parents to see the situation for what it really was. Instead of challenging and then supporting their daughter through her school phobia they genuinely worried that she was having a relapse.

'The knowledge is all still there – but it seems as if the index to it has been lost.' *Parent*

'Spellings were completely forgotten. It was as if we had a dyslexic pupil overnight. He has had to work so hard to claw his way back.' *Senco*

04

Concentration and memory

Certain treatments such as radiotherapy and some chemotherapies may reduce a pupil's ability to remember and to concentrate. They can be easily distracted, particularly in a busy, noisy classroom. This restricts their ability to learn and to reach their potential.

It is worth considering a pupil's preferred learning style and helping them with strategies for coping and improving their memory.

What might I see?

Concentration

- Tuning out or daydreaming
- Lapses of concentration
- Being easily distracted
- Difficulty in following task instructions
- Work may be slow or lacking in detail

Memory

- Difficulties recalling information
- Inability to follow task instructions
- Difficulties retaining new information and learning new concepts
- Difficulty in following homework instructions, leading to incomplete work
- Difficulty getting to the right lesson with the right equipment at the right time

Memory and attention

Attention lapses may be difficult to distinguish from a memory deficit; often they coexist. Lapses may be worse at certain times of the day when the pupil is tired.

Some strategies for the classroom:

Concentration

- Break the task down into small focused steps. The pupil will be encouraged if able to experience success as each small target is reached.
- Praise each achievement
- Provide a tick chart of the steps required and achieved
- Provide the pupil with a template to work to and an example of the end product
- Computers with gap or chart filling tasks are useful
- Keep tasks brief and practical
- Stimulate interest through relevant topics and exciting materials
- Be realistic about attention span
- Provide notes from the lesson



Memory

- Provide opportunities for repetition and over-learning
 - Use a multimodal learning approach such as visual and aural
 - Provide memory tools, eg written instructions, diaries, checklists, clocks, memo board, dictaphone, diary, calculator, worksheets or templates
 - Use cues or triggers to aid recall such as multiple choice questions
 - Teach memory strategies, eg mnemonics, mental imagery, mind maps, spidergrams
 - Ensure homework is written down, with deadline dates
 - Allow the use of highlighter pens
 - Provide notes and handouts
- If the pupil is easily distracted
- Reduce external distractions
 - Avoid open-plan, noisy teaching rooms
 - Seat the pupil at the front of the class where distractions are fewer
 - Pair pupils to encourage good work habits
 - Reduce internal distractions by allowing the pupil to confide worries
 - Gain the pupil's attention before giving simple task instructions
 - Limit the amount of equipment on the desk to essentials only

Further strategies for memory

- Give instructions in the right order
- Use scaffolding techniques for planning and organising work
- Teach effective note-taking skills
- Use diagrams and placemats as prompts

Monitor progress

When Sandra returned to school in year 8 there was joy all around that she had survived and been cured. She was keen to catch up and worked very hard despite her problems with fatigue. Her year 9 SATS results fell short of predictions and it was clear that progress had slowed right down. Sandra found it difficult to learn new skills and concepts and lacked confidence and drive. The Senco arranged for extensive testing of Sandra's memory and concentration. After returning to school, Sandra was offered LSA support, which had to be increased over the years.

'We were warned that some of the drugs would affect memory. The lack of it still frustrates her greatly.' *Georgia's mum*

'Some teachers have been really good at helping me with catching up.' *Tamsin, age 15*



'Although I was in a strong and steady relationship I was totally shocked when my girlfriend announced she was pregnant. We were both in the first year at uni and children were the last thing we needed. After treatment aged 16 I had always thought that I was infertile!'

Peter, age 23

Sexuality and fertility

The sexual development of a young person can be seriously affected by treatment for cancer. For some young people their fertility is also compromised or entirely damaged. However, not all young people will be affected. Any changes they do experience can be either physiological or psychological.

Physiological

The location of a tumour or the treatment received for cancer can create hormonal imbalances. This can lead to problems such as precocious puberty, altered sexual drive, sexual inhibition or lack of inhibition. This can to some extent be treated by a doctor specialising in hormonal problems (endocrinologist). The patient may receive hormonal treatment in the form of tablets or injections, usually for life.

Girls may experience irregular periods and boys may have a low sperm count. Although it may lead to infertility it is still important to stress to all pupils that they should always take precautions during sex in order to protect themselves from the possibility of pregnancy and from sexually transmitted diseases.

Boys will usually be offered sperm banking if their fertility is considered at risk and their pubertal development is sufficiently advanced. Girls may be advised about ways in which their fertility can be preserved, though for them the situation is more blurred. There are constant medical advances in the preservation of fertility, and these may benefit a few.

Psychological

A young person's self-esteem and confidence is closely linked to their body-image and belief in their future. Changes in physical appearance due to treatment can have a profound effect on their ability to form relationships. A diagnosis of cancer can dent a person's belief that life can return to normal and they may feel let down by the fact that they are ill or have been through life-changing treatment. Their social skills and confidence may be impaired by long absences from school. The realisation that life goals such as forming relationships and having children may be in jeopardy can have a severe impact, and the pupil may need psychological support.

The biology teacher may in their lesson planning want to acknowledge sensitively that someone in the class may be worried and unhappy about their future sexuality and fertility.

'She just stormed out of the classroom in tears when the topic of fertility and pregnancy was brought up.' *Biology teacher*

Preparing for the death of a pupil

Most children and young people are successfully treated for cancer and will go on to lead meaningful lives long into their adult years. Sadly, however, some will die from their disease. When there is no more hope of a cure and all options have been exhausted the medical care of the patient changes to ‘palliative care’. The most important focus then becomes to optimise the patient’s well being by good symptom care, including keeping them pain free. This is to enable them to enjoy the time they have for as long as possible and to die peacefully.

The teacher may have to perform several roles when supporting the death of a pupil:

- Accommodate the needs and wishes of the dying pupil and his or her family
- Understand and support the peers and teachers who are grieving
- Answer questions from pupils
- Deal with their own grief and issues surrounding death

Even though a young person is going to die, they and their parents may still wish them to attend school on a part time or social basis. The school is a familiar place containing most of the young person’s relationships outside the family. These important relationships can help maintain a regular routine and some normality. With careful planning and communication the school can nurture the child’s social and emotional wellbeing. The parents and siblings may also find it comforting that their social network of support is involved and maintained.

‘We explained how anyone grieving does not necessarily stop feeling the loss, the pain and the emptiness – but in time they do manage to live with it.’

Mrs Ball, form teacher

The sick pupil may be able to attend school only part time or come in mainly for lunch breaks or their favourite classes. If the pupil is no longer able to attend school then staff should ensure, with the pupil’s or parents’ permission, that contact is maintained through brief visits where possible, cards and letters, texts, emails, or social networking sites.

The school community should try to create a climate where the pupil’s independence, hope and dignity are respected. An awareness of different cultures, customs and religious practices can be invaluable in bridging the gap between individuals at this very important time.

The way pupils and staff respond to the illness and death of a young person is affected greatly by their own experiences and how close they were to the sick pupil. Those who have already experienced significant loss in their lives may need greater support and comfort, though individual reaction can never be predicted. Significant loss need not only be through the death of a loved one but can also be separation through the breakup of families. For refugees the loss of language, culture and home can be traumatising. Those who recognise similar health problems in themselves or their family may need additional understanding, as will those with a particularly close relationship to the person dying or to their siblings.

Communication

A school dealing with the death of a member of their community will need to plan and set up a system of good communication.

- Who will be the key member of staff responsible for co-ordinating information and support? Does everyone know who it is? Do all know how to get hold of them?
- A named member of staff should keep in touch with the family. The family's consent for all action or information passed around school should be sought sensitively. All preparation and support should be done in accordance with their wishes and beliefs
- Make contact with professionals who will be able to support the school and offer advice and counselling (see below)
- Allow staff the space and time to discuss among themselves how to share information, plan what to say to pupils and support each other. Staff should only be asked to speak to classes if they feel able to deal with and manage pupils' reactions and questions
- Consider setting up support for staff as well as pupils
- Consider what teachers need to know and what pupils should know
- Make sure all staff tell the same story
- Who should be told? What should be told? When, how and where should it be told? It is quite important that all are informed at the same time to limit rumours and different stories circulating among the school community
- If parents do not wish details circulated generally among staff, this can be quite a burden to carry for the teacher who is entrusted with information about a pupil's prognosis
- Small groups are usually better than assembly for breaking bad news
- Be prepared for questions, answer as directly and honestly as possible and admit to not being able to answer all questions
- Try to use a normal voice and use straightforward words such as 'dead', 'death' and 'dying'. Avoid using euphemisms such as 'passed away', 'gone to sleep', 'taken by God' or 'gone to heaven'
- Enable pupils to share their feelings. Encourage them to express their grief and sympathy in any form they find suitable. There are no 'right words' and any gesture of sympathy or grief is valid
- Sending home a letter to all families explaining the situation will enable parents to understand and support their children in line with the school. (As always, this will need to be agreed with the family.)
- If a sibling is in the same school, remember to think sensitively about their needs
- Consider the best way to send condolences from the school and letters from staff and pupils

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Further points to consider:

- Is there a private space that can be used for groups or individuals to talk or to go to for time on their own?
- Is there a named member of staff to whom pupils can talk?
- If a sibling or best friend is particularly hard hit by grief they may like to carry a 'time out' card so they can leave the classroom discreetly and go to a designated place for comfort
- Acknowledge the powerful learning experience for pupils and teachers. Allow time for talk and reflection. Be a good listener
- Stick to school routines – even when they seem trivial. Some constancy can be welcome when all else appears in turmoil
- Include issues on cancer research, cure and treatment into the curriculum where appropriate, particularly where pupils raise the topic. It may need revisiting again and again over time
- Are there practical ways the pupils can engage in expressions of grief and sympathy – eg, attending a funeral or memorial service, creating an area of remembrance, raising money for charity?
- Should anniversaries, birthdays, etc. be marked? Many families greatly appreciate the fact that special days are remembered as it shows their relatives are not forgotten

'After Sandra died, friends from school continued to visit the family now and then just as they used to do when Sandra was alive. Her group of best friends would pop in on birthdays or anniversaries, encouraged by the fact that Sandra's mum always gave them a warm welcome. They laughed and cried together about the things they all used to get up to, sharing their memories.'

Mrs Cox, headteacher

'Be prepared to listen – again and again and again!'

Mr Wright, form teacher



Adolescents and grief

Feelings seem to become more intense in adolescence, yet expressing them can be difficult. A grieving young person may be more comfortable expressing anger about death than showing sadness or hurt, which they may perceive to be childish. Some try to cope by joking about death, or may act as if nothing has happened. This may be particularly so for boys who tend to be more controlled and less expressive. Girls are more likely to express grief openly and to cry, and are consequently more likely to get the sympathy and comfort they need.

Grieving young people may act out of character or behave unexpectedly. A number of conflicting emotions may surface such as shock, denial, anger, relief, guilt, numbness, and growing acceptance.

Younger adolescents can have strange or vague concepts of death, whereas older ones have a more definite concept of the finality and inevitability of death. Neither is necessarily accompanied by emotional acceptance or a constructive outlet of grief. Understanding about death is greatly influenced by both experience and preparation.

It is important to acknowledge that this is happening at a time of great change in a teenager's life and to make clear that individual support is available and confidential. But do not expect them necessarily to accept it: young people often turn to their peers for support, which can leave adults feeling helpless and rejected.

Strategies for grief support:

- Let your genuine care and concern show
- Work out what to do if pupils feel upset. Where can they go?
- Talking about the dead person helps the grieving. Make it a normal part of conversation. If they are in your thoughts, make them a part of your conversation
- Be prepared to show your own grief. It will touch others who are affected and provide comfort to know that the sorrow is shared
- Discourage punishing oneself with notions such as 'I should have...' or 'if only I...'
- Do not try to avoid those who grieve more than you. Isolation will only add to their pain
- Don't change the subject when someone mentions their loss or becomes emotional
- Provide some relief from grief. It can be too much to focus on one emotion all the time – some laughter or light activities are sometimes needed
- Involve pupils in arranging for an appropriate memorial for their friend. A bench, a tree or a memorial garden are popular choices. Others have included designing and making a stained glass window or a weather vane, putting on a concert as a memorial, setting up a sports trophy or endeavour prize for speech day, creating a collection or book of memories to pass on to the family

The following organisations offer practical help and advice for schools as well as individuals – including ideas for lessons and assemblies, etc.

The Child Bereavement Trust
www.childbereavement.org.uk

CLIC Sargent – Caring for Children with Cancer
www.clicsargent.org.uk

Cruse Bereavement Care
www.crusebereavementcare.org.uk

If I Should Die. Co. UK
www.ifishoulddie.co.uk

Winston's Wish
www.winstonswish.org.uk

For recommended reading on dealing with grief and loss, please see page 88.

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Information about cancer

Types of cancer

There are two main types of cancer:

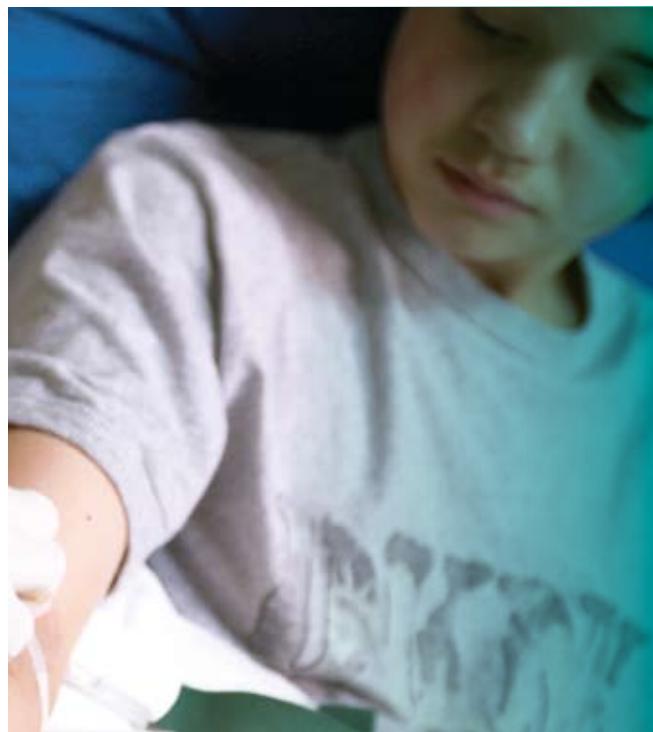
Solid cancers are where a lump forms in the muscle, bone, brain or other organ. The cells divide and multiply abnormally to form a malignant tumour. Sometimes benign (non-cancerous) tumours need treatment similar to malignant tumours.

Blood cancers such as leukaemia and lymphoma result when the blood cells divide and multiply abnormally. In leukaemia the abnormal cells are in the bone marrow and blood stream. In lymphoma they are in the glands (lymph nodes).

The most common types of cancer in children and young people are leukaemia and brain tumours.

For definitions and medical terms, please see page 92.

'Just listening to his medical history made me realise that this boy has been to hell and back – and is scared stiff.' *Mrs Page, form teacher*



Individual cancers and symptoms

It can be very difficult to diagnose cancer, particularly because it is rare in children and young people. Symptoms can be similar to common illnesses and a general practitioner may want to exclude these first. Parents often know instinctively when their child is not well, but may be less aware if the child is older and so more private and independent. Many teenagers fail to report changes in their body to parents and doctors because of general embarrassment at a sensitive age.

Leukaemia

About a third of all cancers in children and young people are leukaemias which affect the blood and the bone marrow. Most have ALL (acute lymphoblastic leukaemia – about 80%) while the remaining 20% have either AML (acute myeloid leukaemia) or CML (chronic myeloid leukaemia).

Symptoms include anaemia and lack of energy, abnormal bleeding and bruising and susceptibility to infections.

Brain tumours

These account for about a quarter of all cancers in children and young people. Symptoms include one or more of: headache, sight and balance problems, nausea and vomiting, clumsiness, gradual decline in school performance, changes in personality and behaviour, lethargy and irritability, sleep or hormone disturbances or seizures.

Information on brain tumours

The book *Returning to School – A teachers' guide for pupils with brain tumours* deals with all aspects of brain tumours and includes practical strategies for the classroom. Hard copies can be obtained by contacting www.cerebra.org.uk and a downloadable pdf version is available on www.royalmarsden.org

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Lymphomas

Hodgkin's and non-Hodgkin's lymphomas make up about 10% of all cancers in children and young people. The lymph nodes may be enlarged and are not usually painful. They may be detected on a routine chest x-ray. There may also be fever, weight loss and fatigue.

Neuroblastoma

This is a cancer of the nerve cells, which commonly develops in the back of the abdomen or the chest, or in the adrenal glands near the kidneys. It is usually detected as a lump and can spread to the bones. It usually occurs in very young children and is rare in adolescents.

Kidney tumours

Wilms tumour is the most common kidney cancer; it usually appears before the age of seven. There may be no symptoms other than a lump in the abdomen. Adult type renal cell carcinoma may be seen in adolescents.

Bone tumours

Osteosarcoma and Ewings sarcoma both affect the bones, usually in teenagers. Pain and swelling are the first symptoms; they are often confused with sports injuries. If 'injury' symptoms persist, further investigation is needed.

Rhabdomyosarcoma

A cancer which arises in muscle cells in the head, neck, chest, abdomen or limbs. A noticeable lump is often the first symptom.

Germ cell tumours

Testicular and ovarian cancers are the most common of these and usually show up as a lump, often with no other symptoms.



Retinoblastoma

This is one of the few cancers which can be hereditary, usually occurring in very young children. It affects the back of the eye. Symptoms are a white pupil which does not reflect the light, or a painful red eye. Some children cured of retinoblastoma are at increased risk of second cancers later in life.

Liver tumours

These are very rare indeed and can be either primary (starts in the liver) or secondary (spreads to the liver from other parts of the body). Common symptoms are a painful swelling, weight loss, nausea and vomiting and sometimes jaundice.

Adult type cancers in adolescents

Exceptionally, a common adult cancer can be seen in adolescents. These cancers include thyroid and adrenal gland tumours, cancer in the digestive or reproductive systems and skin cancer.



Treatment for cancer

When a child or young person is diagnosed with cancer they are likely to be treated in one of the major UK paediatric or teenage cancer treatment centres of which there are more than 20. Often the care of the patient is shared with their local hospital, so it is quite normal for your pupil to spend time in the specialist treatment centre as well as in the local hospital.

The treatment will depend on the diagnosis, stage of disease, age of patient and other individual factors. The duration of the treatment can be from a few months up to three years. Treatment may consist of one or a combination of several of the following:

- Chemotherapy
- Radiotherapy
- Surgery
- Stem cell transplant
- Steroids, hormone treatment, etc.

'The side-effects from the chemotherapy made me look different, feel different and act differently.' Joanne age 11

'The thing I fear most is that the cancer may return.' James, age 13

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Chemotherapy

Chemotherapy works by killing off rapidly dividing cancer cells and stopping them from reproducing themselves. The cancer cells become damaged and eventually die.

Normal cells which naturally grow quickly such as blood cells, hair follicles, the inside of the mouth and intestines are also temporarily affected. This can produce unpleasant side-effects from the chemotherapy.

Many different drugs are classified as chemotherapy. The patient may be prescribed one or a combination of several drugs which are then given either orally or via some form of injection (intravenously). The treatment is planned and measured so that it progressively destroys the tumour cells rather than the normal cells and tissue.

During treatment for cancer, patients often require repeated blood tests and injections to enable chemotherapy and other drug treatment to be given and side-effects to be monitored. Many patients are therefore fitted with a special device called a central line, which is used to take samples of blood and to administer chemotherapy and other drugs, such as antibiotics. It can also be used to give blood transfusions. The advantage is that it reduces the need for needles or similar devices to be repeatedly inserted.



Limit physical activity

While a patient has a central line they should not take part in aggressive contact sports such as rugby. If fitted with a Hickman line the pupil will not be able to take part in swimming lessons.

It is unlikely that a pupil will attend school with a Port-a-Cath ('Port') accessed but occasionally it may be necessary.

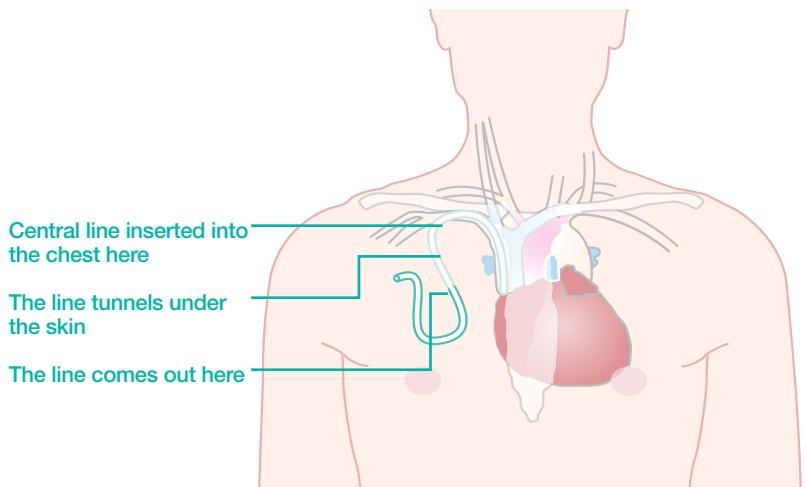
A central line is a fine plastic tube, which is inserted into a vein in the chest. The procedure is carried out under a general anaesthetic. There are two types of line, one that comes out of the skin (Hickman line) and one that is buried under the skin (Port-a-Cath). Once treatment is completed the line will be removed.

See examples of central venous access lines in figures right.

For definitions and medical terms, please see page 92.

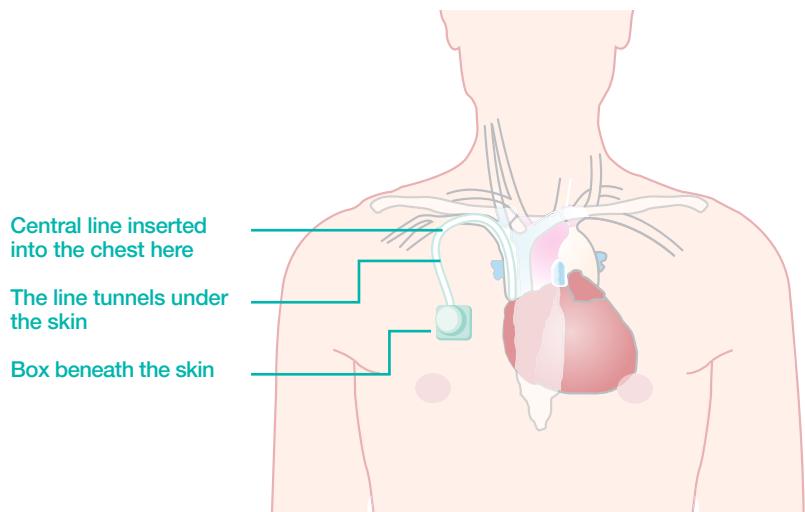
Hickman Line ©

Skin tunneled access



Port-a-Cath Line ©

Implanted port



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'I was impressed with the way the school liaised with the home tuition service and the hospital. By the time we were settled in back home after Dan's stay in hospital the home tutor rang to arrange the first visit.'

Dan's mother

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Side-effects from chemotherapy

Patients may experience one or more of the following:

- Anaemia and low blood count
- Risk of infection
- Hair loss
- Loss of appetite and weight
- Fatigue
- Pain

Anaemia and low blood count

Chemotherapy causes the bone marrow to be suppressed. This means that the bone marrow cannot make the usual number of healthy cells so the patient may need a blood or platelet transfusion. When the white cell count is low (neutropenia) the risk of infection is increased.

Risk of infection

There is an increased risk of infection throughout the period of having chemotherapy. This should not stop the pupil from attending school as they can cope with some minor infections quite normally.

Measles and chicken pox

Some infections, however, such as measles and chicken pox, can be very serious indeed. If the pupil is exposed to either of these, parents should be informed immediately. They will have to seek urgent medical advice as to whether their child needs further preventive treatment. Exposure in this context means close contact with an infected pupil such as being in the same class for at least part of a lesson, or having prolonged close contact in the dining hall or playground. The patient will be at risk for up to six months after treatment has finished (longer in the case of stem cell transplants), so future classes and teachers should also be informed.

Infection vigilance

A proforma measles, chicken pox and shingles letter can be found on page 93. The pupil's teacher or contact person at school should discuss with the parents when and if it is appropriate to send it out to the other families in the school. Professionals from the treatment centre can also give advice about this.

Hair loss and changes in physical appearance

Chemotherapy can make the patient's hair fall out. This can be a very upsetting problem for a young person at a time when they are already anxious about their diagnosis, their future and the unfamiliar changes in their body and their circumstances. Hair usually grows again quite normally within a few months of stopping treatment, though it may change slightly in colour or texture.

The pupil may wish to wear a wig, baseball cap, hat, bandanna or scarf. School rules may have to be waived for that particular pupil. Any special arrangements need to be communicated sensitively within the school, including to all staff involved in implementing the rules.

See also section on hair loss and self image, page 28.

Some drugs used in cancer treatment can cause facial puffiness or swelling. Others cause temporary mouth ulcers, rashes or skin lesions.



Loss of appetite and weight

The feelings of nausea and vomiting usually start soon after chemotherapy is given. Modern anti-sickness drugs are now very effective and are prescribed alongside the chemotherapy. The lining of the stomach may be affected and so the pupil may not want to eat and will consequently lose weight.

The pupil's weight is checked regularly and monitored at the treatment centre. If your pupil is losing too much weight they may need to be given nutrition through a nasogastric tube, which is inserted through the nose into the stomach. Alternatively a gastrostomy tube may be surgically inserted directly into the stomach. Then prescribed nutritional feeds are given overnight while the patient is asleep. Some pupils may feel quite relaxed about attending school with a nasogastric tube inserted, but the situation may need to be explained carefully to the other pupils. The pupil's appetite and weight usually returns to normal once treatment is over.

Some additional drugs or specific tumours may cause weight gain, which can be difficult to control.

'Monthly steroids make him tired and unable to concentrate.'

School nurse

Fatigue

Most patients will suffer from fatigue at some point. Chemotherapy may result in pupils tiring more easily, both physically and mentally. School attendance and activities may need to be modified to allow for this. Fatigue may be ongoing and can become chronic.

A separate section starting on page 44 deals with how fatigue can be managed in the classroom.

Pain

Certain medicines used in chemotherapy can cause ache or pain, commonly in the legs. Each person may experience pain differently from others. Constant pain is debilitating and may distract the learner in the classroom.

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Radiotherapy

Radiotherapy uses high energy x-rays to destroy tumour cells. It is sometimes used to treat the area of the tumour as well as the tumour itself, to reduce the risk of recurrence. Radiotherapy is usually given five days a week for several consecutive weeks with weekends off.

Before treatment begins it is necessary to undergo what is known as 'planning'. This allows the radiographer to work out the exact position in which to place the patient, and ensures that treatment is given to exactly the right area of the body each time. To ensure accuracy the patient may be tattooed with small markers.

Radiotherapy is painless and usually only takes a few minutes each day.

During the treatment the patient must lie perfectly still to ensure precise delivery of the radiotherapy. Sometimes it is necessary to give an anaesthetic to help the patient lie still.

Radiotherapy is a very effective treatment against cancer cells but it can cause some damage to healthy cells close to the area being treated. During daily radiotherapy, the pupil can still attend school if appropriate.



Immediate side-effects of radiation:

- The skin may become sore as if sunburnt
- Hair loss – which can be permanent
- Nausea and sickness
- Sore mouth and diarrhoea
- Headache
- Fatigue

See separate sections on hair loss on page 28 and fatigue on page 44.

Radiotherapy can cause some longer term side-effects which may not be immediately apparent. As time goes by the effect of radiation to any growing tissue may become more noticeable.

These are described in the section on long term side-effects on page 84.

Surgery

Some cancers are treated through surgery, sometimes on its own, but often in combination with other treatments such as chemotherapy and radiotherapy. The surgery may be carried out at a different hospital, but the surgeons will work in collaboration with the oncologists at the primary treatment centre.

What surgery is used, and when, will depend on a variety of factors such as the size and position of the tumour in the body and the speed at which the illness is progressing. Surgery may range from a biopsy of suspected malignant tissue for laboratory analysis, to partial or full removal of affected tissue or bone. Only very rarely do patients need amputations. Instead patients with bone tumours are increasingly offered limb salvage operations (endoprostheses).

Following surgery there may be mobility problems when the pupil returns to school. This may require classroom changes; each case will need to be assessed individually.

See the section on mobility and physical education on page 47.

Many patients undergo regular lumbar punctures (insertion of a hollow needle into the spine) which involves a general anaesthetic and being in hospital most of the day.

'During treatment the teachers and pupils made allowances for Simon. He very much needed that to have carried on but they seemed to expect that he would be "back to normal" the minute treatment was finished. After all this time he still struggles to perform and keep up.' Simon's dad

Example of endoprosthesis



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Stem cell transplant

Some patients with high risk or relapsed leukaemia or lymphoma or certain solid tumours may need high dose therapy with stem cell rescue. This is commonly known as a bone marrow transplant, although often the stem cells are collected from the blood stream. An autologous transplant uses the patient's own stem cells. An allogeneic transplant uses stem cells taken from another person, such as a brother or sister. Allogeneic transplants can also use unrelated donors' cells.

The patient is given very high doses of chemotherapy, sometimes also radiotherapy, in order to destroy any remaining cancer cells. This also destroys their stem cells and bone marrow. The bone marrow is replaced by new stem cells infused into the blood stream through a drip. The patient is usually kept in isolation for 2–4 weeks while the new cells find their way through the bloodstream into the bone marrow, where they start to make new blood cells.

The patient will need antibiotics because they have no resistance to infection. They may also be given a growth factor (G-CSF), which enables the stem cells to mature and facilitates recovery after the transplant. Blood and platelet transfusions will also be needed. When the blood cells have matured to a safe level, the patient can be discharged from hospital but will still require treatment and careful monitoring.

Side-effects

This treatment is potentially very dangerous as well as physically and emotionally demanding. Serious infections and bleeding can be perilous. The patient and their family will receive careful counselling and support when making their decision to go for a transplant as well as during and after treatment.

Loss of fertility is usually a side-effect of the treatment for both boys and girls. Graft failure, where stem cells fail to produce enough blood cells, can lead to repeated infections, bleeding, bruising and anaemia. Total failure is rare and will require a second infusion of stem cells if at all possible.

Graft versus host disease (GVHD) can cause sickness, diarrhoea, jaundice or severe skin rash during the first 100 days after the stem cell transplant. The new cells (the graft) can react against the patient's tissue (the host) causing reactions that weaken the patient. Chronic GVHD occurs later on and may include skin and breathing problems, mouth and eye trouble, muscle weakness, stomach difficulties and repeated infections.

The entire process of a transplant is extremely complex and will mean absence from school for between 3–9 months in total. It is important to report contact with chicken pox, measles and shingles for at least 12 months after the pupil's return to school. The pupil may have sensitive skin and should avoid direct sunlight. There may also be restrictions on the food they can eat.

Close consultation with the parents and the treatment centre is essential.



'Wayne cut himself in a DT lesson and bled profusely, sending the school nurse into a spin. No one had informed her that he might bleed badly even from a small cut.' *Wayne's form teacher*

05

Long term follow up

Most children and young people do not have any serious long term problems after their treatment for cancer. However, everyone should attend a follow-up clinic where they are checked for any problems that may arise. If there is no recurrence within five years, most can be considered cured, though they should continue to be monitored annually until they are 18 years old.

Long term problems may include:

- Growth and development problems
- Kidney, heart or liver damage
- Behavioural and psychological changes
- Effects on intellectual development and education
- Effects on puberty and fertility
- Fear of relapse
- Chronic fatigue

Growth and development problems

Radiotherapy can have important effects on growth and development. It may affect growing bones, so the child or young person may not grow as tall as expected. If a part of the body such as a leg has been irradiated it may end up smaller than the other. Some children, especially those who have had radiotherapy to the head, may need regular injections of synthetic growth hormone. Other hormones can be affected and may need replacing (tablets or regular injections).

Kidney, heart or liver damage

Some drugs can have a permanent effect on the heart and lungs after treatment has ended. Your pupil may need regular echocardiograms (heart ultrasound) and lung function tests when they return to the treatment centre for follow up appointments.

Sometimes the kidneys are impaired by the treatment and it may have been necessary to remove one kidney. It is perfectly possible to function with one good kidney.

Some children and young people may also need long term medication to alleviate any damage to organs.

Behavioural and psychological changes

Some drugs can cause headaches, dizziness, anxiety and restlessness or sleeplessness. Your pupil may also find it hard to concentrate. It is advisable to talk to the parents if you have any concerns about behaviour or general well being. Some young people continue to feel very 'different' from their peers and may need psychological support for months or years.



Effects on intellectual development and education

A pupil's intellectual development is likely to be affected if they have had radiotherapy to the whole brain or have been treated with certain chemotherapy drugs. They will probably need a statement of special educational needs and additional support with their education. All pupils with a diagnosis of cancer should be placed on 'school action' as soon as possible after diagnosis.

The effects on intellect are not necessarily static but may gradually become more noticeable over time. Schools should be guided by the parents and may need additional advice from the treatment centre. Clinical psychologists may offer insights and advice on benchmark testing and how to manage any cognitive deficits.

Effects on puberty and fertility

A number of treatments can affect puberty and fertility. These include radiotherapy to the brain, pelvis or lower abdomen; total body irradiation; surgery to the ovaries, womb or testicles; and certain chemotherapy drugs.

The prospect of being infertile can be devastating for patients and their families. Psychological support may be needed, and the pupil may be particularly sensitive in lessons on or discussions about reproduction.

Older boys may be offered sperm banking. This can be a very challenging process for someone on the brink of discovering their own sexuality while at the same time facing up to a life threatening diagnosis.

Fear of relapse

The fear of a relapse can dominate a pupil's and their family's life to the extent that they will need counselling or other professional help. The general psychological welfare of a patient is monitored by the treatment centre but teachers may be the first to notice if things are not quite right and should not hesitate to communicate their concern to the family or to contact the treatment centre for advice.

Chronic fatigue

Some patients experience fatigue which can last for months or years after treatment has finished. It can seriously interfere with their daily routines and general lifestyle.

A separate section on page 44 deals with fatigue and its impact on education, including strategies for the classroom.

For definitions and medical terms, please see page 92.

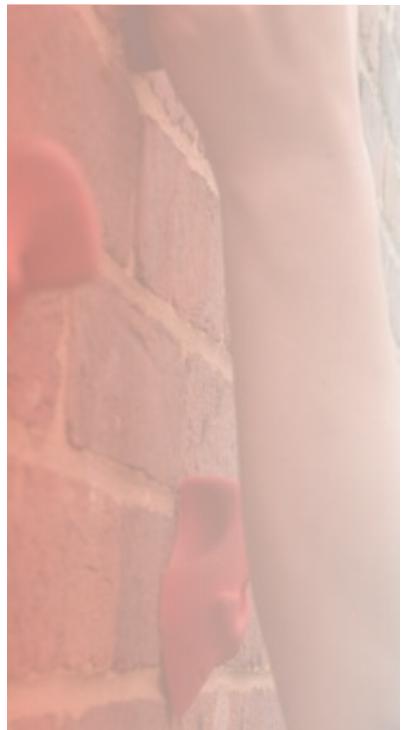
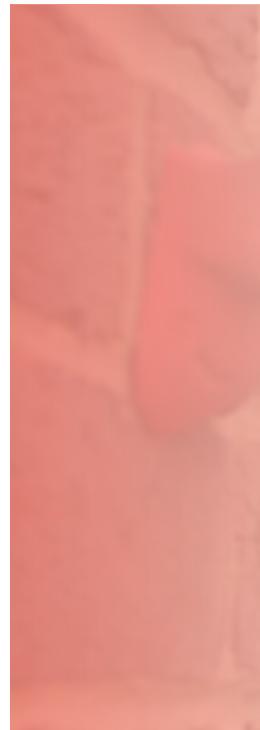
The publication

Returning to School – A teachers' guide for pupils with brain tumours has useful chapters on speech, language and communication as well as cognitive difficulties.

06

Information and support





'When we heard the word cancer we thought that was it! We had no idea just how much treatment is available now and how cure rates have increased over the years. We have every reason to be hopeful for the future.'

Parents of a 13 year old with non-Hodgkin's lymphoma

'I have been in a place of no hope – I did not want to be there – thankfully I no longer am!'

Recovering patient, age 18

'There is more to life than not dying.' *Long term survivor, now an adult*

And finally...

It is clearly important that support and understanding is available for any pupil, including someone treated for cancer. Many schools are getting it right and are able to help their pupils to recover, to catch up and to move on. Thankfully that is the outcome for most young people.

As cure rates for cancer improve it is increasingly crucial that the education and schooling of children and young people is comprehensive and robust enough for them to progress into adulthood and lead meaningful and fulfilling lives.

This highlights the importance of schools being able to tune in to a pupil's needs, to revise their expectations in the light of sometimes rapidly changing circumstances and to support them steadily and effectively.

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Recommended reading for when a pupil dies

- 1 *The Struggle To Be Strong*: True stories by teens about overcoming tough times. Al Desetta, Sybil Wolin. ISBN 1-57542-079-1
- 2 *When People Die*: A book for teenagers. G. Williams. ISBN 0904265765
- 3 *Straight Talk About Death for Teenagers*: How to cope with losing someone you Love. E.A. Grollman. ISBN 0-8070-2501-1
- 4 *Chicken Soup for the Teenage Soul*: Stories of life, love and learning. J. Canfield, M.V. Hansen, K. Kirberger. ISBN 978 0091 826 406
- 5 *Losing Someone you Love*: Shared experiences of the death of a sibling. E. Richter. ISBN 0399212434
- 6 *Helping Teens Work Through Grief*: Useful hints for professionals working with bereaved teenagers. M. Perschy. ISBN 0415946964
- 7 *Good Grief*: Exploring feelings, loss and death with teenagers and adults. B. Ward. ISBN 185302348
- 8 *Making Every Day Count*: Daily Readings for Young People on Solving Problems, Setting Goals & Feeling Good About Yourself. P. Espeland & E. Verdick. ISBN 1-57542-047-3
- 9 *Making the Most of Today*: Daily readings for young people on self awareness, creativity & self-Esteem. ISBN 0-915793-33-4
- 10 *The Dying and Bereaved Teenager*: Aniticipatory grieving, dying and bereavement. J. Morgan ISBN 0914783440
- 11 *What on Earth Do you Do When Someone Dies?* A guide for older children. T. Romain ISBN 1575420554
- 12 *Facing the Death of Your Child*: Advice about preparation for death, grief and life afterwards. L. Edwards & J. Palmer (CCLG and RMH). ISBN 0-949015-57-1
- 13 *Two Weeks with the Queen*: 12 year old Colin finds it hard to accept that his brother is terminally ill. A new friend helps him to express his feelings of grief. Morris Gleitzman. ISBN-0141-303-00X
- 14 *See Ya Simon*: Nathan recounts the final year he spent with his best friend and how they made the best of it. David Hill. ISBN 014 036 3815
- 15 *The Charlie Barber Treatment*: 15 year old Simon initially clams up but is finally able to express his grief after his mother's death. Currently out of print in UK but available on Amazon USA.
- 16 *A Heartbeat Away* by F. Lane Fox: A collection of writings, poems and extracts from many sources that chart the journey of the bereaved through grief, rage and anguish to hope for the future. (The Child Bereavement Trust)
- 17 *I Never Told Her I Loved Her*: Frankie finds it difficult to cope after her mother's death and focuses on all the hard times and quarrels. Talking to her dad eventually enables her to think about her future. S. Chick. ISBN 070 434 9477
- 18 *The Grieving Teen*. Written for and about teenagers in various grieving situations incl. guidance and explanations. Helen Fitzgerald. ISBN 0-684-86804-0
- 19 *A Teenage Guide to Coping With Bereavement*: Practical advice and guidance from a teenager who has had to cope with her confusing emotions after a loved one died. Available from The Child Bereavement Trust
- 20 *The Sad Book*. A poignant illustration of how sadness takes hold after the death of the author's son and the things he does to try to cope with it. Michael Rosen ISBN 978 1406 313 161

Contacts and support organisations

The Royal Marsden Hospital NHS Foundation Trust
www.royalmarsden.org

Children and Adolescent Unit
Downs Road
Sutton, Surrey SM2 5PT

Information about individual cancers, the hospital, services offered, research activities and online versions of support books for teachers.

Specialist Schools and Academies Trust
www.specialistschools.org.uk

21–24 Millbank
London SW1P 4QP

Practical support to the transformation of secondary education in England in partnership with business and the wider community.

Many of these websites have clear information and useful links:

Cancerbackup
www.cancerbackup.org.uk

Information on different types of cancer: 70 booklets and 300 factsheets on cancer, its treatment and practical issues of coping. Information on support groups throughout the country.

Cancerbackup also runs
Teen Info on Cancer (tic)
www.click4tic.org.uk

Gives cancer information written specifically for young people, and hosts an online community of young people affected by cancer.

Cancer Research UK
www.cancerresearchuk.org

Comprehensive cancer information site from a charity dedicated to cancer research and providing up to date information.

Children's Cancer and Leukaemia Group (CCLG)
www.cclg.org.uk

Coordinates research and care for children and their parents. Guides and booklets for parents, children and schools that can be downloaded. Useful links for support groups.

The link www.childcancer.org.uk/allPublications/internet-leaflet provides guidance on how to get the best from the internet in relation to information about cancer.

CLIC Sargent Cancer Care for Children
www.clicsargent.org.uk

Information and support for children and young people with cancer, their families, and schools. Detailed regional information and a monitored message board for anyone affected by childhood cancer.

Macmillan Cancer Support
www.macmillan.org.uk

Improves the lives of people affected by cancer. Practical, medical, emotional and financial support (including a youth helpline). Promotes better cancer care.

They provide practical, medical, emotional and financial support (including a youth helpline) and push for better cancer care.

Teenage Cancer Trust
www.teenagecancertrust.org

Schools programme to improve awareness of cancer. Focuses on the particular needs of UK teenagers and young adults with cancer. Funds and organises support and information services for patients, families, schools and health professionals. Useful links to specific websites for teenagers.

The Adventures of Captain Chemo and Chemo Command (By Benjamin de Garis)
www.royalmarsden.org/captchemo/

An interactive and educational computer game designed to inform patients, family and friends about treatment with chemotherapy.

06

'The teachers have been absolutely brilliant! They spoke to groups and to individuals. They created a supportive and understanding ethos and Simon has never been teased about his looks or his illness.'

Simon's mum





06

Medical terms

Benign

Non cancerous

Biopsy

Removal of a small piece of tissue for examination in order to establish a diagnosis

Blood count

The number of cells of different types contained in a sample of blood

Brain stem

Connects the brain to the spinal cord and involves bodily functions such as breathing, blood pressure and heart rate

CAT or CT scan

X-ray procedure in which a computer is used to produce a three dimensional image

Central line (Hickman line or Port-O-Cath)

A long plastic tube that is inserted, under anaesthetic, into a large vein near the heart. Central lines are used to take blood samples and give blood and medicines

Chemotherapy

Treatment using one or more anti-cancer drugs

Endocrinologist

A medical specialist who treats hormonal and growth problems

Intravenous

Directly into a vein, such as drugs given through a drip

Malignant

Cancerous

Metastasis/metastases

Cancer which has spread from the place where it started

Methotrexate

A chemotherapy drug that is given as a treatment for many types of cancer

MRI scan

Magnetic resonance imaging – magnetic waves rather than radiation used to produce a picture for diagnosis or for monitoring treatment

Neutropenic

Having less than the normal number of the white blood cells which would help fight 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 sick children and young people

Palliative

Relieving symptoms and easing suffering when the option of curative treatment does not exist or in addition to curative treatment

Primary

Original site of cancer

Prognosis

The outlook or expected outcome of a disease and its treatment

Radiotherapy

The use of radiation to treat cancer

Relapse

The return of symptoms of disease after a period of good health; reoccurrence of a tumour after treatment

Remission

A period of good health when there is no longer any visible sign of cancer

Tumour

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

Ultrasound scan

Ultrasound waves used to produce a picture for diagnosis or for monitoring treatment

Measles, chicken pox and shingles letter

Proforma letter for schools to send out before the return to school of a pupil with a reduced immune system

Dear Parents

Re: Measles, Chicken Pox and Shingles

Please may we ask for your cooperation in a vitally important matter?

One of our pupils is receiving medical treatment for cancer. This puts the pupil at serious risk if exposed to measles, chicken pox or shingles.

The best way to protect a pupil from measles is for all pupils to be immunised against measles. Please discuss measles immunisation with your GP if your child is not already vaccinated. If you suspect your child has measles you should let the school know immediately.

Our pupil is also at risk from chicken pox and would need to be given an injection within three days of contact. Please let us know immediately if you suspect that your child has chicken pox.

It is also very important that you let us know if anyone in your household has shingles.

Your own child is not at any risk whatsoever from this situation. However, the health and wellbeing of our pupil with cancer may be at serious risk. We depend on the co-operation of all parents and know we can rely on your help.

Many thanks.

Yours sincerely,

Headteacher

06

Pupil details

This list can be used to keep an accurate and up-to-date account of the pupil's progress and treatments

Name _____

Date of birth _____

Diagnosis _____

Treatment & details _____

- Operation
- Chemotherapy
- Radiotherapy
- Other

Treatment Centre _____

Tel _____

Consultant _____

Tel _____

Psychologist _____

Tel _____

Nurse _____

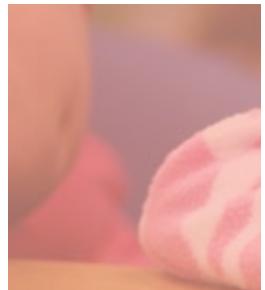
Tel _____

Hospital teacher _____

Tel _____

CLIC Sargent Social Worker _____

Tel _____



It's a good idea to photocopy and share this information with any teacher responsible for the student. One teacher should take responsibility for the dissemination of this information, and ensure it is kept current and safe.

Notes

06

Checklist for schools

Immediately

- Identify and name a contact teacher (p 4, 10)
- Inform staff and pupils according to family wishes (p 16–21)
- Place the pupil on ‘school action’ (p 38)
- Draw up an individual education plan (p 38, 42)
- Provide suitable work and materials for the pupil (p 9)
- Provide information about pupil capability and a programme of work (p 9, 12)
- Notify the Local Authority or Educational Welfare Officer of prolonged absence for medical reasons (p 12)
- Liaise with home and hospital teaching services (p 13–15)
- Ensure sibling needs are considered and their teachers are informed (p 22–24)
- Arrange home tuition and liaise with the home tutor (p 25)
- Ensure the school has a clear policy for pupils with medical needs (p 9, 26–27)

Exams

- Ask the examinations officer to make special arrangements (p 36–37)
- Inform the pupil of changes to procedures in public exams (p 36–37)

Ongoing

- Keep in regular contact with the pupil and family (p 13–15)
- Ensure suitable work from individual subject teachers is provided (p 16)
- Encourage fellow pupils to maintain contact with their sick friend (p 20–21)

- Circulate letters about infection risks when requested by the family or health professionals (p 12, 78)
- Inform staff and pupils sensitively about developments and changes (p 66–69)
- Invite a nurse and other professionals to speak to staff and pupils (p 15)
- Arrange for special educational support and staff training (p 42)
- Agree changes to school rules and circulate arrangements to all staff (p 16, 28, 29)
- Prepare for transitions – inform new teachers, school and support staff (p 38)
- Regularly revise the pupil's timetable and school day as necessary (p 44, 46)
- Teach the class general awareness of illness and supportive strategies (p 20–21)
- Prevent teasing and bullying through teaching strategies, clear communication and sanctions (p 30–31)
- Arrange for ease of movement around the school (p 47–49)
- Follow up signs of distress, poor performance or school phobia (p 51, 54, 59)
- Provide opportunities for extra support and catching up with work (p 42, 51)
- Include the sick pupil as far as possible in all activities (p 10, 36, 47)
- Inform staff about long term effects such as fatigue (p 44)
- Adjust expectations of academic performance (p 51)
- Provide strategies for improved learning, concentration and memory (p 62)



Specialist Schools
and Academies Trust
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The Royal Marsden **NHS**
NHS Foundation Trust

For free copies and all other enquiries contact:

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Email: info@ssatrust.org.uk
Websites: www.ssatrust.org.uk
www.schoolsnetwork.org.uk
www.ssat-inet.net

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Company no. 2124695
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For further advice and information on education
and cancer treatment, contact:

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The Royal Marsden NHS Foundation Trust
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Surrey SM2 5PT

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www.royalmarsden.org