



Returning to school

A teachers' guide for pupils with brain tumours, during and after treatment
(Third edition)

The ROYAL MARSDEN
NHS Foundation Trust

CEREBRA 
Working wonders for children with brain conditions

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without whose vision both the first edition and this one would not be possible

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“A very special thank you goes to the patients, parents and teachers and all the other school staff who took part in the original study.”

This third edition and revised publication has been developed in a partnership between the Royal Marsden's Children and Young People Unit and the children's charity Cerebra. Both organisations are dedicated to the welfare of all children and young people diagnosed with a brain tumour. They both understand the importance of a pupil's well supported inclusion in school life and successful education.

The first edition has been used to great success both by schools and by families of children who have been diagnosed with brain tumours and has been very much appreciated as being a very useful resource. Both organisations are passionately committed to the welfare of children and share a conviction that the recommendations and examples in this resource will benefit and inspire all pupils with a brain tumour and their teachers.

As the UK's leading specialist cancer centre, the Royal Marsden is keen to share good models of patient support and clinical practice. This guide is intended to complement good models of outreach support on behalf of young patients, by enabling teachers and staff to support pupils and the school community more effectively during and after treatment for cancer.

At Cerebra we believe that being a family is about discovering life together. That's no different for families of a child with a brain condition - except that there are more challenges to overcome along the way. We believe the best way to overcome them is by joining families on that journey - at every step. First we use what they tell us to inspire the world class research and innovation that we support. Then we work with them to make the best use of the knowledge we develop. So that they can then go on to discover a more included, fulfilled and enjoyable life.

The Royal Marsden and Cerebra are indebted to the patients and families, teachers, schools and colleges who have been involved in sharing their experiences and stories for this guide. We hope this guide will serve as a useful tool for teachers and other school staff and help to ensure that school and education will be a positive and empowering experience for all pupils, their families and the school community.

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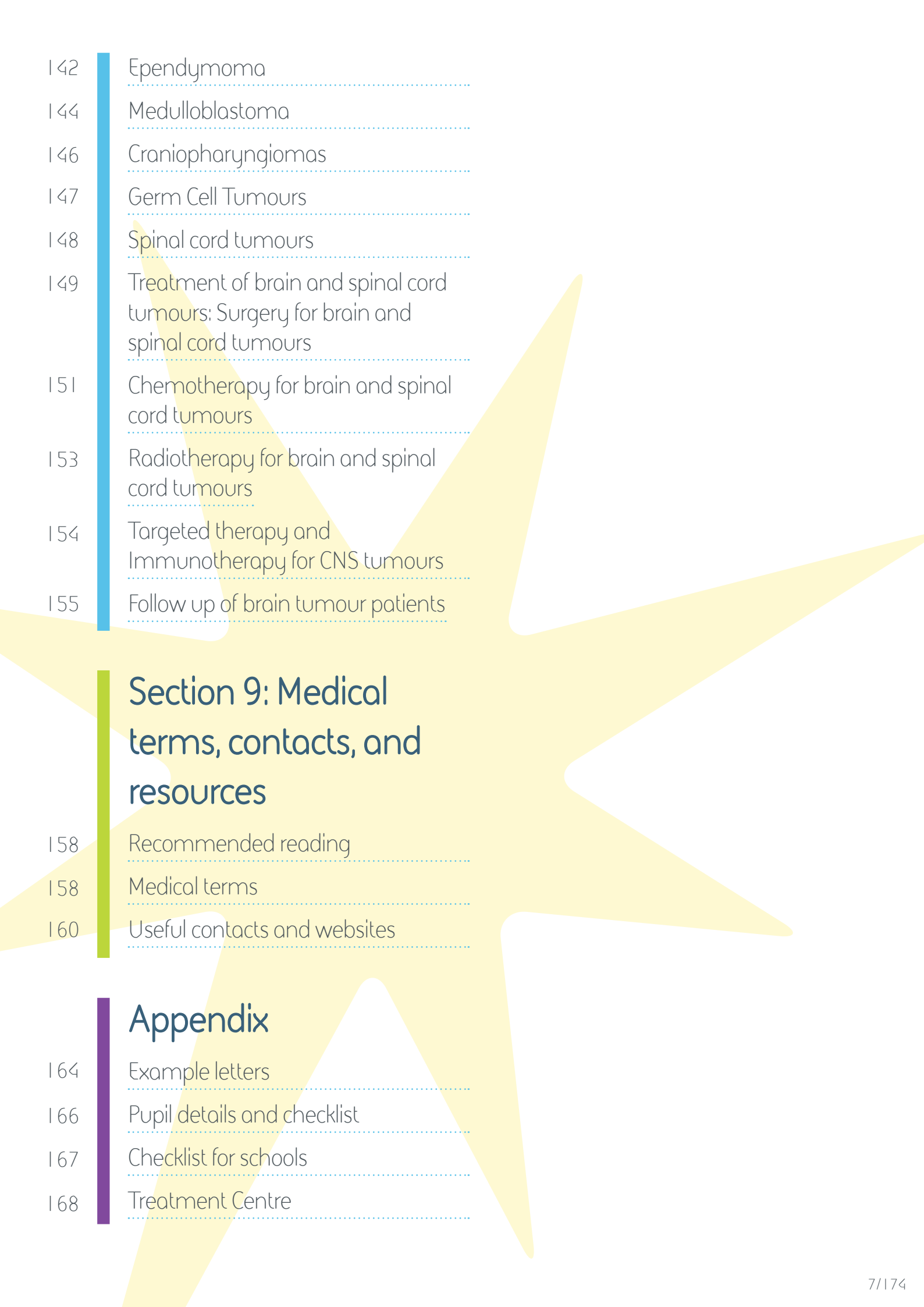
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Introduction

Aims of the book

This publication aims to guide teachers and schools faced with the task of supporting a pupil with a brain or spinal tumour (throughout the book 'brain tumour' will be used to illustrate both types of tumour), who may be absent for some time, or who may have sporadic attendance with a very serious illness and potentially devastating long term effects. It explains what the pupil may be going through both medically and psychologically. It will also offer practical strategies for ensuring a supportive reintegration back to school. Suggestions are given for how teachers, assistants and SENCOs can provide sustained and targeted support for pupils who face extended treatments, devastating long term side effects or an uncertain future. Many teachers will recognise methods and processes they already use successfully in class. 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 so their pupils can reintegrate back to school and have a chance of reaching their potential.

A diagnosis of a brain tumour 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. For children and young people who have been diagnosed with a brain tumour, successful reintegration into school life is of the utmost importance. This is true even for those whose prognosis is poor, and who may have a limited life expectancy.

To these pupils, school represents a resumption of normal life, with an opportunity to socialise, to engage with their peers and to benefit from the stimulation and rewards of learning and being part of a school community. It can greatly reduce the sense of isolation and loneliness which is an inevitable part of illness and hospitalisation. This can also act as an aid to recovery for the young person to feel included and have clear academic goals which reaffirm a belief in a fulfilling future.

For teachers and schools, meeting the needs of such pupils represents a major challenge. Most teachers reading this booklet will be faced for the first time with the prospect of a pupil with a brain tumour in their class, wanting to do their best for the pupil and yet perhaps feeling that they lack the confidence and expertise to do so. This can lead to a feeling of powerlessness and sometimes an idea, often misguided, that the family want to be left alone.



How to use this guide

Teachers, Teaching Assistants and SENCOs

This guide was originally aimed at teachers in secondary school and colleges, but we have found that primary school teachers have benefitted as well and therefore many of the strategies are easily adapted for both settings. We hope staff will extract, adapt and disseminate the sections they find useful. We strongly recommend that this book will not just be used for the first year of a pupil's school life when on treatment: transition between years and effective transfer of information are crucial so each time the pupil changes a year group, information and strategies need to be disseminated and clear communication is vital.

We trust the teacher or member of staff identified as a link person with the family, pupil and cancer treating centre will disseminate our recommendations and ensure all colleagues are informed of how to best 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 meet both social and academic needs and to allow for differentiation in lesson planning.

The 'checklist for schools' section found on pages 168-9 of this publication is a prompt for teachers to ensure they have considered and, where appropriate, acted on guidance as to how best to support a pupil with a tumour.

Health professionals

We suggest that the 'Pupil details form' found on page 166 is filled in by a health professional to ensure the information about the diagnosis and treatment of a pupil is correct and informative.

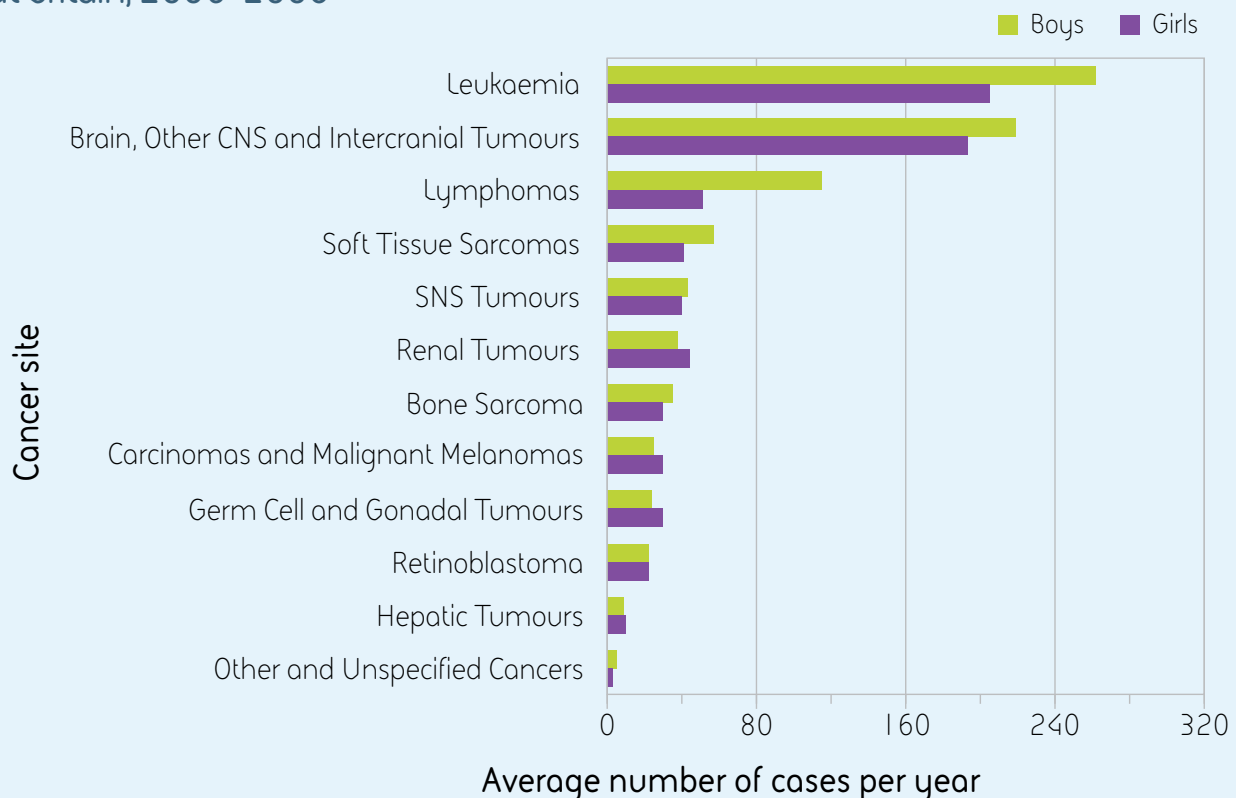
Background facts about brain and spinal cord tumours

The central nervous system (CNS) consists of the brain and spinal cord. Each year in the United Kingdom (UK) around 412 children below the age of 15 and around 275 teenagers and young adults (TYA) aged 15–24 years will be diagnosed with a CNS tumour, in other words a tumour of their brain or spinal cord (Cancer Research UK). Brain tumours as a group make up the second most common childhood cancer type in those aged under 15 (after leukaemia), and are also a very significant tumour group in the TYA population. Unlike in adults, where the most frequent brain cancers are 'secondary cancers' which have spread to the brain from a 'primary cancer' which arises initially in another part of the body (e.g. breast cancer), brain tumours occurring in children and young adults are usually primary brain tumours at the outset, i.e. arise initially in the brain.

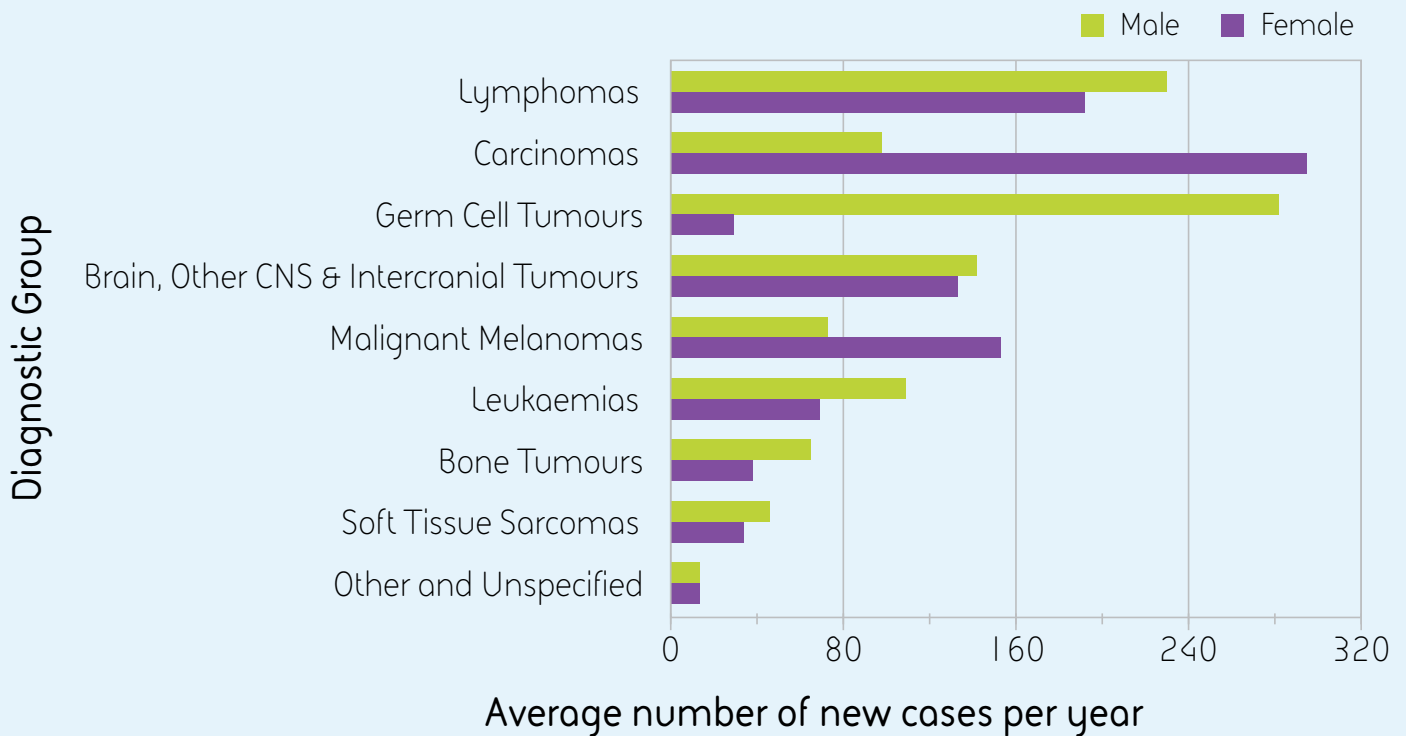
These tumours are very important as they can be difficult to treat and can cause significant morbidity and disability, which may be as a result of the tumour itself, the treatment thereof, or a combination of both, and may include short term and long term difficulties including effects on cognition and education.

Spinal cord tumours are very rare in children and in the TYA age group, but are considered alongside brain tumours since they usually arise from similar types of cells as brain tumours; additionally, some brain tumours may spread to the spinal cord and so therapy sometimes involves treatment of the brain and spinal cord.

Average number of new cancer cases diagnosed per year, children (aged 0–14 years) by diagnostic group (Brain/CNS Tumours: boys 219, girls 193, total 412) Cancer Research UK, Great Britain, 2006–2008



Number of new cancer cases diagnosed per year, TYAs (aged 15-24 years) by diagnostic group (Brain/CNS Tumours: males 142, females 133, total 275) Cancer Research UK, Great Britain, 2000-2009



Signs and symptoms of Brain and Spinal Cord Tumours

The symptoms and signs resulting from a CNS tumour may vary considerably depending upon the size and location of the tumour within the brain or spinal cord, and the age of the child. The symptoms can be due to a build up of pressure inside the head (raised intracranial pressure) caused by the tumour mass itself, or by a blockage to the normal circulation of cerebrospinal fluid around the brain and spinal cord causing the ventricles of the brain to swell, a term known as 'hydrocephalus'. This raised pressure results in headaches, sickness (especially sickness on waking from sleep) and drowsiness. These may be of sudden onset, or develop more gradually, but with increasing frequency and severity.

Other symptoms and signs are related to where the tumour arises in the central nervous system and may include:

- Seizures (fits)
- Weakness of the arms or legs, sometimes one-sided
- Unsteadiness when walking
- Problems with speech and/or swallowing
- Behavioural or learning difficulties; altered school performance
- Visual problems e.g. onset of a new squint
- Hearing problems
- Back pain or disturbed sensation
- Feeding difficulties or failure to gain weight and thrive (young infants)

If a tumour of the brain or spinal cord is suspected, a patient will undergo a scan (computerised tomography, 'CT' or magnetic resonance imaging, 'MRI') to confirm the doctor's provisional diagnosis. After this the patient will usually be referred to a paediatric neurosurgical centre where further investigations are performed on the tumour including a biopsy (where a piece of tumour is removed, stained and examined under the microscope by a pathologist in order to make a specific tumour diagnosis). The patient may also undergo additional surgery, including removal of as much of the tumour as is safely possible, and an initial surgical procedure to relieve any pressure on the brain (e.g. a third ventriculostomy, insertion of a drain or ventriculoperitoneal 'VP' shunt, to restore and assist the flow of cerebrospinal fluid discussed in further detail later in chapter 8).

Main types of brain and spinal cord tumours:

- Glioma:
 - ◆ Astrocytoma:
 - Low Grade Glioma (including pilocytic astrocytoma, diffuse astrocytoma and optic pathway glioma)
 - High Grade Glioma (including anaplastic astrocytoma and glioblastoma multiforme)
 - Diffuse midline glioma including brainstem glioma and diffuse intrinsic pontine glioma, DIPG
 - ◆ Ependymoma
- Medulloblastoma /Primitive Neuro-ectodermal Tumours (PNET)/Pineoblastoma
- Craniopharyngioma
- Germ Cell Tumours
- Rare tumours e.g. Atypical Teratoid Rhabdoid Tumours (ATRT), Choroid Plexus Carcinomas, others

See chapter 8 for a more detailed overview as well as for specific information about individual brain tumour types, including treatment and prognosis.

A large team of health care professionals is involved in the decisions as to how best to treat the child. The different treatments depend on the tumour type, its location, whether the tumour has spread, whether the tumour is benign (low grade) or cancerous (malignant or high grade) and the age of the patient.

Further treatment after surgery may include chemotherapy or radiotherapy.

In addition to the physical, psychological and social upheaval caused by undergoing treatment for a CNS tumour, learning, memory and cognitive problems are common, and tailored and differentiated educational support is vital, both during active treatment and in the longer term (see chapters 5 and 6). Rehabilitation is essential for all children with a brain or spinal cord tumour and many therapists may be involved including physiotherapists, occupational therapists, speech and language therapists, psychologists and dieticians.

Behavioural and emotional difficulties can result both from the tumour and the effects of treatment and need to be considered during long term follow up.



Brain injury/neuro-cognitive impact and brain tumours

Brain tumours and their treatment can result in a distinct pattern of problems when compared to other types of Acquired Brain Injury (ABI) or indeed other types of tumours and cancers. Brain injury presenting as 'neuro-cognitive deficits' (affecting processes such as thinking and memory) is a major issue for the child and family and obviously can have a major impact on education. Not all children have neuro-cognitive problems, but a substantial minority have severe ongoing issues and therefore we always recommend in-depth assessment and ongoing review of performance and abilities, since the earlier support is provided the more a child benefits.

The factors associated with developing brain injury include:

- Early age at diagnosis: the younger the child, the more severe the potential damage
- Tumour type, location, size and extent
- Raised pressure in the head (intracranial pressure caused by a tumour mass effect, or hydrocephalus – swelling of the ventricles in the brain caused by blockage to the normal flow of cerebrospinal fluid)
- Surgery
- Surgical complications (bleeding, infections, etc.)
- Prolonged seizures (fits)
- Radiotherapy (dose and extent)
- Chemotherapy

However, the disability and problems caused by a brain injury may also be compounded by other factors such as frequent school disruption, sensory deficits (vision and hearing), physical disability such as weakness of the limbs, as well as emotional and behavioural difficulties.

Neuro-cognitive problems include:

- Reduced non-verbal intellectual functioning
- Slowed physical functioning, slowness in reading and writing, slowness in thinking
- Memory deficits, especially working and short term memory
- Compromise of visuo-spatial processing
- Compromised information processing
- Susceptibility to distraction and reduced concentration
- Reduced attention and reaction times
- Historically, intelligence quotient (IQ) scores have provided a benchmark against which to measure changes in cognitive development after treatment. One major difference in the brain injury caused by radiotherapy, as compared to other trauma, is that decline in IQ is often progressive year on year in comparison to people without brain tumours who tend to have a stable IQ. This means that over a period of time (i.e. further from time of radiation and treatment), deficits become more apparent and exaggerated when compared to their peers. This is most likely a result of a failure to learn and acquire knowledge at a rate that is appropriate for the age of the child, rather than a loss of previously acquired knowledge (Mulhern, 2004). It is of note that any deterioration tends to slow down after the early 20s and then tends to even out. More details, chapter 5. As a teacher there is a great deal you can do to help and support your pupil and their family both during treatment and in the months and years that follow.

The role of the teacher

It can be difficult to gauge the appropriate level of contact and how much support is needed and welcomed by the family. It is vital to appoint one main contact person from the school to maintain communication. The school should ensure good open communication with the family to determine how the school can support education and ensure social inclusion. Ideally there should also be a policy outlining the approach to pupils with medical needs and reference to the special needs policy, which will be relevant to pupils with a diagnosis of a brain tumour. The SEN Code of Practice says teachers need to see parents of special needs children a minimum of three times a year. However it is best practice to see them more than this, by arranging regular face to face meetings, or using home to school diary and regular phone calls or e-mails would make a huge difference. As the pupil settles back in the timing of such contact can change.

Given there is likely to be cognitive, memory, attentional and potential learning problems and that we know early support and assessment are instrumental in preventing later damage, we always recommend the pupil is placed at least on School Action Plus level of Special Educational Needs (SEN). School Action and School Action Plus are now called SEN Support. With the new Education, Health and Care (EHC) plan they will need to be on this pathway as it will be likely an assessment and intervention will be necessary given the pupil may require special education provision.

Work provided 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 feeling well enough. As pupils are likely to be in and out of hospital with periods of recovery at home, it can be advisable to pass the work directly to the pupil and parents/carer, but this always needs to be followed up and contact maintained. It is usually useful to contact the treating hospital school and link in early with the home tuition service, in which case close liaison between all parties is needed.

Provision of work is in line with official guidance

All pupils should have access to as much education as their medical condition allows so they are able to keep up with the momentum of their education and to keep up with their studies (Department for Education 2013).





References:

Cancer Research UK (2013): <https://www.cancerresearchuk.org/>

Department for Education (2013) <https://www.gov.uk/government/publications/education-for-children-with-health-needs-who-cannot-attend-school> Ref DFE 00307-2013

Ensuring a good education for children who cannot attend school because of health needs
Statutory guidance for local authorities

January 2013 Farrell, P. & Harris, K. (2003).
Access to Education for Children with Medical Needs—A Map of Best Practice ref DCAF RR 393
February 2003

Mulhern, R., Merchant, T., Gajjar, A., Reddick, W. & Kun, L. (2004). **Late neurocognitive sequelae in survivors of brain tumours in childhood.** *Lancet Oncology*, 5 (7), 399-408

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When first
diagnosed with
cancer: what to do,
what to expect



Attending school during and after treatment for a brain tumour can be daunting for the pupil, their family and also for the school itself. The pupil may feel socially isolated after a period of worry and debilitating treatment and assessments. Their sense of identity may have altered as physical and psychological changes have taken place. Confidence and motivation may be at rock bottom and their energy level non-existent. Many worry about missing work and meeting coursework deadlines.

To minimise negative outcomes the young person is encouraged to return to school as soon as possible after initial diagnosis and treatment, even if only for a few hours or half days each week. It is always useful to arrange an early visit to the school to familiarise the pupil with staff and classrooms, to consider use of graded or very part time timetable at first, and planning this timetable with the pupil and family. Making up a welcome 'back to school' pack is invaluable, including such things as the timetable, school maps, photos of key staff and classroom. Socialising and re-adjusting to school routine is hard enough without the additional worry over changes in physical appearance, falling behind with work or bullying.

Some pupils still harbour a genuine fear of a relapse and this may undermine every aspect of school life. Their worry may need to be repeatedly acknowledged and brought to the attention of parents and health professionals, even years after the acute illness.

It must be gauged how the pupil themselves wants to be treated; the pupil may be very reluctant to communicate openly about their illness or difficulties. Pupils often just want to be treated 'normally' and to avoid any potentially stigmatising effects of illness; this can be a very difficult balance to achieve.

There are very good websites and organisations that can provide teaching materials about cancer; see Macmillan resources section, chapter 9.

"All I wanted was to be like everyone else, treated normal. Didn't always work out like that though..." -- Ahmed, aged 13

Keeping in touch with the pupil, appointing a key worker

When a pupil is first diagnosed with cancer the school's first task is to find the best way of communicating with the pupil, parents and the treating hospital if this is needed. Ideally a key worker from the school needs to be organised, a person who the family nominates and feels comfortable with. The contact person at the school will need to take the lead from the pupil and parents as to how much contact they would welcome and how wide a circle of teachers, other staff and pupils they feel should be informed. Some schools already have a home liaison officer, who may be used, especially with helping to fill out any paperwork and issuing lists of useful contacts, this could all be included in the welcome 'back to school' pack. It is crucial that it is agreed exactly what can be shared and what terms to use. Not all families are happy to use the word cancer. Once communication has been set up with the family, the family can let you know who the key worker is at the hospital, or they may prefer all communication to come from the family only.

Usually the family is in severe shock after the diagnosis, but once they have started to adjust to the initial situation they may welcome the opportunity to share treatment plans and more details with schools. Having just one key contact person at the school should minimise the need to repeat information and so lessen the burden on the family.

What teachers could do:

In the classroom:

- Continue to call the name on the register: it helps the class to remember their friend, and often sparks off impromptu updates.
- Continue to send circular letters home: keep the family informed and included.
- Try to create an atmosphere of support where problems can be discussed – by the pupil and/or their parents – to ensure as much continuity as possible regarding classes, teachers, support and supply staff.
- Make sure that the pupil can sit next to an identified friend in lessons to begin with.
- Reintegration to school may need to be gradual and the pupil could start by attending their favourite lessons and/or lunchtimes. Attendance can then be gradually increased depending on their confidence and level of fatigue. The pace of reintegration will vary greatly from one pupil to another.
- A separate and individualised timetable may be needed at first to accommodate for individual circumstances.
- For some pupils, difficulties returning to school and related anxiety may escalate to school refusal or 'school phobia'. Specialist advice should be sought from the hospital where staff are used to dealing with this problem. The hospital teacher or outreach nurse can often offer helpful advice and ideas.
- Invite outreach nurses or hospital teachers to speak to the staff, class or entire school about the pupil's brain tumour, treatment and side effects (see below).
- Sensitively talk about any potential changes in appearance or behaviour, if needed and family suggest.

What other pupils/friends can do:

They can do a great deal to make the pupil feel included:

- Send get well cards/thinking of you cards, individually or as a class.
- Send texts, e-mails or social network (take caution and think carefully about privacy issues).
- Send photos or make a video diary.
- Visit the patient, after checking with family and hospital (if in-patient); small groups are best and not too overwhelming.
- Do continue to invite them to parties and events, even if they can only pop in for a little while; if they can't come, maybe they can come next time.
- Encourage the other pupils in the class to include the pupil with a brain tumour in activities. Set up a buddy system, as maintaining a presence with peers is essential in tackling social isolation.

"I had a couple of friends who acted as my bodyguards. It was fantastic; they always came with me so I was not bumped in the mad rush and they also loved leaving classes early with me too!! We are still friends now."

-- Lisa, aged 15

"I was really hurt that some of my so-called friends seemed just to drop me; I wasn't part of their group any more, never invited to anything, so angry, but then I have made some other friends. It really hurt at the time... I have learned through this though and it is not always what you expect." -- James, aged 14



Useful pointers for staff to give out to friends of the pupil who is ill: (in this section 'friend' is the pupil with the brain tumour)

- Realise that wearing a cap/hat/bandana is partly to keep warm, but most importantly to cover a traumatic loss of hair. All teenagers worry about their looks, particularly hair, so quiet acceptance or compliments about the hat/wig/bandana would be sensitive!
- Understand that mood swings are likely and not to take them personally.
- Be aware that when your friend with a brain tumour snaps, 'I don't want to talk about it!' it usually means just then and not forever.
- Keep in contact if your friend is absent. If they are too poorly to chat on the phone or receive a brief visit you may be told by their parents. Try again later. A text message, other social media instant messaging or e-mail are other good ways to maintain contact.
- If they are too poorly to consider work they may still welcome 'gossip' from school. Keep them informed, even if they cannot take part.
- Invite your friend to parties, etc. but understand they may only stay for a short while or not at all. Continue to invite them every time.
- If a supply 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 defend themselves – again!
- Your friend could carry a note in their planner with a brief indication of the situation and special provision required.
- Do not bump into or wrestle with your friend. They may have a Hickman line or Port-a-Cath in the chest or a shunt in the head. Or they may just be feeling delicate.
- Try to include them in activities such as drama or swimming even if they cannot actively take part.
- Offer to carry bags or books for your friend if they are weak, tired or unsteady.
- Allow them to photocopy your notes, give them access to homework or help them catch up. They have usually missed a great deal and their pace of work may be slower.
- Be prepared to escort your friend to the medical room or elsewhere.
- Never stop supporting your friend – even when they are boring or grumpy. They still need you to be supportive.
- Stand up for your friend if others in the school make insensitive comments or take the Mickey. Report name-calling or teasing to staff.
- Always encourage the other pupils to share their feelings and reassure them that brain tumours are not contagious: you can't catch them and they are in fact very rare.
- The CCLG group has a useful "I have a friend with cancer" card with useful tips on it, which can be downloaded (CCLG, I have a friend card 2014) [https://www.cclg.org.uk/write/MediaUploads/Publications/PDFs/I_have_a_friend_who_has_cancer_\(Mar_14\).pdf](https://www.cclg.org.uk/write/MediaUploads/Publications/PDFs/I_have_a_friend_who_has_cancer_(Mar_14).pdf)

Communication with the family

Establishing open lines of communication with parents is an essential part of good educational practice. Parents are the experts on how their children function and of a young person's strengths or internal struggles which may be successfully masked in school. Some pupils do manage to appear as if they are coping, but are tired and stressed at home after school. Homework may then create real difficulties and cut across the young person's need for a social life as well.

Parents are potentially very useful allies to teachers in making sure that the young person's educational and social needs are fully understood in order to successfully meet their needs and realise their potential both educationally and socially. There are, however, areas of possible difficulty where parents and teachers may have a different perspective on the pupil.

It is important that parents, teachers and hospital align their expectations of the pupil. For example, teachers may feel that the parents have not adjusted their expectations sufficiently as a pupil may show cognitive decline due to treatment for a brain tumour. Alternatively, a parent may feel that the school is too prepared to accept a low level of performance. What is not needed is overcompensating for a capable pupil or disregarding genuine need. Both parents and teachers may be reluctant to share their concerns or observations frankly for fear of appearing demanding, anxious or inappropriate.

John was previously a high flyer academically with top marks in all subjects. On his return to school following treatment for his brain tumour his level of attainment fell to within the 'average' range.

"The school were delighted that John was even planning to sit his GCSEs. John himself was bitterly disappointed and suffered a loss of self-esteem because of his lower academic achievement." -- Mum of John, aged 16

"His parents felt that with a bit more support he would be able to perform in the 'above average' range and this would mean a great deal to him." -- Teacher of John, aged 16

"Mr Field rang us every Monday for an update. It was very good and very reassuring; we could chat about all our concerns and worries." -- Parent of Tim



- Try to meet with the pupil and his/her parents before returning to school, either in hospital or at home.
- Find out how much information the family wants to share with staff and pupils at school. The family may change their views as treatment progresses.
- Listen to concerns – arrange for regular progress checks. Arrange for the pupil to feed back to an identified member of staff with whom they have a good relationship.
- Reassure by informing them of possible strategies to put in place, whether adapting the physical surroundings or allowing special considerations. Be aware of the impact of a brain tumour on siblings and their schooling.
- Privacy is essential.
- Include the young person as much as possible.
- Accommodate the family's distress and have tissues at hand.
- Remember most families do want regular contact. Try to keep to a predetermined time to avoid intruding.
- Remember how religion, culture and customs can all influence how families deal with this experience. Do not assume you know what is right for the family.
- If English is not the family's first language, is an interpreter needed?
- Support the siblings; they will also be adjusting to what has happened and ideally offering them a safe place to go to or a safe person to talk to can help immensely. Support brothers and sisters who may be anxious about their ailing sibling. Some will have to make huge adjustments while their parents are away supporting the sick brother or sister in hospital. Ensure staff teaching siblings are included in the information being disseminated and advise how best to support them.
- Arrange for suitable work to be sent home to family, hospital school or home tutor.
- Keep in regular contact with the parents and pupil and, if agreed by the family, bring the other teachers and pupils up to date.

Guidance from medical and nursing teams

A member of the treating hospital or community nurse with parental permission will usually get in touch with you to discuss:

- Treatment plan: an outline of the treatment with suggestions as to when the pupil may feel able to do some work or attend school part or full time, and to discuss medical and emergency issues.
- Treatment plan and information about a possible return to school.
- What to do if there is a medical emergency.
- Measles and chicken pox can be life threatening to a pupil receiving chemotherapy or radiotherapy. It is advisable to send out letters to all parents asking them to alert the school if their child, or anyone they are in contact with, falls ill with one of these diseases. (A measles and chicken pox pro forma letter can be found at the back of this publication.)
- Attendance: encouraging the school to welcome the pupil whenever they feel well enough and it is medically safe for them to attend. This could result in a temporary 'come and go as you feel' policy. The education welfare officer should be notified about the nature of the absence. A part-time timetable should be considered when returning to school.
- School rules: allowing rules to be relaxed temporarily to encourage the pupil to attend school. This could include allowing wigs, hats, caps and bandanas; leaving class when in need of a rest, medication, or the toilet; allowing drinking water in class; staying inside with a friend in breaks; moving between classes when corridors are empty (leaving class a little early).
- School work: encourage the pupil to keep up with work as much as they feel able. It is useful to send them work in their favourite subject. Many pupils will have access to hospital school or to learning gateways from their own school and work can be made available over the internet. Not having any work sent through may lead some pupils to conclude the school has written them off or that they are unimportant; we need to help the pupil to feel that we all have confidence in their future.
- Exams: if the pupil is due to take exams, access arrangements and special consideration in exams can be arranged and must be discussed with the pupil, parents, school and examination officers. Many hospital schools are also examination centres, but this needs to be organised in advance.
- In-patients are usually taught by hospital teachers. They may liaise with you and ask you to send home some work so that the pupil is covering the same syllabus as the rest of the class.
- Creating a link for further communication between school and hospital. As a teacher you should feel able to ring the hospital for advice and information on how best to manage the pupil's reintegration or any concerns which occur regarding the pupil generally.
- An Education, Health and Care plan (EHC). This is discussed more fully in chapter 4 (The Education, Health and Care Plan 2013).
- Contact: professionals at the treatment centre can help you with questions or issues of concern – within rules of confidentiality. It is possible to ask generic questions that do not require discussions of a pupil's particular situation.

Consideration of home tuition

The primary aim of educating children and young people with brain tumours is to minimise disruption to normal schooling and allow pupils the opportunity to continue to learn and reach potential.

The medical team will discuss realistic expectations with the family both during and after treatment. It can be very helpful for parents if the school establishes early on the likely need or not of home tuition and contacts the Local Authority (LA) with a view to setting this up. The treating hospital can arrange a letter in support from the 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 clear access to education from the start, if it is clear that the pupil 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 a week, if they are educated at home because of illness, as long as their health permits it.
- In some education authorities or in circumstances where a pupil is due to sit public exams it is often more than 5 hours.

"Home tuition once it was there was really helpful. We never realised how different it was to have one to one and they ended up being a fantastic support and helped her to reintegrate back to school which at one point we doubted was ever going to happen." -- Mother of Bethany, aged 11

We recommend that if a pupil is receiving home tuition they should still be able to make visits to school now and then. This may be mainly for social reasons and this is important for their future re-integration back to school.

These visits do not directly impact on academic learning, and should not jeopardise the home tuition arrangements.

"The problem was it took so long to get home tuition sorted out (actually took weeks and weeks). Now I think we should have asked as soon as he started radiotherapy. I think the school just thought he could fit back in, but he was GCSE year and it was impossible to catch up." -- Mother of James, aged 14

Liaison between staff members/between year groups

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. It is clearly not essential for all staff to have all the information, except in situations where school rules may be compromised. For example, if a pupil has been allowed to wear a cap during hair regrowth, it is essential all staff including support assistants and dinner/midday supervisors are informed.

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

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

Promote sharing of school/pupil card

Pupil card: a card that the pupil carries to explain their situation/medical condition to any member of staff who challenges them; this will save having to repeat explanations. This can also include toilet breaks, lift pass and allowing leaving of the classroom.

Symptoms: teachers need to know which symptoms and side effects are expected and what to do, and which are of concern; this should be covered by the visit from the hospital or community staff.

Maintain expectations of behaviour and discipline

Most pupils prefer to be treated as much as possible like everyone else, and to have any special temporary needs accommodated discreetly. Some pupils may exploit the situation and get used to being the centre of attention and getting away with it. Pupils generally need to know the boundaries, but remember pupils may find it hard to readjust to the school routines and be genuinely sensitive and emotional or prone to tears and tantrums. (See chapter 6 on page 89)

In one school the Special Educational Needs Coordinator (SENCO) discussed the best way to disseminate information and updates. They produced an information sheet with a well chosen photo of the pupil, outlining some of the important issues including a brief explanation of what the pupil had been through, the treatment plan and likely side effects. With the family's permission, the information was distributed and put on the notice board, and this was used as a template for subsequent updates.



If a pupil then changes year groups the information must be updated and relevant staff informed. What can be fantastically well planned and all new and important in the first year may be forgotten by the next year group. Ensure a new sheet is done for each year and all staff who need to be kept informed. There have been many instances where what was a well planned integration back to school falls apart when the pupil goes up a year because the next year was not as well prepared. Having a transition person to hand over responsibility, and ensuring the key contact person either remains the same or a new one is chosen can smooth the way and avoid a very traumatic experience for the pupil.

We have reports of a mother who wrote significant updates, made copies and sent them through to the SENCO. This went on for some years, and the mother felt very frustrated that the school offered very little sympathy or help. When she finally confronted the school about this, it was discovered that all the updates had just been filed away by the SENCO and not disseminated, as the SENCO had incorrectly deemed the details to be confidential. If the key contact person had been liaising more helpfully and transparently this would and should not have occurred.

Confidentiality

Both parents and teachers may be reluctant to share worries. Parents may not want to appear demanding or overanxious. Teachers, on the other hand, are sensitive to parents' difficulties and may not wish to raise additional worries, and they are concerned about overstepping the boundaries. Every pupil has the right to expect their school will provide a safe and secure environment. This includes ensuring sensitive or personal information is kept confidential. However, teachers cannot guarantee absolute confidentiality as there may be a need to share information with other teachers who need to know.

- A misguided concern over confidentiality can serve as a barrier to communication. If parents and the pupil concerned are happy for information to be shared within the school, it should be disseminated to all relevant staff and updated regularly.
- Parents should be encouraged to pass on information to teachers regarding all relevant aspects of the pupil's medical care. Some parents or young people may have real reservations about communicating openly about the illness and related difficulties. This may stem from a desire to 'return to normal' and so try to minimise the potentially stigmatising effects of illness. Their wish needs to be respected although it may be a source of tension, particularly if teachers feel thwarted in their efforts to help the young person. Over time, the family may become willing to share information more openly.

Parents play a critical role in their children's education because they hold key information and insights. They have unique knowledge, strengths and experience and should be encouraged to share them with teachers.

It can be very hard for the pupil or siblings to have to field tricky questions. Clear and correct information is always preferable to incorrect or harmful rumours that may circulate outside the classroom.

Pupils should be encouraged to rehearse, either with school staff or parents, 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?"

"What's happened to your hair?"



Preparing and supporting staff for dealing with a pupil who has a brain tumour

Some staff may have personal traumatic experience of cancer and this may bring up raw emotions for them. It is important to recognise and accommodate such feelings and to offer support. Some teachers may have difficulty talking effectively to pupils about illness and fear of dying. Teachers should not feel compelled to do so but be able to draw on the experience of other members of staff or outside agencies. There needs to be identified support options and contact details available to all staff. If a member of staff really cannot deal with the pupil with a brain tumour, make sure there is someone available who can deal with the emotional aspects, to ensure the pupil and family do not feel rejected.

Some matters are outside the mandate and expertise of teachers. Do ask for guidance; it is always better to say you do not know but will find out, rather than being forced into answering a question where you are not confident either of the answer or what impact this could have.

There can be potential conflicts between the values, beliefs, customs and cultures within a school, and therefore awareness of differences is essential. In some cultures illness and in particular cancer is taboo or a source of shame for a family.

Bullying and teasing is always a potential problem. Act quickly and have a zero tolerance policy (see Teasing and bullying on page 43).

"Miss Jones was so upset. A relative of hers has just been through a similar scenario with a negative outcome!" -- Teacher of Bethany, aged 11

Preparing and supporting peers/other pupils

Most children and young people with brain tumours desire more than anything to fit in and be like everyone else. Having a diagnosis of a brain tumour immediately sets them apart from their peers. Some pupils genuinely want to keep the diagnosis totally to themselves, whereas others are happy to share. Every opportunity should be made to include the young person even if only in a passive role.

Talking sensitively to the immediate friends of a pupil with a brain tumour, or to the entire class or year group, can be invaluable, but the content must be shared and agreed by the pupil with the tumour and their family. You need to decide with the pupil if they want the information to go to teachers only, to their class, year group or entire school, and they may well decide to be absent when the talk takes place. Others like to be there, show off scars or booklets and dazzle people with their new medical vocabulary. A variety of problems may be anticipated and prevented even before they occur. Some young people find that the experience of having a brain tumour, the anxiety, hospitalisation and treatment, sets them apart from their peers who have no knowledge or understanding of the trauma they are going through. It can be a huge relief to all parties when that gap is bridged.

Preparation of classmates is important. If the school finds it difficult to know what to say to a class, others may be able to help: the parents of the brain tumour patient, the school nurse or local community nurse or the outreach nurses, psychologist from the treating centre and especially hospital teachers from the treatment centre.

Important: Any discussions in class or information passed to pupils must be in total agreement with the pupil and the family.

"James was upset he could not physically join in that season's football matches. The PE teacher encouraged him to turn up for matches and assist with refereeing and scoring. This allowed him to feel part of the team and was socially very important for him." -- Parent of James, aged 14

"There was no shortage of volunteers when I asked for someone to help Richard get around the school." -- Teacher of Richard, aged 13

"I like to carry his bags for him. Gets me out of lessons sooner!" -- Friend of Richard, aged 13

"I was amazed to see how genuinely concerned and supportive the class could be." -- Teacher of Richard, aged 13

"Because of the tubes we know not to wrestle with Paul. We still tease him, though." -- Father of Paul, aged 14

"I let them all look at the bump from the shunt and told them about it. Some of the girls were very squeamish at first but now it's cool." -- James, aged 14

"It is important for the school to support the sick pupil's peers. Allow them opportunities to talk about their feelings and worries. Reassure them that brain tumours are not contagious and are very rare!" -- Teacher of Bethany, aged 11

Siblings

The brothers and sisters of a young person diagnosed with cancer can be deeply affected in a variety of ways. They have to face up to great disruption and upset at home, and can often feel rejected, and have an uncomfortable mix of worry, resentment and guilt. Families of very ill children have to make huge changes to their usual way of life. Often a parent will live in the hospital with an ill child, sometimes for months at a time. Some parents share this role, but whatever arrangement is made, it inevitably means less of a parental presence at home, and less attention for siblings. Daily routines are often disrupted.

Take note: Teachers may find that the pupil fails to bring items to school, wears inappropriate clothes or is unable to complete homework simply because they are being cared for away from home or by a changing succession of relatives and neighbours.

Teachers should all be aware that the siblings of an ill child are likely to experience adjustment problems and may need very sympathetic handling including time and space to talk. With parental permission, all teachers should be informed of the situation. If the pupil agrees, it may be appropriate to talk about the situation to the whole class. Friends at school can be very supportive and understanding but may need to be shown how to provide support. Teasing and cruel comments are not uncommon. In some cases it may be appropriate to invite an outreach nurse or a hospital teacher in to school to speak to staff or pupils.

Frightening fantasies about their sick brother or sister are more likely to occur if the sibling is not told about what is happening at hospital. We often hear of rumours going round the sibling's school along the lines of "Your sister has cancer, she is going to die." In such cases the staff need to act promptly, agree on a party line and help the sibling find the right words to say.

We have included in chapter 9 a pro forma letter for schools to use to inform about the sibling of the ill pupil.

"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 heads slanted in sympathy, a look I have come to resent with a passion! My stomach immediately tied into a knot, I had goose bumps 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 sheer 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 real difficulty holding back the tears of relief." -- Sophie (aged 14), sister of Toby, aged 4

"We don't seem to have much of a family anymore." -- Sophie (aged 14), sister of Toby, aged 4

Some points to be aware of:

- Rumours about illness can quickly gather momentum in school. This can be very hurtful, cause panic or isolate pupils. The best way to prevent rumours or deal with them is to be honest, answer questions frankly and create empathy.
- Pupils may feel keenly the loss of parental attention, which can lead to feelings of resentment.
- Feelings of guilt can be strong and debilitating. The pupil may feel the illness is their fault, feel guilty for being healthy or have unsettled issues with their brother or sister.
- Some pupils may be very scared and have frightening fantasies about what is happening to their sibling, and can think it is their fault. Fantasies are more likely to take hold if the sibling is not kept informed about the up-to-date medical picture. Parents may experience a dilemma about what information they pass on to siblings, and at what point in time. Parental views on this must be respected, although it may be appropriate for staff to report to parents any undue anxiety they observe in their pupils.
- The pupil may irrationally imagine they are ill like their sibling or, conversely, ignore illness symptoms in order not to worry already overburdened parents.
- The additional stress experienced by siblings can manifest itself in a number of different ways. Anxiety, low mood, angry outbursts, poor concentration or somatic symptoms such as headache or tummy ache are all common.
- If appropriate, help the pupil in keeping a positive outlook.
- Channel attention towards the pupil's interests and provide feedback to parents about their achievements.

"After the nurse spoke to the class she agreed to pop in to Lauren's sister's class. They had just as many questions to ask. The sister looked so relieved! I almost don't know who I feel most sorry for!" -- Teacher of Lauren, aged 12

"I can understand why everyone always asks after my brother, but I sometimes wish they would also worry a bit about me." -- Sophie (aged 14), sister of Toby, aged 4

If the treatment ultimately fails, the sick brother or sister may die. Their sibling is probably left in a whirlpool of emotions and may need sensitive support for a long time. The school will need to inform the student body, but the sibling's needs must be sensitively considered before announcements in class or in assembly are made, or at future memorial ceremonies such as a tree-planting.



References:

CCLG (2014) I have a friend with cancer card:

<https://www.cclg.org.uk/publications/School/I-have-a-friend-who-has-cancer/IHAVEAFR>

The Education, Health and Care Plan 2013

<http://www.ehcplans.co.uk/>

Organisation offering support for brothers and sisters:

'Siblinks' Website: <https://www.sibs.org.uk/> Email: info@siblinks.org

Do contact the treating hospital for advice.

3

Getting back to school



Welcome back

Returning to school can be daunting after prolonged absence or debilitating illness. The pupil may feel socially isolated or think 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. Helping as much as possible and ensuring the pupil feels welcome and that both peers and staff want them back will help the child to make the first steps in re-engaging with school. To help ensure the pupil settles in and has all their needs met, do call in other professionals as early as possible to anticipate issues and create solutions. Consider involving education psychologists, occupational therapists, speech and language therapists or other specialist services which may be needed such as the visually or hearing impaired teams.

"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 my brain tumour can be up to a year long! I can't miss all that work!" – Alex, aged 14

Falling behind with work: the importance of differentiation and consideration of reducing number of subjects

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. Reducing the number of subjects is crucial if there has been a slowing of information processing or slowing of learning, as this will allow a better chance of the pupil being able to achieve better marks for a few subjects rather than failing at a larger number of subjects.

Repeating a year

Sometimes 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. This has to be negotiated very sensitively.

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, aged 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, Lisa, aged 15

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. Some pupils can see the challenges of a brain tumour as an experience that adds to their strength and that coping with it makes them stronger. Many, however, are preoccupied by how they are different and it can take a long time to come to terms with the 'new person' they are. 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 thin hair or a change to the shape of their face 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 can be preoccupied with their weight, appearance or dress. 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 or look very patchy. This might mean that there are bald patches rather than an overall bald appearance. Very few children actually have permanent hair loss.

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 bandana.

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 bandana in class even if this goes against normal school rules. On sunny days outdoors it is essential for health reasons.
- Any changes to school rules will need to be explained to the other pupils as well as members of staff, but exactly what is said needs to be agreed with the pupil and their family.
- 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 and midday supervisors.
- 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. Many pupils with brain tumours are on steroid medication for a period of time, or can have hormonal imbalances which can lead to a massively increased appetite, and there can be a significant weight gain or weight loss, which may leave permanent stretch marks and have devastating effects on their self-confidence. Some pupils may have a feeding tube inserted through their nose (nasogastric tube, usually referred to as an NG tube) 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. 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, the effect 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 will probably be needed during outdoor games and sports.

Friends

Ensuring the other pupils and friends are told what is happening and including them in welcoming their peer back will be instrumental in helping the pupil with a brain tumour to start belonging again. As in chapter two, ensuring the friends themselves have support is essential as it can be very difficult to welcome back a friend who can appear very different. (See chapter 6 for more information on peer relationships.)

"I still looked the same, but find it really hard to speak and drag my legs when I walk. It took ages before I made friends; they were different to the ones I had before. I was no longer one of the popular girls, my old friends seemed to have no patience or time for me and just ignored me. It was a really hard time and I felt so left out, but now I have made some different friends, they are real friends. I have learned a lot." — Ruby, aged 14

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 have been 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. Ensure the school's bullying policy is adhered to.

Cyberbullying or trolling 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 other risky behaviour.

"I'm bullied all the time – I've just become used to it. It toughens you up!" -- Simon, aged 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." -- Father of Abdul, aged 12

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
- Ensure the pupil feels listened to, and work out a way that the pupil can talk about bullying without feeling they are grassing on others
- Gently keep probing if you suspect bullying
- Take seriously all information about or signs of bullying
- Teaching about e-safety is important as targeting on social media, with a platform to hide behind is very common, but it can be very difficult to share when this happens
- 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
- 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 pupil 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,

Tests, exams and special arrangements

Apprehension about exams is difficult enough, but for those pupils with a brain tumour these anxieties can be overwhelming. The pupil may fear how they will cope in an exam as well as worry about the future consequences of a poor performance. If being treated for cancer means having to face lower results than they 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 many pupils it may be sensible to reduce the number of exams they sit, and also reduce the number of subjects they study so more time is available for support or guidance. Others may have to have the burden lifted altogether and delay all exams.

It is important that the school or exam board gains an accurate picture of that pupil's talents and abilities if large amounts of schooling and coursework have been missed due to prolonged illness. A sympathetic discussion between the school's exam officer, the candidate and the family regarding the best way forward should be arranged as early as possible in order to reduce worry and uncertainty. Even so, exam concessions cannot remove the difficulties faced by the candidate but may provide some assistance at a very anxious time. In some cases the only realistic solution for a pupil who has missed large amounts of schooling is to repeat a year.

For some this will be an abhorrent idea, especially when the pupil is concerned about fitting in and the reliance of friendships. Very careful negotiation will be needed, in order to allow the pupil a better chance of achieving, but balancing this with finding a way to keep up social relationships and not dismissing how important they are. Discuss the possibility sensitively and be flexible about subjects taken and year groups joined. It may also need to be discussed with senior education staff in the LA, who may have a policy of not allowing out-of-age placing in education.

"Sophie returned to school after six months' absence at the start of Year 11. It was clear she would be struggling to keep up with the demands of studying and attending lessons for 9 GCSE subjects. After discussion with her Form Tutor and Year Head, it was decided that she should continue with only 5 GCSE subjects. Her tutor contacted the college Sophie wanted to attend to find out which 5 subjects were essential for her chosen course. The other subjects were dropped, leaving Sophie time to concentrate on a manageable amount of work. Her school had clearly understood the importance of not setting Sophie up to fail." -- Mum of Sophie, aged 15

"I've realised now with Fatima that it is more important for her learning and wellbeing to be with her friends rather than in the correct set. I'm only sorry it took me so long to pluck up the confidence to bend the 'rules'." -- Mum of Fatima, aged 15

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 47). 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
- Arrange for enhanced grading or transfer of candidate in case the pupil is hospitalised or too ill to sit the exam. Many hospital schools are recognised examination centres

Teacher strategies for tests and exams

- Reassure the pupil that allowances can be made in judging their academic performance, and describe these 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; adjust your marking system to allow for the gaps, only testing work covered by the pupil

- Help the pupil plan their revision and provide a summary of work covered
- 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
- It can be difficult for pupils with a brain tumour to concentrate and sustain attention and they may easily tire. Arrange for a quiet room where frequent breaks, drinks and food will be possible
- 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 the history of well established need but must still meet the requirements of the assessment. Those with physical disabilities, profound hearing loss or sight impairment, or with a variety of learning disabilities, will be eligible. Someone treated for a brain tumour with significant and lasting side effects will fall into this category,

"Mr Smith is the kind of teacher who just makes life so much easier. He 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 Simon 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." -- Parent reflecting on when son Simon, aged 22, was at school

Access arrangements at the discretion of the examination centre:

- Up to 25% extra time.
- Breaks for food and drink or for rests – this can be extended up to 50% in line with Joint Council for Qualifications (JCQ) guidelines.
- A separate room.
- Transcribing and a reader if needed, particularly if both reading and writing speeds have been compromised.
- Prompter – this is especially important for those whose attention is compromised, reminding them to start the next question if they seem to have frozen.
- 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.
- Taking exams in a smaller group.

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. This is updated regularly.

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.

Department of Education 2013

School transitions

Transitions within school and between schools or college can be exciting, but also a time of worry and anxiety for any young person. This is particularly so for those with a brain tumour. Their natural ability to adapt to changing circumstances may have become impaired. They may find different environments overwhelming and confusing or take a long time to get to know new teachers or pupils, particularly if they have been away from school for some time.

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 most pupils who have been treated for brain tumours, the problems associated with treatment rarely disappear as soon as treatment is completed.

Strategies to reduce pupil anxiety during transition:

- Keep change to a minimum, whether classroom layout, seating plan or working patterns
- 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
- Consider social/emotional needs when allocating tutor groups, setting or streaming
- A teacher-designated seating plan accommodating special requirements
- Inform the new class or school well in advance, if possible, and make early visits and introductions with all relevant staff including SENCO
- Share successful strategies used for supporting the pupil in class or between home and school
- The new teacher should try to meet with the pupil and parents before the transfer and discuss any special considerations or needs
- Inform pupil in advance of any change and arrange support if necessary. Allow them to meet with a new teacher before any change
- Secure the assistance of outside agencies to assist with preparations, e.g. visually impaired or mobility team to check over any physical problems in school layout
- When 'setting' or 'streaming' try to ensure that consideration is given to meeting social and emotional needs as it can support and enhance the academic progress of an individual pupil
- Find out as much background information as possible. Speak to the pupil and parents as well as the previous teacher or school. Contact the hospital staff for an update, if cleared with the family. In particular, it is important to make a note of and disseminate any successful strategies for coping used at home or at school
- Allow pre-transfer visits by the young person and wherever possible their present and future teacher or LSA
- Ensure that reports and written communication regarding the pupil are shared between all relevant agencies
- Familiarise primary school pupils with secondary school features such as any complicated school layout, where the lockers are found

The learning problems associated with brain tumours tend to become more apparent with time, in line with increasing cognitive challenges at school. This is one reason why the pupil's learning and cognitive abilities needs to be reviewed regularly.

Further strategies:

- Share information and prepare in advance as far as possible. It is much better to foresee potential difficulties rather than wait for them to happen!
- Make a home visit or arrange for the LSA to do so. This will give a clearer picture of the pupil's abilities and circumstances and help break down future communication barriers between home and school.
- Familiarisation with secondary school features such as lockers, homework diaries and timetables is useful prior to start in year 7/key stage 3.
- Inform all staff of the pupil's needs, special circumstances, useful recommendations and strategies, subject to gaining the family's permission.

Good example of transition 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.

Based on working with Laura during the summer before her transfer, the SENCO produced an Induction Document for Laura and distributed it to her subject teachers and to school staff likely to be in contact with her. A copy was left on the staffroom notice board to inform new or support staff. The document had a picture of Laura at the front and contained information under the following headings: Special Educational Needs, Access to the Site, Social Integration, Position in Classroom, Concentration and Quantity of Work, Differentiation, Worksheets, Laptop Computer, Literacy, Numeracy, PE and Outings. The document, including the photograph, was updated annually! Such a brilliant initiative clearly belongs in an ideal world. For Laura, now in year 11, her years at secondary school have been happy and fulfilled and she has been able to achieve a great deal within her level of ability.



Physical Education and outings

Some young people returning to school after treatment for a brain or spinal cord tumour will find it very difficult to take part in Physical Education (PE) lessons, camps and outings. These difficulties may be temporary while the pupil is still fitted with a skin tunnelled catheter (also known as a Hickman line or a port). During this time it is inadvisable for the pupil to take part in contact sports. However, they should be included in activities as much as possible. They may have lost confidence in their physical ability and will need gentle persuasion to feel they can take part. Discussions must be had with the pupil and parents to work out the optimal way of persuading the pupil to take part, and how this can be done sensitively. The CCLG has written an excellent booklet in 2017 about sports and exercise https://www.cclg.org.uk/write/MediaUploads/Publications/PDFs/Keeping_active_during_and_after_treatment_2017.pdf

Barry fiercely resented the idea of having to return to school with restrictions on his participation in PE lessons. Being sporty both in and out of school, this was the worst aspect of his illness. Fortunately, Barry's PE teacher understood this and found ways to include him. For football and rugby, Barry would take part in all pre-match warm ups and skills training. Towards the end of the sessions when actual games were played, Barry would be involved as referee or score-keeper.

Some pupils are fitted with a shunt, draining fluid from the brain into the stomach. The shunt may be permanently in place and it is important for that young person not to get into an inverted position with the head down as this may cause a blockage.

There may be other reasons why pupils may find it hard to take part in activities. Some are only temporary while others may be of increasing severity or permanent:

- Balance or coordination difficulties
- Muscle weakness
- Poor fitness after hospitalisation
- Fear of further injury
- Fatigue
- Poor self-confidence after changed body image
- Hemiplegia (one sided weakness)

"Rosy cheeks and a smile at the end of a game is what it is all about." -- PE Teacher of Lauren, aged 12

"As soon as we had all understood about not being 'upside down' with a shunt we were off! Andrea is the best goal shooter we have had for years." -- Form Teacher of Andrea, aged 13

"I hate it when people tell me what I can and cannot do. I almost know more about my illness than the doctors. If they can trust me so should the teachers." -- Sophie, aged 15

Swimming

While still having a Hickman line inserted the pupil will not be able to go swimming. However, with a Port-a-Cath or a shunt, straightforward swimming should not be a problem. Re-introduction to swimming may need to be carefully monitored. A previously competent swimmer may have become slow or weak and so needs specialist teaching to regain ability. They should be assessed for water safety and all staff made aware of the potential risks involved. Seizures can be a particular potential risk when in the water.

Warm-up and cool-down

It is good educational practice for all to take time to warm up and cool down before and after sport as this decreases the risk of strains and muscle injury. If a young person has balance and coordination difficulties or muscle weakness following treatment for a brain or spinal cord tumour this is even more essential. 5- 10 minutes including jogging on the spot and a series of stretches at the beginning and end of every lesson is advisable.

Appropriate sports and activities

The benefits associated with a successful return to sports and leisure activities include fitness and physical skills as well as improved self-confidence through socialising and interacting with other young people. To make participation possible and successful the teacher should:

- Adapt the activity to meet individual needs
- Allow the pupil to build up participation at a speed appropriate to them
- Consider activities from a practical and social viewpoint – both are important
- Set different rules and goals for an individual in order to be able to participate
- Use yoga techniques such as visualisation and relaxation
- Build up skills gradually, e.g. practise arm and leg movements separately before putting them together
- Use verbal cues such as instructions as well as visual cues or demonstrations
- Ask the pupil's physiotherapist to give advice on appropriate activities
- Create a 'can do' culture by being creative, adapting activities, motivating and offering choices

Some pupils will try to avoid PE/Games when they are in fact well enough to participate. They may use their illness as an excuse.

Hormonal or tumour related problems may alter the pupil's weight or physical appearance. This might be a factor in not wanting to do PE/Games.

"ALL my pupils have to learn to listen to their bodies when doing exercise. It is a life skill!" --
PE Teacher of James, aged 14

School trips and outings

The educational and social benefits of well planned and appropriate trips and outings are numerous. It is a real shame if such trips are avoided altogether because the obstacles for full participation from all seem impossible or difficult. The best solution is to carry out a risk assessment for all planned trips or outings. To exclude the pupil with difficulties is discriminatory. Instead it is possible to attempt to include all pupils by inviting a parent or LSA along to support the pupil with difficulties. Preferably they should be included in any planning so that alternative activities can be organised where appropriate. It would also be a good idea to take the parent or LSA along on any preliminary visits where a risk assessment can be carried out.

For any child who may need use of a wheelchair at some times, it is imperative that for school trips or outings it is assumed a wheelchair will be needed with an accompanying helper. Arrange the extra support for every trip, otherwise it is likely the pupil will miss out on school trips if the wheelchair cannot be accommodated.

Useful Contacts:

The Local Disability Sports Organiser should be able to give teachers information on how to adapt activities, their details can be found in: <https://www.yourschoolgames.com/>

London Sports Forum for Disabled People
436 Essex Road
London N1 3QP
Tel: 020 7354 8666
<http://www.enabledlondon.com/default/52.healthLiving/gym/>

Activity Alliance (previously English Federation of Disability Sport)
SportPark- Loughborough University
3 Oakwood Drive
Loughborough
Leicestershire
LE11 3QF
Tel: 01509 227750
<http://www.activityalliance.org.uk/>

References

CCLG: 2017: **Keeping active during and after treatment.**
https://www.cclg.org.uk/write/MediaUploads/Publications/PDFs/Keeping_active_during_and_after_treatment_2017.pdf

Department for Children, School and Families (DCSF) Guidance—**Access to education for children and young people with medical needs.**
Ref DfES 0732/2001, DoH HSC 2001/019

Farrell, P. & Harris, K. (2003) **Access to Education for Children with Medical Needs—A Map of Best Practice** ref DCAF RR 393 February 2003

4

Special educational
needs, statementing
and the Education,
Health and Care plan
(EHC)



Your pupil may return to school with severe deficits or, over a period of time, it may become clear that they are overwhelmed with school or making insufficient progress. Additional support over and above what the school is able to provide may be required, and an assessment carried out to determine if your pupil meets the criteria for what was called a statement of educational needs but has now been replaced with Education Health Care Plan EHCP (Department for Education 2014). The majority of young people with a brain tumour may require specialist help within school at some time in order for their individual needs to be met (Mabbott et al 2005, Barrera et al 2005). Speech therapy, physiotherapy, psychological support or specific teaching advice and teaching from the local visually and hearing impaired units or mobility unit are all examples of help available.

When Sandra returned to school in year 8 there was joy all around that she had survived and been cured of her tumour. She was keen to catch up and worked very hard despite her problems with fatigue. Her year 9 SATS results fell short of her 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.

More than 1 1/2 years after returning to school Sandra was offered LSA support which needed to be increased over the years.

'Statement' or Statutory Assessment of Special Educational Need

The statement of special educational needs is still being being phased out, and most statements have now been replaced with EHC plan.

If your pupil got support before September 2014 this will continue until your local council changes to SEN Support or an EHC plan. (Gov.uk 2015)

Your pupil should have moved to:

- SEN Support by summer 2015 if they already get help through School Action, School Action Plus, Early Years Action or Early Years Action Plus
- an EHC plan by spring 2018 if they have a statement
- an EHC plan by September 2016 if they have a Learning Difficulty assessment (LDA)

Your school will tell you when they plan to move your child to SEN Support and your council will tell you when they are going to transfer your child to an EHC plan. If possible, this will happen:

- at a time that makes sense, e.g. at a planned annual review
- when they move school, e.g. from nursery to primary

"Finally now I am happy that the support she is getting matches her needs—finally! If only we had started the process sooner!" -- Mother of Sandra, year 10

"As a parent it is so hard to accept that your child is almost a different person. Had it not been for the brain tumour, our son's schooling would in all probability have been plain sailing with A levels and university to cap it all. Instead we struggled and battled to get the support he deserved. 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! Thankfully we did not give up and our son now feels he can cope." -- Father of Mark, aged 20

The Education, Health and Care plan process

An EHC plan is the document which replaces Statements of SEN and Learning Difficulties Assessments for children and young people with special educational needs, and covers children and young people up until the age of 25. EHC plans identify educational, health and social needs and set out the additional support to meet those needs. When the pupil starts back in school, after the initial settling in period, the school ideally should assess the pupil's academic levels and, if necessary, arrange an emergency statement review/EHC plan review to ensure the correct support is in place.

An EHC plan can only be issued after a child or young person has gone through the process of EHC needs assessment. A Local Authority has 6 weeks to decide whether or not to carry out an EHC assessment. At the end of that process, the Local Authority has to make a decision, either to issue an EHC Plan or not. (Ipsa 2015)

If the LA refuses to issue an EHC plan, the parent/young person must be informed of the reasons and that they have the right to appeal to the Special Educational Needs and Disability Tribunal.

Disagreeing with a decision

Parents can challenge your Local Authority (LA) about:

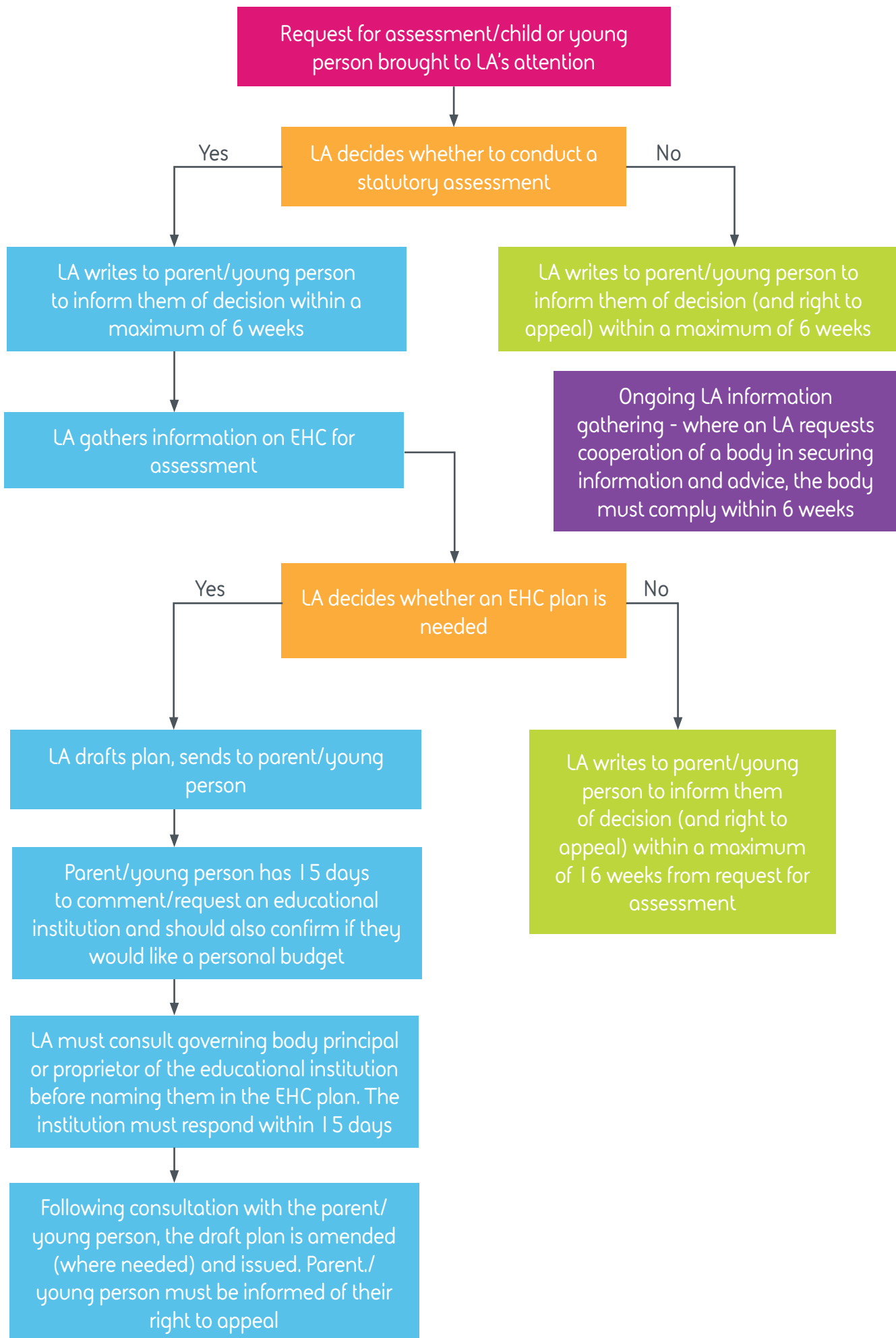
- their decision to not carry out an assessment
- their decision to not create an EHC plan
- the special educational support in the EHC plan
- the school named in the EHC plan

If the decision is to issue an EHC plan, the LA must first issue a draft EHC plan for the parents or young person to consider. Only at this stage will parents/the young person be asked to name the type of school/college. The LA will then consult with that school/college about being named in the EHC plan. As well as the special educational needs and special educational provision of the child/young person, the draft EHC plan should also detail:

- Health care provision that has been assessed as reasonably required;
- Social care provision which is being made for the child/young person under the Chronically Sick and Disabled Persons Act 1970 and any other social care provision that has been assessed as reasonably required.

The LA will then finalise the EHC plan.

Figure 2: The education, health and care assessment planning process



Maximum time for whole process to be completed is 20 weeks

The aims of the EHC plan are to:

- Introduce a single assessment process for education, health and care and to include parents of children and young people with SEN in the assessment process
- Replace SEN statements and Learning Difficulty Assessments with a plan for children and young people with SEN aged 0 to 25 years. It is important however to note that the continuation of the EHC plan is considered at every transition time, and you can not assume it will transfer from secondary to further education etc. The review process is crucial for ongoing needs assessment.
- Introduce the option of personal budgets for young people and parents of children with SEN so they can choose which services are best for their family
- Make sure local commissioners work together in the interest of children and young people with SEN and improve communication between institutions and services
- To improve educational provision for pupils with SEN
- Make sure all state-funded schools and colleges, including maintained schools, free schools and academies, are fully brought into the support system for children with SEN
- Fund degree-level specialist training for talented support staff working with children with SEN
- Give young people with SEN in further education and training similar rights and protections as those for children with SEN under 16
- Put in place supported internships, an employer-based study programme designed to help young people with SEN learn the skills they need for the workplace



The content of EHC plan

The exact format of an EHC plan will be agreed locally. However, all EHC plans must include:

- The views, interests and aspirations of the child or young person and their parents
- The child or young person's SEN
- The outcomes sought for the child or the young person, including outcomes for adult life, where appropriate
- The special educational provision required by the child or the young person
- Any health or social care provision reasonably required by the learning difficulties and disabilities which result in the child or young person having SEN
- The name and type of the school, maintained nursery school, post-16 institution or other institution or the type of school or other institution to be attended by the child or young person where no such institution is named
- Where there is a personal budget, the details of this and the outcomes to which it is intended to contribute
- The advice and information gathered during the assessment (in appendices). There should be a list of this advice and information
- In addition, where the child or young person is in or beyond year 9, the EHC plan must include the provision required by the child or young person to assist in preparation for adulthood and independent living, for example, support for finding employment, housing or for participation in society

The main changes from the Statement to EHC Plan are:

- The EHC Code of Practice (2014) covers the 0-25 age range
- There is a clearer focus on the views of children and young people and on their role in decision-making
- It includes guidance on the joint planning and commissioning of services to ensure close co-operation between education, health services and social care
- For children and young people with more complex needs a co-ordinated assessment process and the new 0-25 Education, Health and Care Plan (EHC plan) replace statements and Learning Difficulty Assessments (LDAs)
- There is new guidance on the support pupils and students should receive in education and training settings
- There is a greater focus on support that enables those with SEN to succeed in their education and make a successful transition to adulthood

The role of the learning support/individual needs assistant

A Learning Support Assistant (LSA) or Teaching Assistant (TA) can provide invaluable support for a pupil. It is important that they are fully informed about the particular needs and circumstances surrounding the pupil they are to support and, where appropriate, share the detailed information they gather with the rest of the staff, provided parental permission has been given.

The LSA should be involved in the planning and review of the child's Individual Education Plan (IEP) so that they are clear about the overall aims and objectives of their work and the strategies that they will be expected to use to achieve these. Much of the LSA's work will involve adapting curriculum materials to meet the child's needs and they will need noncontact time to prepare these, as well as 1:1 time with the teacher where they are shown the materials that will be required. It is sometimes better for LSAs to work with their pupil as part of a small group as this helps the pupil to feel less isolated and to see that all pupils have individual strengths and weaknesses. It can also make working more fun, as it can be too intensive for pupils to be working 1:1 with an adult for much of the day.

Some young people are reluctant to be 'singled out' from their peers by receiving additional classroom support. It is always necessary to consider how LSA funded time can best help each individual pupil and meet their needs.

- Reliance on an LSA has implications for the social isolation, welfare, independence and confidence of any pupil and therefore needs to be carefully managed
- LSAs need to ensure pupils are supported in such a way that the work accurately reflects the pupil's ability
- The support given should be recorded
- The LSA should be aware of any particular skills or knowledge being assessed as part of class work and withhold inappropriate support at such times in order for the teacher to be able to assess the pupil fairly
- An LSA is unlikely to have experience of young people with a brain tumour. They may need additional support and supervision

"Without the LSA there I could not even begin to meet Simon's individual needs." -- Teacher of Simon, aged 10

LSAs do:

- Discuss problems and offer constructive criticism
- Praise ideas and work well done – build up a pupil's strengths and independence
- Show patience – it may not be realistic for the pupil to work to the same speed as the rest of the class
- Allow the pupil to try their best and gain a sense of achievement
- Although it is hard to sit back and watch a pupil flounder with a task, it is sometimes necessary and in the pupil's own interest

"Some LSAs see their role as primarily sustaining comfort, contentment and well-being in their assigned pupil. When Megan is delivered to or collected from school her mother and the LSA nearly always have a brief chat. Mum, Megan or the LSA inform one another of events, moods, achievements or concerns and in this process they have developed a very friendly and relaxed relationship. Megan's very individual and fluctuating needs are always in focus and the LSA is able to adapt support or to inform teaching staff where appropriate.

At the beginning of every academic year, the LSA, with the SENCO, draws up a detailed profile of Megan's strengths and difficulties, with a photograph chosen by Megan on the front. This is handed to every member of staff to keep in their professional file and is over and above the brief summary of all pupils with individual needs." -- SENCO for Megan, aged 15

LSAs do not:

- Allow pupils to take credit for work which is not their own
- Complete assessed written work for the pupil
- Make decisions for the pupil, but help the pupil decide
- 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
- Offer hints and suggestions, but instead elicit responses carefully
- Make contributions to the creative process
- Help inappropriately – it can be disabling

"Paul is receiving LSA support in most lessons. The LSA's role is different from one lesson to another, according to the style of teaching and Paul's skills in that subject.

In Physics the teacher allows pupils to sit where they want. The lessons are very noisy with inappropriate chatting or calling out in class. Paul chooses to sit as far to the front left of the class as possible. He wants the LSA to sit on his right in order to separate him from the noise and 'buffer' him from distractions. Like many brain tumour patients Paul is noise sensitive and quickly feels 'overloaded' in noisy surroundings. The LSA practically runs a lesson in parallel with the subject teacher, but meant for Paul only. He works in near total isolation from the mainstream.

In Chemistry lessons, however, the teacher has arranged a boy/girl seating plan informed by information of individual pupils' needs as provided by the SENCO. Paul sits at the front in the middle to accommodate his visual problems, surrounded by pupils, while the LSA moves around helping any pupil and assisting the teacher in his teaching. Paul is far happier in his Chemistry lessons; he puts up his hand to answer questions and interacts appropriately with his peers. He can call on the assistance of the LSA or other pupils as he needs. Paul does not feel singled out.

The calm atmosphere means that Paul is able to concentrate, to interact and to achieve." -- Teacher of Paul, aged 14

Some practical points

- Teachers should encourage LSAs to write down how long a piece of work has taken the pupil and what support was given
- Teachers need to give the LSA plenty of advance warning of tests and exams in order to make special arrangements as required
- LSA keeps a working black or blue marker for the whiteboard in their bag so that they can always ensure the teacher uses legible ink
- Enable the LSA to go on outings and residential trips. The extracurricular learning and social interaction on such trips can be invaluable. The LSA may need to be involved in any prior arrangements and risk assessments. In some schools the LSA is funded directly by the school to support a pupil on residential trips and outings
- 1:1 interaction may in some respects be considered 'best' for the pupil. However, this may make the pupil feel isolated. For some brain tumour pupils, social skills and interaction should be the main aim of the school, particularly where the pupil's chances of long term survival are slim
- Homework clubs run by LSAs provide a logical continuation of work covered in class

"It is such a pleasure to work with Molly and I feel almost part of her little gang of friends. Educational progress is not really on the cards, but she is happy – and so are her parents."
-- LSA for Molly, aged 11

"Fred easily becomes dizzy or disorientated if he has to copy work from the board. The constant up and down movement of his head and neck is painful and debilitating after his operation and radiotherapy treatment to the back of the head. His LSA helps him out by dictating or writing down text for Fred to copy. Whenever she can, she provides Fred with a gap filling worksheet or questions to fill in on the sheet as this makes it possible for Fred to cover the same work as the rest of the class without laborious copying which slows him down unnecessarily." -- Teacher of Fred, aged 13

"At first I was really tempted to just do the work for her. It is frustrating to see her struggle so hard, but she has to – for her own good."
-- LSA for Sian, aged 11

"I try to help the others in class also. Shay hates to be singled out, and the friends are also needy in different ways." -- TA for Shay, aged 12

The role of the SENCO

The Special Educational Needs Co-ordinator (SENCO) is the member of staff responsible for working closely with the head teacher of the school, in order to ensure the implementation of the SEN policy. The SENCO manages and works alongside the LSAs, TAs and INAs, in addition to liaison with the pupils' parents and associated health and social care professionals regarding additional support.

Specialist schooling

"The first time someone mentioned Greenwood School for Alice we were horrified! We could not have been more wrong. It is just brilliant and she loves it." -- Parents of Alice, aged 15

Specialist schooling

Schools and parents may consider whether a young person severely affected by a brain tumour would be better placed in a specialist school. If struggling within mainstream education, despite all efforts to support and include the pupil, it may be deemed in their best interest to consider specialist schooling. In some circumstances the changes wrought by the tumour or the treatment can be so devastating that in educational, cognitive or personality terms they are now a different person and it may be in their best interests to become part of a different peer group and change to a more specialist school. Reintegration into their former school setting may therefore be inappropriate.

Where there is an emphasis on inclusion it may be considered best for the needs of the pupil to be met in the mainstream classroom. When backed up by appropriate specialist expertise this can be a good solution if the pupil's educational and social needs are met.

Ultimately the decision should, of course, be up to the young person and their family. However, provision of schools, funding and a readiness to meet demand will vary greatly between different education authorities.

There are many types of specialist schools. Some schools have specialist units attached to them:

- Emotional and Behavioural Difficulty (EBD)
- Severe Learning Difficulty (SLD)
- Moderate Learning Difficulty (MLD)
- Profound and Multiple Learning Difficulties (PMLD)
- Visually Impaired (VI)
- Hearing Impaired (HI)
- Physical Handicap (PH)
- Dyslexia
- Autistic/Autistic Spectrum Disorder (ASD)
- School for 'delicate' children – physically or emotionally vulnerable

Arguments for specialist schooling include:

- Specialist tuition
- A sense of belonging
- Access to therapies
- Specialist facilities
- Specific preparation for practical life skills
- Small classes
- Fully differentiated curriculum
- A feeling of being valued and understood

Arguments against specialist schooling:

- It can be perceived as discrimination not to be included
- Segregation can lead to isolation or a protected view of the world
- Travelling issues, particularly if the special school is a long way from home. This may be especially difficult for brain tumour patients suffering from fatigue
- Loss of regular contact with existing friends

Ultimately, the issues are complex and individual. A sensitive awareness of abilities, opportunities and fairness should guide any decisions taken.

"As the head teacher I had to accept that we were failing Daniel. However much we wanted to help we just did not have the expertise and the resources. It took all parties a long time and a lot of anguish to come to terms with that." -- Head of Daniel's school, aged 14



References and resources

Aspire for SEND <https://www.theaspireacademy.org.uk/parent-info/send/>

Barrera, M., Shaw, A., Speechley, K., Maunsell, E., & Pogony, L. (2005). **Educational and Social Late Effects of Childhood Cancer and related clinical, personal and familial characteristics.** *Cancer*, 104, 1751–1760.

Department for Education (2014) **Guidance on the special educational needs and disability (SEND) system for children and young people aged 0 to 25**, from 1 September 2014
<https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>

IPSEA: Independent Parental Special Educational Advice <http://www.ipsea.org.uk/what-you-need-to-know/ehc-plans>

Gov.uk; Children with special educational needs <https://www.gov.uk/children-with-special-educational-needs/support-before-september-2014>

Mabbott, D., Spiegler, B., Greenberg, M., Rutka, J., Hyder, D., & Bouffet, E. (2005). **Serial Evaluation of Academic and Behavioural Outcome after Treatment with Cranial Radiation in Childhood.** *Journal of Clinical Oncology*, 22(10), 2256–2263.

5

Cognitive and
learning issues
in the classroom:
recommended
teaching strategies



Children who have a brain tumour, or who have been treated for one, are very likely to have ongoing cognitive problems. These can range from none at all to severe. Those most at risk for having most long term effects are those who were diagnosed and treated at a young age; below the age of 4 is especially damaging. This is directly associated with the rapid development of the brain, which occurs at this stage of brain development. It is well documented that damage is done to the development of white matter in the brain by chemotherapy and to greater extent by radiotherapy. The impact upon learning ability is not so much that already acquired skills are lost, but much more that the ability to learn and process new information can be vastly slowed down, therefore the gap between the pupil and his or her peers widens as they go through the academic years (Mulhern et al 2004, Lancashire 2010).

Information processing, non verbal skills, memory and attention span are often affected in young people with a brain tumour. School work can take a large amount of effort and be really hard work if difficulty with information processing or memory skills are evident. Pupils may struggle in particular with maths, music and foreign languages, all of which demand quick information processing, executive functioning and memory skills. The pupil's ability to access new information, to follow instructions, and to carry out a sustained activity may be impaired. Previously learnt knowledge and organisational skills might also be compromised and altered following treatment.

Because of this changing picture over time, repeated assessments (ideally at 18 month intervals and at transition points) are needed to provide a detailed description of cognitive difficulties.

It is highly recommended to consult with other professionals if you have a child with a brain tumour. The Educational Psychologist and psychology team at the treating hospital ideally need to liaise and will decide who can carry out assessments; usually the treating hospital will advise, but many Educational Psychologists will actually carry out the assessments. In addition to these assessments a teacher's perceptive monitoring of a pupil's difficulties in the classroom is an invaluable source of information. The clinical/neuropsychology team and schoolteachers at the treating hospital can also give additional advice or support. Consultation with speech and language therapists is recommended if speech, receptive or expressive language or information processing seems to be a problem. These areas of difficulties are often masked by a good intact vocabulary. It is also of use to consult with occupational therapists, as there is often the slowing down of processing and associated motor difficulties, and specialist advice from an OT could make a significant difference in the classroom through simple adaptations.

What problems might I see in the classroom?

Problems in one or more of the following areas:

- Working at a very slow pace
- Spelling and handwriting
- Reading and reading comprehension
- Auditory or visual language processing – trouble with vocabulary and syntax
- Understanding concepts
- Remembering facts
- Sequencing
- Understanding symbols, columns and graphs
- Using computers or calculators
- Attention span
- Concentration and impulsiveness
- Memory and information retrieval
- Planning and organisation skills
- Social skills and maturity
- Academic performance poorer than expected
- Frustration with the learning process
- A seemingly 'lazy' and/or inattentive attitude

"We want our pupils to be independent learners. We bring that about through imaginative support, technology and adapted equipment – and respect!" -- Teacher at treating hospital

"There were so many obvious difficulties at first that we were quite blind to the more invisible cognitive ones!" -- Teacher at treating hospital

General intellectual functioning

Many parents are terrified that the effect of treatment and having a brain tumour will mean their child will lose their intellectual capacity. Usually IQ is stable, but for children with brain tumours there can be a loss of up to 1-4 IQ points a year after treatment, slowing down and then plateauing around late teens (Palmer et al 2003, Palmer et al 2007, Spiegler et al 2004). Generally verbal intelligence tends to be better preserved, with decline more apparent in the performance aspects; this may mean for an articulate child that difficulties can be masked. Attention must be paid to slowing down of performance: taking much longer to complete tasks greatly impacts upon learning capacity.

We recommend early referral to the SENCO and Educational Psychologist, early and repeated testing of IQ, memory, attention and executive functioning and early intervention, as the earlier the intervention the more the child will benefit (Mulhern et al 2004). A pupil's performance may not be significantly different when measured as an overall IQ score (often a total score is not calculable due to a wide scatter of scores), therefore the scatter of scores on intelligence indices are important to examine. Often children present with a spiky profile, with clear strengths and weaknesses. They can appear to be coping, and only gradually do the cognitive difficulties become clear.

Academic performance and expectations

Having a brain tumour may have a detrimental effect on a pupil's academic performance, which may result in the individual attaining less than expected at school. For this reason, children and young people who have had cancer are generally more likely to repeat a year at school, with brain tumour patients in particular generally showing more significant educational difficulties in comparison to their peers (Barrera et al, 2005). This outcome may, in part, be due to the intensive treatments often accompanying brain tumour diagnosis, such as cranial radiation therapy, which has been associated with declines in attention, social skills and academic ability (Mabbott et al 2005, Barrera et al 2005).

Whilst a patient may return to school after recovering from a brain tumour with comparable academic performance as before diagnosis, difficulties may start to emerge over time, including problems understanding spoken instructions (verbal comprehension) and memory of new material in class (knowledge acquisition) (Saury & Emanuelson 2011), in addition to attention and social impairments in the years post treatment (Mabbott et al 2005). Therefore, it may be important for both staff and parents to understand and formulate new, more realistic expectations of academic achievement.

Some practical points

- Be clear and realistic about expectations – for the sake of both pupil and teacher! Expectations regarding a pupil's workload may need to be considerably adjusted following their return to school.
- Work with the student to determine if the workload is too demanding – discuss deadlines and whether they are realistically achievable.
- Allow extra time for tasks and examinations (usually a minimum of 25%) (explained in chapter 3 on page 37).
- Regular communication provides both academic and emotional support and allows teachers to effectively measure progress and identify any additional resources which may be useful.
- Expect delays in milestones and monitor difficulties in academic and social settings (Barrera et al 2005).
- Arrange a meeting with the pupil's parents, TA, SENCO and class teacher to discuss realistic expectations and what is observed in class.

Memory problems and strategies

Young people with a brain tumour can often have memory difficulties. There is a substantial body of research documenting the effect of various brain tumours and radiotherapy upon memory (Mulhern et al 2004, Spiegler et al 2004). When assessing a pupil's memory, it can be helpful to consider his/her memory for both visual and verbal/auditory information, in addition to their ability to remember information both immediately and after a delay. It is not uncommon to see strengths or weaknesses with different aspects of memory, and it is also useful to enquire about the young person's ability to remember information at home. After radiotherapy treatment, young people with a brain tumour can also find it difficult to concentrate and sustain their attention. This, together with anxiety, can be detrimental to the pupil's memory. Careful assessment of the potential underlying problem is required. It is important to note that some pupils may also have reduced insight into their memory difficulties, which can affect their ability to learn and use new strategies. Care must be taken addressing this if the young person lacks insight or denies such difficulties.

What might I see?

- Difficulties recalling information, immediately and/or after a time delay
- Inability to follow task instructions, particularly as length and complexity increase
- Some young people may be unable to find their way around school or remember where their locker or desk is
- Difficulties retaining new information and learning new concepts
- The pupil may ask for repetition of instructions or may say they do not understand
- Difficulties following homework instructions, which may lead to incomplete work
- Difficulty getting to the right lesson with the correct belongings at the right time
- Memory difficulties may fluctuate from day to day and can vary if the pupil is tired or unable to concentrate
- Attention lapses may be difficult to distinguish from a memory deficit and the two often coexist. Poor concentration can be exacerbated by memory problems and vice versa
- The young person may confabulate (fill in gaps or make up information) if they cannot remember and this may make it difficult to sustain a conversation

"Luke was treated for a brain tumour located in a part of the brain responsible for memory. In addition, he had received a high dose of radiotherapy to that part of the brain. He found it difficult to follow instructions given to him by both his teacher and his parents, and he was unable to complete work in the classroom. Further assessment of his memory by his teacher and LSA revealed that Luke struggled to recall verbal information as opposed to written material. This meant that he would find it particularly difficult to remember what his teacher had said out loud in the classroom. For example, if Luke was asked to get his book out, turn to a page and complete an exercise, he would often have to ask his neighbour what to do as he was lost. Luke was presented with written instructions supplementing what the teacher had said, in addition to a checklist that allowed him to tick off which sections of a task he had completed. This allowed Luke to work independently and an LSA was asked to help prepare materials for him in the classroom." -- SENCO of Luke, aged 16

Strategies for memory problems

- Developing a personalised guide/IEP for the pupil so it is clear what resources are needed/ what support has been arranged, and an understanding of what works and does not work
- Adapting the environment/classroom
- Tools used by teachers to improve memory
- Following a set routine
- Combining several strategies to make a substitute 'memory system'
- Specific rehearsal classroom strategies
- Consultation with other professionals
- Developing a range of resources/advice suitable for memory improvement including the CBIT website (see resources list) and Headway guidance (see references)
- The rest of this section will provide suggestions for each of these categories (adapted from Headway guidance see Reference section on page 87)
- Use of ICT (see separate section below on page 82)



Adapting the environment/classroom guidance

- Adapt the environment, so they have to rely on memory less.
- Put essential information on a notice board, make it routine to refer to this regularly and check this every day.
- Assess strengths and weaknesses in the pupil's memory. Does the young person understand and remember information better when it is presented in a particular way (i.e. written/orally/pictorially)? Each pupil is unique.
- Reassure the young person. It can be frightening not to be able to remember things.
- Have one special place to keep important objects, for example their drawer, or a folder they always carry with them. It needs to become automatic to use this special place so the pupil always knows where to find things. I usually give the example, do you know where your toothbrush is? Most people say yes, because they know exactly where it is – by the sink – and they use it regularly so finding it has become automatic.
- If needed, possibly find some way of attaching important items to the pupil, e.g. neck cord for glasses, strap for pencil case.
- Labelling cupboards, drawers so pupils can find things without having to always ask.
- Having toilet or specific rooms' doors painted different colours as a reminder of which room is which.
- Try to minimise distractions when the pupil is trying to remember information.
- Reduce memory demands in the classroom where possible.
- Use a buddy system to help the pupil find his/her way around school and get to classes with the right books, or use visual cues such as symbols for lesson subjects (e.g. book for literacy, maths sum for maths etc).
- Some may be helped by multiple choice type questions as opposed to open-ended tasks. It may be easier for them to recognise the correct answer rather than recalling it freely, and this may reinforce successful searching, perhaps making it easier for them to find the answer themselves next time.

Tools often used by teachers to increase memory functioning

- Teach memory strategies e.g. mnemonics, mental imagery, mind maps. 'Mnemonic' strategies may help the pupil to remember common groupings of words or letters (e.g. 'Never Eat Shredded Wheat' to remember compass points). However, some pupils will find learning the mnemonic sequence an additional burden, and it is unclear how helpful these strategies are for someone with a memory impairment. Check with the pupil how useful this is.
- Have a homework diary and check each day that this has been completed appropriately before the young person goes home.
- Use spider diagrams to help organise thoughts.
- Use write-on sheets for work to increase focus.
- Ensure that work can either be done in a book or is filed into a folder as loose sheets of paper may get lost.
- Provide as much information as possible in a visual or written form to reduce the demands on the child's memory.
- Tell the pupil specifically what to do or repeat instructions, not 'get back to work'.
- Allow time for repetition to give additional opportunities for learning.
- Review what has been covered at the end of each lesson and the beginning of the next.
- Model the activity with them to give them experience of the objectives.
- Additional strategies are covered in optimal teaching section.

Following a set routine

Having a daily and weekly routine means that people with memory problems can get used to what to expect, which helps to reduce the demands on memory. Some suggestions for doing this are:

- Make a note of regular activities in a diary or on a calendar.
- Make a chart of regular events, perhaps using pictures or photographs, on a notice board. Using social story-type photographs can help the pupil to see the sequence of events easily.
- Changes in routine are often necessary, but can be confusing. It is a good idea for relatives, teachers and carers to explain any changes in routine carefully and prepare the pupil with memory problems well in advance, giving plenty of spoken and written reminders.

Combining several strategies to make a substitute 'memory system'

Most people with memory problems find it useful to combine several aids and strategies. A combination of two or three strategies can cover the areas where there would otherwise be problems and provide a safety net for things that must be remembered, for example, using the daily set routine in combination with diary and dictaphone.

"Sarah's friends are becoming better at 'reading' when she is struggling to remember something. They help a lot, but at school she seems lost without them." -- Parent of Sarah, aged 9



Rehearsal/teaching strategies

- Provide opportunities for repetition and over-learning, using a multimodal learning approach. Start with the pupil's most intact modality.
- Use pictures or colour prompts to aid memory (e.g. using the same colour sheet or highlight for a particular topic).
- Give instructions in the right sequence and one step at a time, NOT 'I would like you to tackle the questions on page 44 after you have completed the experiment and noted down your findings.' Do not give a complex list of instructions.
- Make sure you provide the pupil with a checklist to follow.
- Check that the young person has understood and remembered task instructions. Get them to repeat information back to you.
- Use cues or triggers to help the pupil recall information, particularly if retrieval of learned information is a problem. Their memory system may be disorganised and they may not be able to locate the information they require.
- Try to link new learning to the pupil's previous knowledge and experience.
- Use scaffolding techniques for planning and organising work, such as an essay structure with examples of how to start the introduction, key paragraph headings etc.
- Numeracy skills and concepts to be taught in small steps and with a clear structure. Reinforce visually and through real life examples.
- Break down text into small, structured steps.
- Provide positive, specific feedback.
- Encourage and teach effective note taking as an aid to poor memory.
- Repeat information frequently.
- Break down work and make it practical wherever possible.
- With regards to homework, make sure someone writes down the homework in the planner. Often only a part of it is noted down and therefore the pupil has little chance of being able to complete it. Use time limited rather than completed projects and tasks, unless it's coursework for exams when longer time will always be needed.

Reading and writing problems

Some children also present with reading and writing problems similar to acquired dyslexia. There is evidence that this is more frequent for some children treated below the age of 7 (Palmer 2007). Such problems can respond well to an intensive approach such as fast forward or other phonic based creative multi sensory teaching programmes. The child can really benefit from using dyslexia-type teaching and classroom strategies including multi sensory teaching and over-learning techniques.

"Spellings were completely forgotten. It was as if we had a dyslexic pupil, and totally disorganised pupil, overnight. He has had to work so hard to claw his way back." -- SENCO

Cognitive remediation and medication

For some children who seem to be caught in a pattern of continuing poor working memory, a structured memory re-training programme may be of use. Consult with the Educational Psychologist. Ones which may make a difference are Cogmed, Jungle Memory and, for younger children, Dyslexia Quest; even though this is aimed at children with dyslexia, it follows the same sort of cognitive training (Mulhern et al 2004, Palmer et al 2007). Some children who are experiencing severe problems with attention and impaired memory may benefit from medication such as Ritalin/methylphenidate used with children with ADHD (Mulhern et al 2004). Any potential use of medication will lie with the medical professionals either at the treating hospital or through CAMHS if they are already being offered support.



Concentration and attention problems

Young people with a brain tumour commonly have decreased concentration and attention, particularly following radiotherapy treatment. They may find it difficult to sustain attention and they can easily be distracted, particularly in a busy, noisy classroom environment. This can have a profound effect on their learning and behaviour.

What might I see?

- Tuning out or day-dreaming
- Lapses of concentration after just a short period of time
- Being easily distracted by noise or any other stimuli in the classroom
- The pupil may leave the desk or talk to his/her neighbouring peers
- Unable to follow task instructions, particularly as length and complexity increase
- Attention and concentration may worsen at certain periods of the day when the pupil is tired or when task complexity increases
- Work may be slow or lacking in detail

What appears to be a behavioural problem in the classroom may have a number of different possible causes. Attention lapses may be difficult to distinguish from a memory deficit and the two often co-exist. Poor concentration can be exacerbated by memory problems and vice versa. If a pupil is frequently off-task, they may have a problem sustaining their attention. Alternatively, they may be easily distracted. Some may have receptive language or memory problems that lead them to 'switch off'. Problems concentrating may be caused by a combination of all of these factors. Whilst a full neuropsychological assessment might identify specific causes of observable behavioural problems, it often falls to the teacher to elicit, through a process of elimination, what exactly is causing the pupil to lose concentration.



If the pupil has difficulty sustaining attention to a task:

- Do use ADHD strategies, as they are equally applicable for children with impaired attention (See ADHD guide reference).
- Break the task down into small focused steps. This may be less daunting and the pupil is able to experience success as each small target is reached. Praise even after small steps is helpful.
- Provide a visual flow chart of the steps required. The child can tick off each step as it is completed and if the child becomes distracted, they can refer back to the diagram to find where they had got to.
- Provide the child with a template to work to and an example of what the end-point should look like. Computers are useful for providing templates as they enable the pupil to insert their work into a pre-prepared but adaptable format.
- Keep tasks brief and practical rather than purely verbal. Young people often find it easier to hold their attention to tasks with which they are physically involved rather than when they simply have to listen. Try not to overwhelm them with too much verbal information!
- Work to the pupil's interests and use stimulating materials to engage them. Even the most inattentive pupils can play computer games for hours, simply because they are stimulating and they are motivated to succeed.
- Frequently prompt the pupil to remain on-task using visual or verbal prompts. This could be a visual cue card, touching the pupil on the shoulder or using their name. Use instructions such as 'listen' and 'concentrate' as genuine reminders, not discipline commands.
- Be realistic about the pupil's attention span. They may only be able to concentrate for 10- 15 minutes at a time, and regular breaks may be required to optimise concentration. Praise them for staying on task.
- Don't expect the pupil to be able to concentrate on more than one thing at a time. Allow someone with very poor concentration to listen only and not be expected to take notes at the same time. Provide the pupil with notes.

If the pupil is easily distracted, classroom strategies:

- Reduce 'external' distractions. Avoid open-plan, noisy teaching rooms and place the pupil at the front of the class so that visual distractions are minimised. Ideally, for independent work, the pupil should sit at an individual workstation so that he/she can avoid distractions. For young people who find this too isolating, they can work in pairs, sitting beside rather than facing another pupil and facing the teacher at the front of the class. Consider who they would best be placed next to. Individual, paired or small group working may facilitate attention and it may be helpful to reduce copying from the board.
- Reduce 'internal' distractions. If the pupil is preoccupied with worries or intrusive thoughts, time should be set aside with an adult to discuss these. Young people often find they can relax more during lessons if they note down what it is they wish to talk through and they are allocated a time later that day to do so.
- Gain the pupil's attention before giving task instructions and simplify the starting point of tasks. Ask them for 'pencils down' before instructions are given. Ensure the pupil has everything they need to commence the task and prompt them to do so at the right time. The first step should be brief and easily achieved to enable the teacher to address any problems with the rest of the class before returning to the target pupil to give him further instructions. Limit the amount of equipment on the desk to only that which is essential.

"We allow her a lot of time to express herself. If too many ideas or issues build up in her mind she gets frustrated."

-- Teacher of Sarah, aged 9

If the pupil has trouble understanding or paying attention to the teacher's instructions:

- Use brief, concrete language at a level they can understand.
- Leave pauses between instructions to allow the pupil time to process the information.
- Review what has been said, in order to provide additional opportunities for interpretation.
- Request a language assessment to determine the child's language level and understanding and to see whether speech therapy might be warranted.

"Andrew found it difficult to concentrate in class following his radiotherapy treatment. His teacher often noted him daydreaming, and he frequently failed to finish his work in class. In order to gain his attention and get him back on task, a visual cue card was used, which the teacher would show him whenever his attention wandered. It was important to Andrew that his class mates did not notice, and the teacher made sure that she simply tapped him on the shoulder and showed him the card discreetly." -- Teacher of Andrew, aged 10



Executive Functioning

Executive functions are the essential self-regulating skills that we all use every day to accomplish just about everything. They help us plan, organise, make decisions, shift between situations or thoughts, use our working memory, control our emotions and impulsivity, and learn from past mistakes. Pupils with brain tumours often have some impairment of their executive functions, and therefore in the classroom find it difficult to stay on track, to sequence tasks and know where to start with a task. (Executive function tips 2013).

Teachers therefore need to be creative and devise ways to bolster the organisational skills that don't come naturally to a child with poor executive functioning. Teachers need to be able to teach a mix of specific strategies, creative use of scaffolding and alternative learning styles that complement or enhance a child's particular abilities.

Slowness of information processing

It may take much longer to absorb information, to think about or consider what has been said, and much longer to respond. Writing and reading speed can also be much slower than previously. The speed at which information is processed can also affect a child's physical activities, for example being physically much slower in running around or playing games, which affects how the child is included or viewed by peers (CBIT). Giving extra thinking time as well as extra completing time is crucial, and not jumping in with the solution or answer is needed. Otherwise the pupil can lose confidence and this may inhibit their willingness to try to answer (Spiegel et al 2004). Anecdotally, in the time most children read or complete 2 sheets of A4 paper, a child with a brain tumour may read or complete half a page due to this type of slowness.

"When Fred returned to school after his operation and radiotherapy to treat a rare brain tumour, he had missed all of the first term of year 8. During the spring term he sometimes left school early because he was tired, but gradually he seemed to gather strength and carried on much as before his illness. His exams at the end of the year were reasonable, considering all he had been through. Everyone at school and at home seemed to rejoice in the fact that he was doing quite well and that he was even back at school. In time he would no doubt be entirely back to his usual self.

Fred's SATS results at the end of year 9 surprised everyone at school. He had not done nearly as well as had been predicted in year 7. When analysing the SATS results, teachers began to piece together a picture of Fred which surprisingly revealed some specific underlying difficulties. His English teacher reported that his writing was still quite slow and not as vivid and expressive as expected from 'a boy like Fred'. He had been able to produce little in terms of written material when tested.

His Maths teacher noticed how his mental maths marks over the year had been in almost imperceptible decline, and he had seemingly failed to retain many basic numerical skills. Fred had also abandoned complex questions before having a reasonable attempt at them, which was out of character. Despite appearing to participate well in class and never asking for help, it was apparent at the end of the year that Fred was failing to meet expectations." -- Parent of Fred, aged 14

Using external aids including ICT

Many people use external memory and organisational aids, regardless of whether they have a brain injury or not. External memory aids are particularly important for people with memory problems as they limit the work the memory has to do. It is important to remember that this isn't cheating and using external aids will not inhibit any natural improvement of memory.

Some examples of external memory aids include:

- Diaries, Filofaxes, notebooks; we often promote use of the homework planner joined to a 'memory' notebook, with separate sections for a to do list with to do by and completed dates. It is worth training TAs to help set up this system, as to get the pupil to use it successfully will need a helper to remind until it becomes automatic.
- Notebooks
- Lists
- Alarm clocks/reminders on phones/tablets
- Watches
- Calendars
- Wall charts
- Tape recorders and dictaphones
- Electronic organisers
- Pagers
- Pill reminder boxes for medication
- Sticky-backed notes
- Photo albums
- Cameras

At the end of this chapter there is a list of useful websites where you can buy memory aids (Headway memory aids list on page 88).

ICT

- AbilityNet can provide useful ICT guidance (reference at end of chapter along with other useful software and hardware suggestions from Headway)
- Use mind map programmes
- When using scaffolding, use word banks/ scaffolding software such as Clicker6, Read and Write Gold, with repeated opportunities to help the child become independent in using this software. Although this is often aimed at children with dyslexia or reading difficulties, it is also very useful with children who have problems with working memory (reference at the end of chapter)
- Use electronic reminders on phones. Tablets, digital recorders, linking of electronic devices
- Dictation software such as Dragon Dictation
- Consider use of text to speech software as an aid to memory and if there is slow information processing, as this can read things out for the pupil. This means they can just listen rather than having to process the information if reading is slow or a huge effort for them. This can include using Microsoft Word voice activated speech commands, and also using packages such as docs plus, where information can be highlighted to be read aloud.



Optimal teaching strategies for children with brain tumours

Teachers know only too well that cognitive and developmental progress is closely dependent on how relevant the learning is and to what extent the young person experiences success in the process. There are a number of general strategies described below, some of which may be recommended in psychologists' reports. Some require the 1:1 input of a teaching assistant.

Active learning

Pupils demonstrate their level of understanding through active participation, being encouraged to ask questions of teachers and of themselves, and to set their own goals.

Pace and size of tasks

Break down tasks into their component skills and work on mastery of these skills in turn. The impulsive and impatient pupil or those overwhelmed by complex tasks might respond well to this approach.

Comprehension cueing

Cues will help a pupil to process, store and retrieve information. Strong visual, written and verbal cues can support the learning of all pupils. Multiple choice questions can be more helpful for pupils with retrieval, concentration and memory problems.

- Teach the pupil to identify key points before and after receiving information
- Take time to ensure that the pupil has understood the instructions and the information given
- Model tasks, processes and outcomes
- Encourage the pupil to rephrase information in their own words and to request clarification
- Limit the amount of verbal information given at any one time
- Use concrete language
- Move from general to specific, from concrete to abstract and from nonverbal to verbal
- Use signals, such as gestures and voice, to alert the pupil to key elements and issues

Technology as above

Computers can help with attention, reaction time and visual perception as well as processing, reasoning and problem solving. The independent work style and flexible pace suit many pupils and some programmes contain in-built reward systems.

Self-monitoring

Pupils can become more independent learners and more aware of their strengths and difficulties through the use of self-monitoring. Thinking processes can be coached, with cues to get pupils to ask relevant questions to guide them in their work. This may enable the pupil to make informed decisions and assume more control of their own learning.

Use checklists

The steps necessary for completing a task often aren't obvious to children with executive dysfunction, and defining them clearly ahead of time makes a task less daunting and more achievable. Following a checklist of steps also minimises the mental and emotional strain many kids with executive dysfunction experience while trying to make decisions.

Organisational skills

Pupils may have difficulty organising themselves and their belongings. Some find it hard to organise their thoughts in both oral and written communication.

- Help the pupil to make plans and sequence tasks
- Use organisational aids, e.g. checklists, templates, a diary or modified timetable or electronic organisers which can be set to remind the wearer of what, when, where, who or how things need to be organised.

Sequencing skills

If a pupil has sequencing deficits they may find it difficult to understand, recognise or describe a sequence of events. The details of the event may be related out of order and they may find it hard to follow complex directions, plots or activities.

"In such an academic family her cognitive difficulties seem even more startling." --
Mother of Lily, aged 14

- Limit the number of steps
- Rehearse sequences
- Use cues to aid steps and sequence
- Offer an overall outline before focusing on any one step
- Enable the pupil to verbally rehearse the sequence of events before or after an activity

Flow charts

Written or pictorial flow charts offer the pupil a structure to the work they are doing which they can then tick off as each is accomplished. The charts can be used for academic work as well as a reminder of practical tasks.

Backward chaining

For pupils with a greater degree of learning disability, learning new tasks, particularly motor tasks, can be demanding and demoralising. The tendency when teaching a new skill is to show the individual the whole process and then teach them from the beginning. 'Backward chaining' approaches things from the opposite direction and teaches them the last step of the skill first. This often means they start with the easiest part and are successful 100% of the time, encouraging them to continue increasing their learning. Each time they master a step, the previous step should be introduced. This strategy could be applied to setting up equipment for a science experiment, for example.

"We have seen a very gradual but clear decline in academic performance."

"It is so hard to plan for the future when the present is constantly being eroded."

"Organisation is everything! And it is one area we have control over."

"The usual meaning of the three Rs applies to all pupils. For pupils treated for a brain tumour there are the additional 3 Rs. They are Routine, Repetition and Rest."

-- Quotes from teachers

Writing frames and mind maps

Where young people find it hard to generate and sequence ideas (e.g. when writing a creative story), it can be helpful to teach them to use 'mind maps'. These provide a framework for brainstorming ideas but then organising them in a systematic way that enables pupils to write about them coherently. It also provides them with a written reminder of what they want to write about to aid memory.

Science and essay templates

Where pieces of work tend to follow a repetitive structure (such as in a science experiment), providing templates (e.g. on a computer) enables the pupil to insert their work into a similar format each time it is required. The template can also provide prompt questions and sample answers.

Precision teaching

'Precision teaching' refers to a method that teaches pupils information or skills only at the rate at which they are able to learn them. This enables clear tracking of their progress. For example, if a pupil with impaired sight vocabulary after a brain tumour can only recognise three key words consistently, teaching them one more word would increase their repertoire by 33.3%. The word to be taught should be decided upon and only the four target words taught during the teaching session. Once the new word is mastered, and the pupil also retains the original words, a fifth word should be introduced. Some individuals simply do not learn unless the exact information to be learned is made explicit and taught repetitively until it has become consolidated.

Errorless learning

'Errorless learning' allows the pupil to learn through a procedure which prevents them making a mistake, and guides them towards the correct response. For example, if applied to mental arithmetic, the teacher needs to ensure that the pupil does not have to guess any part of the working out of the answer. They should ask to be shown how to proceed if they do not know the answer. If the pupil were to be asked 'What's 3×9 ?', the teacher would need to ask the pupil if they know the answer. If they do not, they should be given a copy of their times tables to look up the answer. By doing so they learn to associate the answer, '27' with the question, ' 3×9 '. If the pupil were to guess and say, '30', they would be erroneously reinforcing that answer. As the pupil becomes more competent in retrieving the learned information, a system of 'vanishing cues' will help to reduce the external support they receive without leaving them to flounder.

Presenting pupils with model answers for open-ended pieces of work provides them with a framework around which to structure their own work. It makes the task seem less daunting and prevents them proceeding in completely the wrong direction and becoming frustrated.

Adapting timetables

For some pupils who have memory or organisational difficulties, it can be helpful to adapt their individual daily timetable to include information such as the specific location of lessons, the particular equipment required (i.e. books, lab coat) and the homework expected of them for each particular lesson. A pupil's individual timetable could also be further modified to include the 'topic' for each lesson. Using a picture alongside the written subject, e.g. a picture of a sum for maths, will help children who take a long time to read and process so they can see at a glance which class they should be doing.

Realistic expectations

Be clear and realistic about expectations – for the sake of both pupil and teacher! Expectations regarding a pupil's workload may need to be considerably adjusted following their return to school.

Patience, sensitivity, routine, repetition, rest, consistency

All will be particularly important for a young person returning to school after treatment for a brain tumour.

Extra training which could offer further advice

The Child Brain Injury Trust: <http://childbraininjurytrust.org.uk/> Accessed 19.12.13

The Child Brain Injury Trust (CBIT) has developed a one-day workshop for teaching staff entitled "Don't judge a book by its cover: Supporting a child with an acquired brain injury at school". The workshops run throughout the year across the UK and can also be delivered at in-service school training days (INSET days). The CBIT website also has some excellent resources for young people.



References and resources

AbilityNet: (<http://www.abilitynet.org.uk>)

A UK based charity helping disabled adults and children using computers and internet by adapting and adjusting their technology.

Barrera, M., Shaw, A., Speechley, K., Maunsell, E., & Pogony, L. (2005). **Educational and Social Late Effects of Childhood Cancer and Related Clinical, Personal and Familial Characteristics.** *Cancer*, 104, 1751-1760

Clicker: <https://www.cricksoft.com/uk/clicker>.

COGMED: <https://www.cogmed.com/>

Cognitive remediation intervention aiming to improve working memory and attention.

Dyslexia Quest, an iPad app: <https://www.nessy.com/uk/product/dyslexia-screening/> teaches memory and attentional skills in a fun way; especially good for primary aged children.

Executive functioning tips: <https://childmind.org/article/quick-facts-on-executive-functions/>

Headway – Coping with memory problems after brain injury, practical strategies: <https://www.headway.org.uk>.

An excellent charity that provides information, support and services to people affected by brain injury (including cancer), their family and carers.

Headway Memory Aids: Useful websites, list of resources/ organisations

The following list is not exhaustive and there are many other suppliers of memory aids, such as regular high street shops. Headway does not endorse any of the products on these sites.

Some websites may lapse over time

- <https://www.epill.com/> (medication reminder alarms, etc)
- <https://enablingdevices.com/> (vibration cueing devices, etc)
- <https://www.medicalert.org.uk/> (alarm watches and pill boxes)
- <https://www.cobolt.co.uk/> (reminder devices for the visually impaired)
- <http://www.shandrum.co.uk> (Post-it materials, Whiteboards, etc)
- <http://www.connevans.co.uk> ('photo phone' attachment and devices for the hearing impaired)
- <http://www.talkingproducts.co.uk> (voice recorders and related products)
- <https://dayclocks.com/> (clocks that specifically indicate the day of the week)
- <http://www.timestrip.com> (smart labels that monitor elapsed time)
- <http://www.loc8tor.com> (location detection devices)
- <http://www.keyringer.com> (location detector devices)
- <http://www.alzstore.com> (wide range of memory aid products)
- <http://www.ablelinktech.com> (specially designed hand held devices for memory problems)

Lancashire, E., Frobisher, C., Reulen, R., Winter, D., Glaser, A., & Hawkins, M. (2010). **Educational Attainment Among Adult Survivors of Childhood Cancer in Great Britain: A population-based cohort study.** *Journal of the National Cancer Institute*, 102, 254-270.

Mabbott, D., Spiegler, B., Greenberg, M., Rutka, J., Hyder, D., & Bouffet, E. (2005). **Serial Evaluation of Academic and Behavioural Outcome After Treatment with Cranial Radiation in Childhood.** *Journal of Clinical Oncology*, 22(10), 2256-2263.

Mulhern, R., Merchant, T., Gajjar, A., Reddick, W., & Kun, L. (2004). **Late neurocognitive sequelae in survivors of brain tumours in childhood.** *Lancet Oncology*, 5 (7), 399-408.

Palmer, S., Reddick, W., & Gajjar, A. (2007) **Understanding the cognitive impact on children who are treated for medulloblastoma.** *Journal of Pediatric Psychology*, 32(9) 1040-1049.

Read.write.gold: <http://www.readwritegold.com>

Saury, J-M., & Emanuelson, I. (2011). **Cognitive Consequences of the Treatment of Medulloblastoma among Children.** *Pediatric Neurology*, 44, 21-30.

Spiegler, B., Bouffet, E., Greenberg, M., Rutka, J., & Mabbott, D. (2004). **Change in Neurocognitive Functioning After Treatment with Cranial Radiation in Childhood.** *Journal of Clinical Oncology*, 22 (4), 706-713.

6

Other social,
behavioural and
disability issues in the
classroom



Taking medication, eating and drinking

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.

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, aged 12

Fatigue

'Somnolence Syndrome' often develops between 6-8 weeks after radiotherapy. Apart from an excessive desire to sleep it can also present as irritability, headaches and temperature. It can last between a couple of weeks up to about a month." Consultant

Pupils treated for brain tumours can experience debilitating fatigue, particularly after radiotherapy. It can last for months or years. This is different to the one off somnolence period described above. Pupils may suffer from mental/cognitive or physical fatigue during treatment which can affect everything they do. Mental or cognitive fatigue or over stimulation is less obvious. Tasks which previously involved little effort may make a pupil feel mentally exhausted. They may be unable to do homework after a full day at school. Fatigue can compromise other areas of learning such as memory and concentration.

What might I see?

- The pupil may complain, using words such as 'fuzzy' or 'confused'
- Work may be slow or lacking in detail or focus
- Apathetic or 'lazy' speech and behaviour
- Difficulty getting around school on time and arriving late for lessons
- Not interacting with peers
- Poor appetite
- Irritability
- Falling asleep or drifting off and not paying attention
- Poor concentration or difficulty remembering

Strategies

- Arrange bursts of work with frequent rests
- Reduce expectations of homework and class work – provide the pupil with an information card to show a teacher when homework is late or incomplete
- Allow the pupil to leave class 5 minutes early in order to get around school more easily, preferably with a friend so they do not feel too different
- Provide a coloured card for the pupil to indicate when they need time out – physically out of class or just 'switching off'
- Make a note in the homework diary explaining why work may be late or incomplete
- Modify time limits in tests and with coursework; for children with brain tumours it is useful to set a timed task rather than a completed project e.g. spend 20 minutes on...
- Allow typed work if the handwriting is too unsteady or tiring for the pupil
- Reduce the timetable or number of subjects studied
- Provide a calm and restful environment like the library for time out periods
- Use puzzles as a relaxing activity between work
- Allow the pupil snacks or energy drinks in class if appetite is affected
- Ask how they feel – even then they may find it hard to articulate. They may benefit from discussing fears and worries
- A time out/rest card if they feel overwhelming tiredness will allow them to go to a quiet place for a rest or just to rest in the class. This is a good strategy to allow the pupil to have some control over the day, but must be carefully implemented

"I hate not being able to do the things I used to!" -- Connor, aged 10

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.

"When Holly is overwhelmed by tiredness she lies across her desk until she feels better. Sometimes she shows her coloured card. This is a signal for the teacher to arrange for a friend to take her to the medical room where she can lie down to sleep." Father of Holly, aged 12

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). A gradual increase in the timetable is recommended with accompanying rest periods and careful pacing. 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.

"Simon's biggest problem is fatigue. It stops him doing things and being part of a group." -- Mother of Simon, aged 14

"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, aged 11

Sleep

Impaired sleep can persist for many years after treatment and it is worth looking out for and mentioning this to the referring hospital for specialist advice and strategies.

"We never realised just how long term and how debilitating the tiredness would turn out to be." -- Mr Jones, form teacher

"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." -- Mother of Jane, aged 16

Emotional Aspects

Young people who have had a brain tumour are often faced with a major readjustment following treatment. 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.

In some cases there will be a change in intellectual capacity, with a different pattern of cognitive abilities; some have only subtle changes, others can be hugely affected (see chapter 5 on page 67). Sometimes subtle changes in personality are seen. In addition, the pupil may have to cope with changes in physical appearance, about which teenagers in particular are likely to feel acutely sensitive. 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. A kind of grieving process then occurs, until the gradual acceptance of a new identity and new level of functioning. 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. It is as well to tackle these problems proactively and perceptively, as anxieties about school can quickly escalate to school phobia.

Most teenagers are preoccupied with identity issues. What sort of person am I? How do other people see me? They want desperately to be accepted as normal, as 'one of the crowd' within their peer group. They may well have anxieties on returning to school that their unusual experience may make it harder for them to feel that they belong. Some young people are very resilient, and will survive with their self-confidence intact. Others will emerge with a fragile self-esteem which will need careful handling and nurturing by those around them.

Not all young people with brain tumours will exhibit emotional difficulties. When difficulties do occur, the pattern will vary enormously, depending on the individual's temperament, history of earlier emotional difficulties preceding the brain tumour, the influence of the treatment on the brain, and the type and location of the young person's brain tumour itself.

"I don't seem to know who I am anymore."
-- Abdul, aged 12

"I feel really sorry for Bev. She tries so hard but then gets even more frustrated with herself."
Mother of Bev, aged 17

"It is difficult to reason with him in a meaningful way. As we talk he is compliant and remorseful – then shortly after he will have another carbon copy classroom confrontation!" -- Teacher of James, aged 14

What might I see in the classroom?

- Mood swings, melancholy, withdrawal, lack of enjoyment or motivation, tearfulness.
- Low self-esteem, emotional immaturity, over-dependence and clinginess.
- Frustration, anger, aggression, irritability.
- Anxiety, worry, depression and agitation about keeping up with work, choice of subject, exams and the future.
- Poor concentration and memory, poor motivation, restlessness, impulsive behaviour and academic underperformance.
- Impaired social skills or egocentricity and inflexibility.
- Attention seeking behaviour.
- Isolating behaviour such as withdrawal from social activity and interaction.
- School phobia/school refusal (more details later this chapter).
- Psychosomatic symptoms, which may include complaints of headaches or abdominal pain. In a child with a history of cancer it is important to firstly exclude any medical or physical cause for an ailment.
- Ongoing complex pain and persistent somatising presentations may emerge and need to be addressed by a tertiary multidisciplinary clinic as the issues are multi-factorial and difficult to treat.

"My experiences are totally different from my friends'. I sometimes think we inhabit different worlds and however much I try to explain they will never understand." -- Ruby, aged 14

Strategies and advice for emotional aspects

It is important to try to explore all the potential underlying causes of an emotional difficulty exhibited in order to gain an accurate assessment. The following should be considered:

- Did the young person have emotional difficulties prior to their illness? Longstanding emotional difficulties would suggest that the problem may not be directly related to the pupil's brain tumour. There may be other factors that are relevant relating to the individual or their family. Similarly, pre-existing emotional difficulties may be exacerbated by a serious life-threatening illness.
- Access to medical reports and liaison with the hospital may describe emotional difficulties related to the brain tumour itself and its treatment. This has implications for management, and professional advice should be sought.
- Some young people may benefit from talking to a counsellor, mentor or someone whom they trust. Some may prefer to share their worries by writing them down. Speaking sensitively to the pupil about your concerns is important as they may be reluctant to admit there is a problem or to accept any support. If the pupil appears to be at risk of self-harm, the parents and other professionals will need to become involved.
- Consider a referral to the school counsellor if available, the local Educational Psychologist, CAMHS or contact the psychological support service at the cancer hospital.

"My hair 'unit' from HDC cost a fortune. It is glued to my head and I can brush it and wash it like real hair. Nobody in my college has a clue that I am almost totally bald – and that is the way I like it!" -- Helen, aged 16

Behaviour

Teachers may notice changes in a pupil's behaviour on their return to school following treatment for a brain tumour. It should be stressed that 'behavioural problems' can include disruption and aggression as well as the more subtle behaviours such as withdrawal and dependency. It is also important to recognise that some behaviour may be beyond the control of the pupil. The CBIT website has some excellent strategy factsheets on dealing with behaviour changes in children with a brain injury which are very appropriate for pupils with brain tumours. (CBIT website factsheets on behaviour see Resource section on page 113)

Behavioural changes may present a problem in the classroom. They can develop for a number of reasons:

- They may be related to the type and location of the young person's brain tumour and/or associated medical and treatment complications. For example, a tumour located in the frontal part of the brain may result in changed behaviour such as aggression, disinhibition and inflexibility and obsessive compulsive tendencies.
- There may have been behavioural difficulties prior to the illness. These may be exacerbated and magnified by both the tumour and treatment and the extra stress of the pupil's return to school.
- The behaviour may mask an underlying emotional difficulty resulting from the illness. For example, there may be frustration, withdrawal or irritability as a response to having difficulties coping. A failure to recognise this may lead to the pupil being inappropriately mislabelled as 'difficult' and being managed incorrectly. Good management may require seeking further professional support and advice for the underlying emotional difficulty.

- The behaviour may mask an underlying academic difficulty. It is not uncommon for behaviour to deteriorate in the classroom or for children to become unmotivated when they are struggling with their academic work or in keeping up with their peers.
- Difficult behaviour may be due to specific cognitive deficits and/or communication difficulties such as short attention span, rigidity, lack of insight or speech and language impairment.

"Peter is clearly frustrated about his lack of ability compared with his former self. We know it is hard for him, but rules are rules! We cannot let him get away with things just because we feel sorry for him." -- Teacher of Peter, aged 13

"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 of Mark

"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, aged 14

What might I see in the classroom?

Common patterns of behaviour changes may include:

- Angry outbursts, frustration, irritability, verbal and/or physical aggression, oppositional or challenging behaviour
- Poor concentration and attention span, being easily distracted, restlessness and impulsive behaviour
- Inappropriately dependent or overly compliant behaviour, reassurance-seeking
- Inflexibility, overly literal or concrete thinking, lack of insight
- Impaired social skills, egocentricity
- Inappropriate behaviour such as sexualised behaviour
- Attention-seeking
- School phobia
- An excessively perfectionist attitude or obsessive behaviour

"She much prefers the company of adults. If I am busy she will find an excuse to go to the office or the medical room." -- Teacher of child, aged 15

Strategies

Understanding the behaviour is the key to successful management. For this, careful observation is necessary. Try to identify the following, perhaps using a behavioural diary over the course of a week or using an ABC (Antecedent, Behaviour, Consequences) chart:

- What triggers the behaviour? Is it in a particular lesson, at a particular time, in the company of particular pupils, etc?
- Define the behaviour clearly (i.e. description of frequency, intensity and duration).
- What happens as a result of the behaviour?
- Does the pupil get more attention as a result of the behaviour and people's response to it?
- Use a consistently applied behaviour strategy with clear consequences, and ensure all apply this consistently with understanding as to why the behaviour occurs.
- If appropriate, refer to specialist agencies as below.

The teacher will need to consider the pupil's behaviour in light of normal adolescent development, and in comparison to their peer group.



Useful contents to go into a 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?

It may be necessary to seek professional advice on behavioural management strategies. The Educational Psychologist may be able to advise, especially where cognitive difficulties may make it difficult to implement a behavioural programme. Some schools may have access to a Behavioural Support Service as an additional resource. There may also be a need to liaise with or refer to the Child and Adolescent Mental Health Service (CAMHS). Most oncology hospitals will also have a psychological support team on site available for consultation and advice, who are used to giving advice about children with brain tumours, or may already be offering support. Do contact them through the hospital.

"Talking things through with Simon and his parents helped such a lot. That boy has been to hell and back and he is scared." – Teacher of Simon

Good communication about behaviour problems

A sensitive acknowledgement of the problem with the young person should ideally take place. A discussion with parents will clarify whether this is exclusively a school-related difficulty. Communication with other staff members is important both to establish a thorough picture of the difficulty and to ensure consistency in behavioural management.

Finding the right balance

There can be an understandable tendency to be overly lenient or protective of a young person with a brain tumour. This can unwittingly maintain or exacerbate behavioural problems. It is important in some instances to treat the young person in the same way as their peers. However, it may well be inappropriate to discipline a young person for behaviour which is organic and beyond their control.

Perseverance and patience

It is not uncommon for behaviour to get worse before it gets better. Try to focus on a single problematic behaviour at a time and apply the same strategy consistently and patiently. Any improvement, no matter how slight, should be noted and praised.

Individuality

It is important to recognise that behavioural management strategies that may work for one pupil may not be appropriate for another. Individual assessment is required.

"Mark had a frontal brain tumour resulting in specific difficulties in temper control, emotional outbursts and disinhibited behaviour. His Head of Year asked his respective subject teachers to record specific incidents, noting potential triggers to difficulties that Mark displayed in class and the frequency of his outbursts. It emerged that Mark appeared to become particularly frustrated and angry in his maths lesson, and his teacher noted that difficulties began to arise if he was asked to share his work or to answer a question out loud in front of his peers. Further questioning individually with Mark and his parents revealed that these were subjects that he had previously felt very competent in, but that he was now finding more difficult. A careful analysis of the pattern of Mark's behavioural difficulties led to a sensitive discussion with him about his expectations of himself in these subject areas. His teachers also agreed to use alternative ways of monitoring his progress as opposed to verbal responses in front of the class." -- SENCO

Social functioning, autistic type presentation and peer relationships

Following treatment for a brain tumour, pupils may have a lower level of social functioning. They may have difficulties with:

- Reading social cues
- Interpreting the subtleties of non-verbal communication (e.g. body language, facial expressions, tone of voice, etc.)
- Being able to listen to others in a sensitive manner
- Taking turns or sharing
- Understanding jokes
- Controlling impulsive behaviour and outbursts
- Behaving in a socially inappropriate manner
- Making new friends or keeping old ones

It is becoming recognised that some children with brain tumours are now presenting with autistic-like mannerisms, for example very literal thinking, inability to see life from another perspective, poor social relationships, poor initiation of conversations, no social chit chat (Bonner et al 2008). In these cases, it is very useful to apply the strategies used with children with autism when dealing with pupils presenting with autistic type difficulties (Resources pack 2013 National Autistic Society).

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 set your pupil apart from their peers at school. Additionally, the profound experience of dealing with the diagnosis, treatment and life after cancer can be 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.

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 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 as a result, grown apart.



School refusal and school 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. This will need to be addressed quickly before it becomes a long-standing problem. Speaking to the pupil and the family is essential but outside agencies may also have to become involved.

Warning signs to look out for:

- Reluctance to attend school, including increasing reports of physical complaints such as abdominal pain, headache, sore throat
- Pupil presents with physical signs of anxiety such as racing heart, shaking, sweating, difficulty 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.

Managing school related anxiety

● With parents

- ◆ 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 communication can help the pupil
- ◆ 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
- ◆ Draw up a stepped plan for a return to school and agree with all parties to keep to it as far as possible
- ◆ Modify usual practices – such as allowing parents on school premises to build up the pupil's confidence

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

-- Mr Brown, form teacher

● School implemented strategies

- ◆ Form a trusting relationship, gathering information and implementing strategies
- ◆ Discuss with the pupil what the areas are that cause most distress, e.g. 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
- ◆ 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
- ◆ Reward success
- ◆ Manage distress calmly
- ◆ Consider using home tutors, who can help in the transition and integration between home and school, and can move from tuition in the home to tuition at school
- ◆ Have set meeting arrangements away from other pupils

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.”

Psychologist

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 changes

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 some boys may have a low sperm count.

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 complex. There are constant medical advances in the preservation of fertility.

Psychological changes

Psychological factors include the frequently negative impact on self-esteem and confidence, which is such an important aspect of sexual development. Adolescents are usually preoccupied with their looks and self-image. Changes in their physical appearance, due to a brain tumour and subsequent treatment, can have a profound effect. Changes may include short stature, hair loss, skin conditions as well as altered body weight and shape.

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 some people in the class may be worried and unhappy about their future sexuality and fertility.

Social skills difficulties can create problems in developing age appropriate social and sexual relationships. Young people with a brain tumour may appear immature, partly as a result of actual brain injury. There may also be other subtle signs of social impairment such as difficulty reading interpersonal cues and understanding inferences. This can have a major effect on their capacity to develop relationships. They may also have missed a considerable amount of time from school and therefore have less social experience and confidence compared to their peers.

Sexual knowledge can be affected by cognitive impairment such as memory loss and difficulties in processing new information. Mastering the factual aspects of sexual knowledge can therefore pose a real difficulty. The sexual safety of these young people might be further compromised if they are easily persuaded, do not have the skills to resist or if they send out inappropriate messages through impulsive and uninhibited behaviour.

Strategies to consider

- Teach or practise appropriate behaviour, possibly through role play
- Provide opportunities to develop structured group activities, e.g. grouping of pupils in drama or discussion
- Offer supplementary sex education
- Make all subject staff aware of individual concerns, particularly PHSE, Citizenship and Biology teachers
- Identify models of appropriate behaviour
- Provide assertiveness and social skills training
- Enhance self-esteem and focus on strengths and skills

"She just stormed out of the classroom in tears when the topic of fertility and pregnancy was brought up."

-- Biology Teacher of Sophie, aged 15

Speech, language and communication

After treatment for a brain tumour some pupils experience speech and language difficulties which may fluctuate over time. A teacher's vigilance and sympathetic attitude can help to identify a problem. Early recognition can prevent secondary problems such as frustration, low morale and social isolation. Speech may not flow as well and children may have difficulties finding the right words. Younger children may have difficulties with words and sentences (grammar) and understanding even simple language. Older children may appear to cope well when talking on a one to one basis, but struggle to follow the general conversation in group situations. Teenage children may have difficulties with conversations involving complex ideas and when words have more than one meaning. (CBIT website: thinking and learning)

What might I see in the classroom?

- Changes in speech
- Increased or decreased volume
- Slurred speech
- Poor voice quality or intonation
- Articulation difficulties
- Slow or hesitant speech
- Changes in language
- Trouble finding the right word, reduced fluency and other difficulties in expressing thoughts and ideas in words
- Difficulties with comprehension, both speed of processing and ability to take in more complex communication
- Changes in social communication
- Difficulty in taking turns and reading verbal and non verbal cues
- Difficulty in holding a conversation
- Problems in interpreting abstract language such as metaphors, humour and sarcasm

A speech and language therapist will be able to provide more specific guidance. A referral should be made for any significant speech and language difficulties.

Strategies

Some general principles are important in dealing with young people with speech and language difficulties. The teachers must speak slowly and clearly themselves. Instructions should be broken down into short and simple commands that the pupil can easily understand. If the teacher senses that the pupil is becoming flustered or frustrated by his/her difficulties in communicating, they should adopt a calm and reassuring attitude, gently suggesting that the pupil slow down or start again. It is important to take pressure off the pupil by respecting the need for additional time to communicate. Frequent praise is extremely helpful.

Some specific strategies can be put in place in the classroom:

- Where word finding is difficult, it is worth trying to introduce the first sound of the word for the pupil to complete or to give descriptions which might trigger the word. If a pupil is genuinely stuck it is better to simply tell them the word.
- Offer feedback on the information they have given you so far and gently prompt them to fill in the gaps.
- Provide the pupil with a framework to break down communication into manageable chunks, e.g. who, what, where, when, why.
- If comprehension is a particular difficulty, it may be useful to give the pupil an unobtrusive way to signal to the teacher that they have not understood.
- Never rush a pupil who is struggling to get the word out. If people are always jumping in with the word they are searching for, it can make pupils feel de-skilled and disempowered.

"David is just different – in speech and behaviour – and that's that. He does not get hung up about it and nor do his friends at school." -- Mother of David, aged 10

"You just have to be patient. There is always a slight delay before Lucy starts to answer a question – a bit like long distance calls in the past! And she speaks very slowly." -- Teacher of Lucy, aged 8

"Mark had a well developed vocabulary and good comprehension skills regarding factual information. However, following treatment for a brain tumour his social language skills were impaired. Pupils in his class complained that he was standing too close to them and speaking too loudly. He did not seem to notice that this bothered them. Mark wanted desperately to be one of the crowd but his efforts were misjudged and only alienated his peers even more. They complained that he had a 'weird' sense of humour and wrote him off as a 'geek'. Mark's increasing social isolation caused him considerable unhappiness." -- Teacher of Mark, aged 13



Vision and other visuo-spatial skills

"At first we were all totally devastated. Then you learn to adapt and to compensate. He is doing well now. School is not so daunting."
-- Father of Peter, aged 15

"Sally's problems are greater than you would think. She can see if things are in the right position but her tunnel vision makes her disorientated." -- Parent of Sally, aged 8

A pupil with a brain tumour may have their vision affected in a number of different ways:

- Decreased visual acuity (direct vision reduced, blind or partially sighted)
- Visual field defect ("blind spots", can be both eyes or just one)
- Squints and double vision (eyes do not move together)
- Poor coordination (eyes may flicker and be slow to follow objects)

"Nina was lucky to have several supportive friends whom her teacher had briefed on how they might best help her. They checked that homework was recorded accurately and showed her where in the book they were reading. In the canteen they read out that day's menu and made sure they found somewhere to sit together." -- Teacher of Nina, aged 13

An ophthalmologist will assess the pupil and may be able to help correct some of the problems (glasses, prisms or patching). Occasionally surgery can help correct fixed squints. Advice will be given by the ophthalmic team to schools.

Visuo-perceptual and spatial skills: Even though eyes and vision may not always be affected following a brain injury, a child's interpretation (understanding) of what is seen can alter. These difficulties tend to show themselves in changes in writing, drawing, work presentation, doing things like puzzles and when making things. It can also affect sports and 'social distance' (how close to someone they stand). (CBIT)

Contact the Visually Impaired Service in your Local Education Authority for specific help and information

What might I see?

- The pupil may be socially isolated because they cannot read gestures and social cues and are therefore unable to send out effective non-verbal cues
- Confusion if the group is large or the class noisy – the pupil may suffer from sensory overload
- Odd head movements or eye movements
- Difficulties getting started on work, misunderstanding or 'switching-off' if the pupil cannot read instructions

Position in class

- Sit at the front of the class. This needs to be arranged sensitively, perhaps seating the pupil with his peers
- Sit on the front left of the class if tunnel vision is directed towards the right (and vice versa)
- Sit next to a helpful pupil (left or right side depending on dominant side of vision)
- Encourage teachers and pupils to address the pupil by name before asking a question – the pupil may be unable to read facial expressions and gestures
- Work in small, sympathetic groups

Using print

- Use font Arial Black and assess the font size needed for all print
- Enlarge worksheets to desired size before lessons and provide personal copies of planned board and whiteboard/Overhead Projector (OHP) work
- Provide notes in suitable font size if unable to see work on the board
- Use 'Low Vision Aid', which is a device that enhances or enlarges print
- Give verbal commentary on all classroom demonstrations and activities
- Only use blue or black pen on the whiteboard
- Provide the pupil with their own text book – sharing can be a problem
- Make sure worksheets are clear, good copies. Avoid page turning and ensure vertical positioning and numbering as opposed to a more horizontal spread of information
- The most suitable colour of paper for printing is very individual, but buff or light green are often preferred by the partially sighted

"Peter's small and neat handwriting was often praised by the teacher. However, when Peter wanted to use his essays for revision before his exams he struggled to read his own writing. Once he was familiar with a new laptop he used it for class work as well as homework. He coped much better as he was able to enlarge the print to a readable font size." -- TA of Peter, aged 15

Using information technology

- Encourage the pupil to use their laptop for enlarging, note taking and revision
- Arrange for the pupil to learn touch typing
- Consider the use of a dictaphone for notes in class
- Seek permission well in advance of tests and exams for the pupil to use a laptop (with the spell check removed!)

Other

- Use resources from RNIB (see Resources section on page 113) and consult with the visually impaired local team for input and classroom advice
- Use extra large dice and cubes in Maths – also helpful for pupils with a tremor or motor skill problems
- Use coloured rulers rather than see through clear plastic
- Use centimetre squared paper instead of normal graph paper. Ensure clarity of lines and background colour
- Allow the pupil to leave the class early, with a friend, in order to reduce pushing in the busy corridors at changeover between lessons. Reduced vision in a rapidly moving crowd can be problematic
- Shapes on paper may need to be shaded in
- Allow stickers and colours in workbooks as an aid to locating topics
- Watching TV/video at school can be too difficult in a restless group
- Arrange for the pupil to borrow the video to watch at home

Movement around school

- Practise moving from class to class without pupils present
- Encourage friends to protect the pupil from collision in corridors and playground
- Arrange for lines to be painted on steps, etc. (The Visually Impaired Team will help assess the needs of pupils and the potential hazards in school)

“Over time Nigel’s teacher found that buff coloured paper with bold black squares meant that Nigel was able to complete his work much more quickly than when conventional white paper was used.” -- Mother of Nigel, aged 8



Hearing

After treatment for a brain tumour, some young people develop hearing problems which can range from mild to severe. This acquired deafness can be devastating both educationally and socially and will need both time and patience to adapt to, not just for the pupil but also for the teacher. Deafness has a major impact on language development, so the age at which the deafness occurs is crucial. Speech patterns and sentence structures are picked up, almost automatically, from listening to people talking. A deaf person may not hear every word spoken or every sound in a word. Their spoken and written English may reflect this. For instance it is common for deaf people to leave off endings of words as these are more difficult to discern, 'hat' rather than 'hats' or 'walk' rather than 'walked'.

Contact the Hearing Impaired Service in your Local Education Authority for specific help and information.

Hearing aids

All hearing aids have a microphone which will receive sounds and then amplify them. However, hearing aids do not restore hearing completely. All noise, including distracting background noise, is amplified so communication may still be compromised in noisy environments such as a classroom.

Direct audio input

This allows you as a teacher to connect the pupil's hearing aid or cochlear implant directly to audio equipment such as a radio or computer or to a number of other devices.

There are a number of other communication options available. A Hearing Impaired Specialist will give detailed advice on these:

- Natural aural approach
- Structured aural approach
- Maternal reflective and auditory verbal theory
- Lip reading
- British Sign Language (BSL)
- Finger spelling
- Sign bilingualism
- Total communication

Additional sign systems include: Sign Supported English (SSE), Signed English (SE), Paget Gorman Signed Speech (PGSS), Cued speech, Signalong and Makaton.

Communication Support Worker (CSW)

- A CSW assists by translating English into sign language
- Allow sufficient time for the deaf pupil to 'read' a question being signed to them. There will always be a brief time lag
- Speak directly to the deaf child, not the CSW
- Allow time for demonstrations or experiments to be explained in sign language
- Ask the CSW to teach you a few signs

"I sometimes tell my friends that I am not stupid—only hard of hearing." -- Paul, aged 8

"Poor hearing means you can so easily become socially isolated." -- Mother of Paul, aged 8

Strategies for the classroom:

- Promote being 'deaf aware' by acting as a role model for hearing pupils
- Introduce communication and sign language classes/sessions for hearing pupils
- Consider where the pupil should sit and whom they should sit next to
- Can they see who is speaking and what they are saying?
- Insist that pupils put their hand up to speak – it enables the hard of hearing to focus and ensures only one person is speaking at a time
- Ensure homework and information about school activities are communicated/written down in the pupil's homework diary
- Use visual aids as often as possible
- Keep unnecessary noise to a minimum
- Provide handouts – taking notes whilst lip reading is difficult
- Provide transcripts of video material used in the classroom
- Use hearing loops in the classroom

Mobility and motor skills

Most young people with a brain tumour make good physical recovery after treatment. However, some are left with impairments which can affect both fine and gross motor skills. The complex interaction of mobility and stability may be affected by factors such as balance and coordination, muscle tone and strength, attention and concentration as well as mood and motivation.

Gross motor skills involve the whole body in activities such as walking, running and jumping and are needed for general mobility around the school, in the playground and in PE/Games. The young person may appear awkward, clumsy, slow or weak. More severely affected pupils may have a weakness down one side of the body, called hemiparesis or hemiplegia. Where coordination and weakness affects all four limbs of the body, called quadriplegia, the young person may need assistance, aids or a wheelchair to move about.

Strategies to consider

- Use classrooms on the ground floor or which involve a limited number of stairs
- Limit or adapt expectations
- Get a friend or buddy to carry bags around school
- Allow the pupil to leave class five minutes early in order to negotiate the corridors without the rush and noise of crowds
- Have procedures in place for the safe evacuation of a pupil with mobility problems
- See separate section on PE and Outings on page 50

"Jim is in a wheelchair and has very limited movement and control of his hands. At the special school he attends, the home economics department is fully geared up for any problems which might occur. Anti-slip mats are placed under bowls when stirring, utensils have ergonomically correct grips and the tabletop, including the sink and cooker, can be raised or lowered to suit the needs of individual pupils. The workshop technicians at the school pointed out that while most schools cannot go to such lengths to accommodate individual pupils, there is still a great deal that can be achieved through the acquisition of off-the-peg learning aids." -- Teacher of Jim, aged 12

"We could do with having a new lift installed. Apart from that there are hardly any problems with movement around the school. At school I have a tray with special equipment such as scissors and pens and we have the same at home." -- Sophie, aged 15



Fine motor skills

The ability to grasp, manipulate and release may be slow, weak or unsteady to the point where the pupil will need assistance in the classroom with certain activities.

A young person with fine motor skill problems may find any of the following difficult:

- Writing and drawing
- Folding paper and using scissors
- Doing up buttons and shoelaces
- Eating and drinking
- Carrying out science experiments
- Operating tools and machinery in Craft Design & Technology (CDT)

Strategies to consider

- Use specific aids where possible such as pencil grips, adapted scissors and equipment
- Ensure a good sitting position. Consider table height, chair and how well the body is supported
- Use equipment of an appropriate size, with a non-slip surface or convenient grips or handles, particularly in Food Technology, CDT and for Science experiments
- Use paper with larger lines or squares
- For writing, a sloping board may be useful

Ask for advice and specific strategies from the pupil's physiotherapist, occupational therapist or neurologist.

Resources and references:

Bonner, M., Hardy, K., Willard, V., Anthony, K., Hood, M., and Gururangan, S. (2008) **Social Functioning and Facial Expression Recognition in Survivors of Pediatric Brain Tumors**. *Journal of Pediatric Psychology* 33 910 pp 1142-1152.

The Child Brain Injury Trust: <https://childbraininjurytrust.org.uk/>

<https://childbraininjurytrust.org.uk/wp-content/uploads/2018/11/Behaviour-practical-strategies.pdf>

Companies selling special needs products:

Inclusive Technology Ltd
Gatehead Business Park
Delph
Oldham
OL3 5BX

Tel: 01457 819790

<http://www.inclusive.co.uk>

The National Autistic Society: <http://www.autism.org.uk>

The leading UK charity for people with autism (including Asperger Syndrome) and their families. We provide information, support and pioneering services, and campaign for a better world for people with autism.

Royal National Institute for the Blind

<http://www.rnib.org.uk/Pages/Home.aspx>

RNIB offers support and advice to blind and partially sighted people, including advice for children with impaired vision.

“Without imaginative technology Ian would not have been able to return to this school.”

— Teacher of Ian

7

What to do if the
pupil becomes
palliative and may die

Managing bad news

Despite most young people being successfully treated for a brain or spinal cord tumour, some will, sadly, die from the disease. Medical care of the patient then changes from curative to palliative. The most important focus in palliative care is to make the patient comfortable, and to have the best symptom care, including aiming to keep them pain-free. This is to enable them to enjoy the time they have left for as long as possible and to die as peacefully as possible.

What needs to be considered before setting up a plan at school

- Nominate one named key member of staff who will keep in touch with the family, to avoid family having to continually go over the story and be responsible for co-ordinating information and support. Do take the lead from the family, as it needs to be someone they feel comfortable with.
- Make arrangements to allow for discussion among staff, to prepare themselves before telling pupils. Acknowledge that any talk about death or the potential of death may bring up strong feelings for staff, who then have to feel able to deal with and manage pupils' reactions.
- Consider how to tell other members of staff, and what staff members need to know. Liaise sensitively with the family, and ensure all preparation/support is done according to their wishes/beliefs, including always finding out how much the pupil himself may know.
- Prepare who should be told, what should be told, when, and how?
- Decide how to tell pupils, and in what format.
- Think clearly about other members of the family i.e. siblings.
- Who is available to support staff/pupils, how available are they/do outside agencies need to be involved?
- Is there private space for those needing time on their own? This applies to staff as well as pupils.

The role of the teacher when a pupil becomes palliative

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

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

The communication with the family is crucial at this point, as not all children or siblings are aware that the pupil might die. The role of the school is to support the pupil, other pupils, staff and family through this process, and to ensure the family have every confidence that the school will meet their expectations and never break any confidence. Even though a young person is dying, they and their parents may wish them to attend school in a limited way. The school is a familiar place where most of the young person's relationships outside the family exist. Through these important relationships, some kind of a regular routine and normality can be maintained. With careful planning and communication the school can nurture the child's social and emotional well-being. The parents and siblings may also find it comforting that their social network of support is involved and maintained. Surprisingly some children do manage to attend school up to a date very close to when they die.

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

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 greatly affected by their own experiences and how close they are to the sick pupil. Those who have already experienced significant loss in their lives tend to need greater support and comfort, although individual reactions to loss can never be predicted.

Preparation for staff:

- Make sure the teachers have some time alone together, to plan what to say, and to support each other. Instigate a meeting with professionals from the hospital for support and information if needed.
- Be aware of your own feelings, and set up a forum where teachers and other staff can share what is happening, so they too feel supported. Facing a death will always bring up issues in private lives, re-living of own losses, or experiences of illness and cancer, death and dying. Not all teachers feel they can be available for others, if they themselves are vulnerable.
- Acknowledge that this may be a powerful learning experience for pupils and teachers alike, a deeper understanding of important issues. Always remember that all members of staff may be deeply affected.
- 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 told at the same time so that 'rumours' and different stories are not circulating among the school community. Be prepared for questions that you can't always answer, and say that you don't know. It is often more important to let people explore. You can always say that you will think about the question and get back to them, and ensure that you do.
- The more prepared you are, the more likely the children will feel prepared, which may well avoid later problems.
- Be a good listener. Let the pupils or staff members finish; let them have opportunities to talk either in a group or individually, if you feel able to talk with them. If you can't, then who can?
- Include issues in the curriculum if appropriate, particularly where pupils raise the topic. It may need revisiting again and again over time. Don't avoid the dying pupil because you or other staff feel uncomfortable.
- Acknowledge the powerful learning experience for pupils and teachers. Allow time for talk and reflection. Be a good listener.
- If you want more support, make contact with professionals who will be able to support the school and offer advice and counselling.

Communication between school and family

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

- Communicate through the nominated key member of staff.
- Agree with the family exactly what can and what cannot be shared with the school and pupils.
- Remember some families never want the fact their child is going to die made public. In that case, discussion can only be around how ill the pupil is, and support will be needed after the pupil has died.
- Sending home to all parents a letter 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.)
- Consider the best way to send condolences from the school and letters from staff and pupils.

"It was so important that we were given both time and space. It made it dignified when it could so easily have been anything but."

-- Parent of child, aged 14

For pupils: preparation for a death or acknowledging that a pupil is gravely ill

It varies enormously from family to family if the impending death can be shared with the school. 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 confidential information about a pupil's prognosis.

Always start with those in same year/form group as the pupil facing death. Small groups are more personal than discussing at an assembly.

- Remember to make sure that the family and, if appropriate, the pupil facing death are in agreement with how the school are planning to prepare others. Remember these should not be one-off conversations, more of an ongoing process. As the teacher, know your own resources within and outside of school, and acknowledge your feelings in the process.
- It is important to tell pupils at the same time where possible or closely together so that rumours do not circulate around the school.
- Explain that the pupil is very ill and that you are waiting for further news.
- Many dying pupils wish to attend school as this provides familiarity, regular routine and a sense of normality for them. They may attend on a very part-time basis e.g. break times or their favourite lesson. It can be difficult to know how to respond to the young person, and often it can be best to act normally. Contact can also be made with the young person through letters, cards, social media, Facebook, Twitter, email, videos, instant messaging or text messaging.

- Think about what your class or year group could do, to maintain links with the pupil. Help them to know what to expect when visiting or talking to their friend. Give them time to reply, always double check that is it still ok to visit/chat. Work out who the right person is to talk to, if they have more questions: is it class teacher, form tutor, Head of Year, nurse?
- Give pupils opportunities to ask questions: 'Is there anything you want to ask?' Make it clear they can ask in the group, and make sure you're available for individual questions as well. Be prepared for questions, answering them as directly and honestly as is possible, bearing in mind what permission has been given.
- Work out what to do if people feel upset. Where do they go? Have an escape route planned.
- Acknowledge that this is happening at a time of great change already in the students' lives, i.e. developing identity, relationships, the whole importance of the teenage developmental period. Many pupils can learn a great deal by experiencing powerful episodes in their lives during their child and teenage phase.
- If a sibling is in the same school, remember to think sensitively about their needs.
- Explore where teenagers may get support from, both in and out of school.

If you have permission to share the fact the pupil is likely to die:

- Explain how treatment is no longer working and now they may die. It is important for fellow students to understand what has happened, about the treatment and now the prognosis. Very precise guidelines need to be drawn up about what information can be shared, and the family need to agree to any information being disseminated.
- Explain it is difficult to say exactly the time scale, but that it is likely to be in the order of days/weeks/months (check with the family first).
- Explain that the pupil knows what is happening (if this is the case), but for him/her the most important thing is to try to have as normal a life as possible, which includes maybe visiting school if s/he is up to it, seeing friends, and maintaining contact.
- Encourage exploration of feelings, and explain what other children in their situation have felt. Pupils might well go through stages of grief, anger, withdrawal, disbelief, euphoria, denial, acceptance, fear.
- Explore spirituality, and personal views of what may happen when people die.
- Ensure pupils know how to get support and advice.

After the death

- Make sure all staff know the pupil has died.
- It is important for the school community to acknowledge the death of a pupil, something that will convey the importance of each individual in the community, and respects the child and his or her family.
- Is there a private space which 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?
- Be clear about who will be in contact with the family.
- Agree what exactly will be told to pupils.
- Tell pupils in small groups, allow time to talk about what has happened if they want, or the chance to have private time, or to attend classes as normal.
- Use a normal voice and 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 sympathy or sadness in any form they find suitable. There are no 'right words' and any gesture of sympathy is valid.
- It is important to allow extra time for discussion for those in the same year/form/close friends as the pupil who died, and the same for those in the same form/tutor group as any siblings.
- Make sure pupils know who (agreed beforehand with staff) they can talk to if they want to.
- Make sure all staff are telling the same story.
- Ensure there is a place pupils can go to if they wish to talk, or have time on their own, and that they know where this is, and who they need to tell if they want to go there.
- The key contact staff member needs to acknowledge the death and with agreement send a card. Never be in the position of not having any contact with the family, as this can just add to the sense of loss and abandonment. Make contact ideally in written form as often phone calls are not remembered and merge into one in the memory.

"The only thing I felt able to do was make cups of tea and provide tissues." -- Teaching assistant, year 8

"I felt so angry and abandoned that we never got any contact from the school at all, no card, phone call. Months later the secretary did phone and said she had been told we all had to respect the family's privacy. We felt so rejected. Even if done for the right reason, it really never came across like that." -- Mum of child, aged 6

- What is the staff position on attending funerals for staff/pupils? How will school deal with anniversaries of death? Should anniversaries, birthdays, etc. be marked? Experience has shown that families really appreciate the fact that their child is not forgotten on these special occasions. This needs to be planned well in advance with someone taking responsibility for coordination.
- Will the school be pro-active in helping staff/pupils who are having difficulties in coping with the death?

- Consider the best way to send condolences from the school, letters from staff and pupils.
- Recognise the loss, acknowledge what has happened, understand why it has happened, in small groups.
- Consider, with the family of the pupil who has died, if a letter should be sent out to other parents and children at the school about the death. Consent from the family will be required.
- React to the imminent reactions. Do expect the unexpected, but the more they are prepared in advance, the more likely they will be able to manage the best way they are able.
- React to the separation from the person who has died. Some will experience pain and express reactions; some will be numb; some will act as if nothing has happened: all are usual reactions.
- Expect a wide variety of responses. Some will be very attention seeking and say very challenging things (these are likely to be children who are already presenting with problems and feel angered that they are no longer the ones in the spotlight).
- Remember the person who has died, and your/pupils' relationship with them. Do people (staff, pupils, siblings) want to be involved in memorial/funeral/fund raising/supporting siblings/anniversaries, what will the school offer? Remember that it is not only the pupils who will be affected; staff will be too.
- Accept there will be changes. Something important has happened, and will affect many people, make them re-evaluate life, priorities may change. Life for some will never be the same again.
- There will be re-adjustment to life without that special person, but this will be individual. Think about how to live with the loss of a friend/brother/fellow pupil/pupil/acquaintance.
- Very few teenagers or younger children ask for extra support after a death of someone close, but a few will need individual support, either in or out of school. Good preparation will help to ensure potential problems are picked up early and appropriate help offered if needed.
- Be aware that many teenagers present with delayed reactions, maybe even one or more years after the death. This is important and they will need the same support structure as the newly bereaved.
- 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.



Grief

Young children often show grief feelings as an intense outburst of questions, and then act as if nothing has happened and go back to playing, much like jumping in and out of a puddle, jumping in and out of grief. Any discussion about death or grief really needs to be short and repeated, allowing the child to feel at ease about asking questions or showing their feelings, and giving them permission to talk about death is a good move. 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 some may act as if nothing has happened as a way of coping. This may be particularly so for boys, who tend to be more controlled and less expressive. Girls are more likely to openly express grief and cry, and are consequently more likely to get the sympathy and comfort they need.

Young people often turn to their peers for support which can leave adults feeling helpless and rejected. Young 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 are necessarily accompanied by emotional acceptance or a constructive outlet of grief.

What behaviours to expect in children and teenagers after a death

- Variety of often intense emotions, numbness, feelings of nothingness, guilt, lack of concentration, rushes of overwhelming feelings, denial, surfacing of other deep feelings related to own experiences. Some may find it difficult to express their emotions and may make jokes as a way of coping.
- A sudden interest in the child or teenager from people not seemingly involved, which may be to do with unexplored feelings, or guilt at never having known him/her very well, re-emergence of other feelings. There may be feelings of guilt from pupils who have not had a good or ambivalent relationship with the pupil who died.
- From his/her close friends, a need to have quiet time, an identified person to be contactable if they want to express feelings, or the opposite, a sudden burst of frantic activity.
- Often people act as if nothing has happened. This can be a form of denial. In this case, do not push the child, but offer them a time on their own; it can just feel too threatening to show feelings.
- A need to be involved in planning some kind of memorial to help them feel they are playing a useful role.
- Perhaps a chance to take part in the funeral/memorial service.
- An increase in risky/withdrawn behaviour.
- A surge of existential questioning, which is prevalent especially in teenagers anyway, now is much more pertinent, as teenagers are supposed to be invincible.
- A teenager may need extra help. Offer support to all, but be on the watch for the following:
 - ◆ Symptoms of chronic depression, ongoing sleeping difficulties, restlessness, change in self-esteem.
 - ◆ Academic failure, or change in interest in school activities.
 - ◆ Deterioration in relationships with family, friends and staff.
 - ◆ Increased risk taking behaviours, drugs, alcohol abuse, fighting, sexual experimentation.
 - ◆ Denying pain, whilst acting overly strong/protective/over-mature.



Stages of adult grief (Kübler-Ross)

Many people do not experience the stages in the order below, and indeed the emotional stages are not meant to be seen as a strict sequence. Most people move from one emotion to another and not in any particular order. The key to understanding the stages is not to feel like you must go through every one of them, in precise order. There are five stages of normal grief that were first proposed by Elisabeth Kübler-Ross in her 1969 book "On Death and Dying". This model can be a useful way of understanding the emotions people go through, including staff.

- 1. Denial and Isolation:** It is a defence mechanism that buffers the immediate shock. We block out the words and hide from the facts, can feel numb and like this is all happening to someone else. This is a temporary response that carries us through the first wave of pain.
- 2. Anger:** As the masking effects of denial and isolation begin to wear, reality and its pain re-emerge. The anger may be aimed at inanimate objects, complete strangers, friends or family. Anger may be directed at our dying or deceased loved one. Rationally, we know the person is not to be blamed. Emotionally, however, we may resent the person for causing us pain or for leaving us. We feel guilty for being angry, and this makes us more angry.
- 3. Bargaining:** The normal reaction to feelings of helplessness and vulnerability is often a need to regain control. Secretly, we may make a deal with God or our higher power in an attempt to postpone the inevitable.
- 4. Depression:** Sadness and regret dominate this type of depression. It is our quiet preparation to separate and to bid our loved one farewell.
- 5. Acceptance:** Reaching this stage of mourning is not afforded to everyone. Death may be sudden and unexpected or we may never see beyond our anger or denial. It is not necessarily a mark of bravery to resist the inevitable and to deny ourselves the opportunity to make our peace. This phase is marked by withdrawal and calm. This is not a period of happiness and must be distinguished from depression. The best thing you can do is to allow yourself to feel the grief as it comes over you. Resisting it will only prolong the natural process of healing.

Strategies for grief support

- Make sure pupils and staff know support is available, either through the school or contact the treating hospital for advice.
- Work out what to do if people feel upset.
- Let your genuine care and concern show.
- 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 some of your own sadness as this can help pupils to know that the sorrow is shared and that it is all right to show your feelings.
- 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.
- 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.
- Do allow them to talk about their feelings whatever they are, both positive and negative.
- Do get rid of the word 'should', as in 'I should be doing this, I should be feeling this..... there is no right or wrong way to feel after a loss, everyone will find their own way of dealing with it.
- Don't let your own feelings of helplessness keep you from reaching out.
- Don't ever say you know how they feel, unless you have had the same loss. Never tell them what they should feel.
- Don't ever say 'you should be feeling better/ be moving on by now'.
- Don't change the subject when a pupil mentions the loss.
- Don't try to find something positive to say about their loss. This can trivialise it in their eyes.
- Do be available, or arrange for someone to be available for them.

"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

"Be prepared to listen – again and again and again!" -- Mr Wright, Form Teacher

"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, Head Teacher

References/Booklist/Useful Resources

Reading for adults/teachers

Good Grief – Exploring feelings, loss and death with U I I s (separate book for over I I s)

Barbara Ward & Ass.

Excellent school resource. Written for teachers – contains information, activities and ideas to help children explore issues around separation, loss and death. Photocopiable material.

Helping Children Cope with Grief

Rosemary Wells

Very helpful and easy to read. Practical advice and suggestions, real life examples of children's reactions to bereavement. Particularly suitable for adults working with children.

Grief in Children – a handbook for adults

Atle Dyregov

Useful and readable. Explains how children understand and react to death. Contains specific information about how to handle death in school and school's response to the needs of bereaved children.

Grief and bereavement, Understanding children

Couldrick, A (1991)

Sobell Publications. Very short booklet, explaining how children respond to grief.

Death and Loss – compassionate approaches in the classroom

Oliver Leaman

For teachers involved in the pastoral care of pupils. Includes ideas about curriculum content within PHSE.

Giving Sorrow Words (Video and Book)

Killick & Lindeman

Useful training package designed for school staff to help them deal with the effects of bereavement. Offers practical advice and demonstrates effective techniques for working with children and young people.

(Available via <http://www.luckyduckpublishing.com/books-and-products>)

Wise before the Event

William Yule & Anne Gold

Describes some of the ways crises can affect schools, and suggests ways that schools can lessen the physical and emotional effects of disasters. Very readable and useful.

Saying Goodbye to Greg – Understanding bereavement at Foundation, KS1 and KS2

Christine Chapman

Very good bereavement training resource set in story form, using the "real life" situation of the death of a pupil in a primary school. The aim is to lead primary teachers through the bereavement process.

The Social Curriculum – Death and Bereavement – Guidance for Schools

Essex County Council

Very useful and readable booklet detailing all aspects of managing death and bereavement in schools. (Available via Essex County Council Learning Services 01245 431021)

Loss Change and Grief – An Educational Perspective

Erica Brown

Useful book exploring the experiences of bereavement within an educational setting including suggestions about supporting children with learning difficulties.

Reading with primary school children

Badger's Parting Gifts

Susan Varley

When Badger dies his friends ease their sadness by remembering the special "gifts" he gave them.

Waterbugs and Dragonflies

Doris Stickney

This short book uses the analogy of the waterbugs' short life under water as humans' time on earth and their emergence as dragonflies into the bright sunlit world above the water as humans' life after death. It is designed to provide adults with the opportunity to talk about death as being part of the life cycle, which can be a reassuring way of explaining death to children.

I Miss You – a first look at death

Pat Thomas

Simple factual and sensitive exploration of death which includes interactive questions.



Always and Forever

Alan Durant

The animals talk and laugh about their memories of their friend Fox following his death.

Beginnings and Endings with Lifetimes In Between

Mellonie and Ingpen

Beginning with small creatures and ending with humans, the cycle of life and death is told factually.

Scrumpy

Dale and Joos

Tells the story of how a young boy reacts and copes when his much loved dog dies.

The Huge Bag of Worries

Virginia Ironside

Jenny's worries build up and get out of control. She just can't get rid of them, until she meets an old lady who helps her sort them out. A lovely story with fun illustrations encourages children to talk about their worries.

The Sad Book

Michael Rosen

Book about Michael Rosen's sadness at losing his son – reaches out to adults and children alike

Muddles, Puddles and Sunshine: Your Activity Book to Help When Someone Has Died

Diana Crossley

Fantastic interactive workbook with fun and very creative activities to help children when someone dies.

Reading for Teenagers/secondary school pupils

Vicky Angel

Jacqueline Wilson

Even after she dies Vicky makes her presence felt through her close friend Jade.

The Charlie Barber Treatment

Carole Lloyd

When Simon's mum dies he begins to find life difficult. Through his friendship with Charlie he rebuilds his life and relationships.

When a friend dies

Marilyn E. Gootman

Practical suggestions about what can help and full of quotes from bereaved adolescents.

When Parents Die

Rebecca Abrams

Written for older teenagers/adults. Looks at issues surrounding bereavement. Autobiographical.

Straight talk about death for teenagers

Earl A. Grollman

Easy to read, concise and informative about what feelings and issues might arise for adolescents.

When people die

Williams G. (1983)

A straightforward book for teenagers.

Losing someone you love

Richter E. (1986) Putnam

Young people share their experiences about the death of their sibling.

Websites

www.winstonswish.org.uk

Information for schools, downloadable lesson plans, message board for young people, booklists, general information about grief and bereavement

<http://archive.teachfind.com/ttv/www.teachers.tv/series/school-matters.html>

School Matters – Coping with bereavement – video about two schools managing a death

www.childbereavement.org.uk

Information for schools, general information about grief and bereavement

<http://hopeagain.org.uk>

Designed by young people to help other young people through bereavement (Cruse)

CCLG: Childhood Cancer Leukaemia Group
(cclg.org.uk)

CCLG has a long list of downloadable resources and publications including

Bereavement: Where to Go for Help—a guide for families, health professionals and schools, when a young person has died from cancer.

<http://www.cclg.org.uk/our-publications/bereavement/bereavement-where-to-go-for-help>

Facing the death of your child, Lesley Edwards

<http://www.cclg.org.uk/our-publications/bereavement/facing-the-death-of-your-child>

Guidance written for families to prepare for the death of their child, includes a chapter for schools.

8

Central Nervous
System tumour
information and
treatment

Brain and spinal cord tumours (Central Nervous System Tumours)

As summarised and detailed in the bar graph figure below, central nervous system (CNS) tumours in children and adolescents/young adults may be most simply classified as follows:

- Glioma:
 - ◆ Astrocytoma:
 - Low Grade Glioma (including pilocytic astrocytoma, diffuse astrocytoma and optic pathway glioma)
 - High Grade Glioma (including anaplastic astrocytoma and glioblastoma multiforme)
 - Diffuse midline glioma including thalamic glioma, brainstem glioma and diffuse intrinsic pontine glioma, DIPG
 - ◆ Ependymoma
- Medulloblastoma/Primitive Neuro-ectodermal Tumours (PNET)/Pineoblastoma
- Craniopharyngioma
- Germ Cell Tumours
- Rare tumours e.g. Atypical Teratoid Rhabdoid Tumours (ATRT), Choroid Plexus Carcinomas, others.

The main features of each tumour type, including presenting symptoms, treatment, outlook (prognosis) and long term effects, are detailed in the individual subsections below.

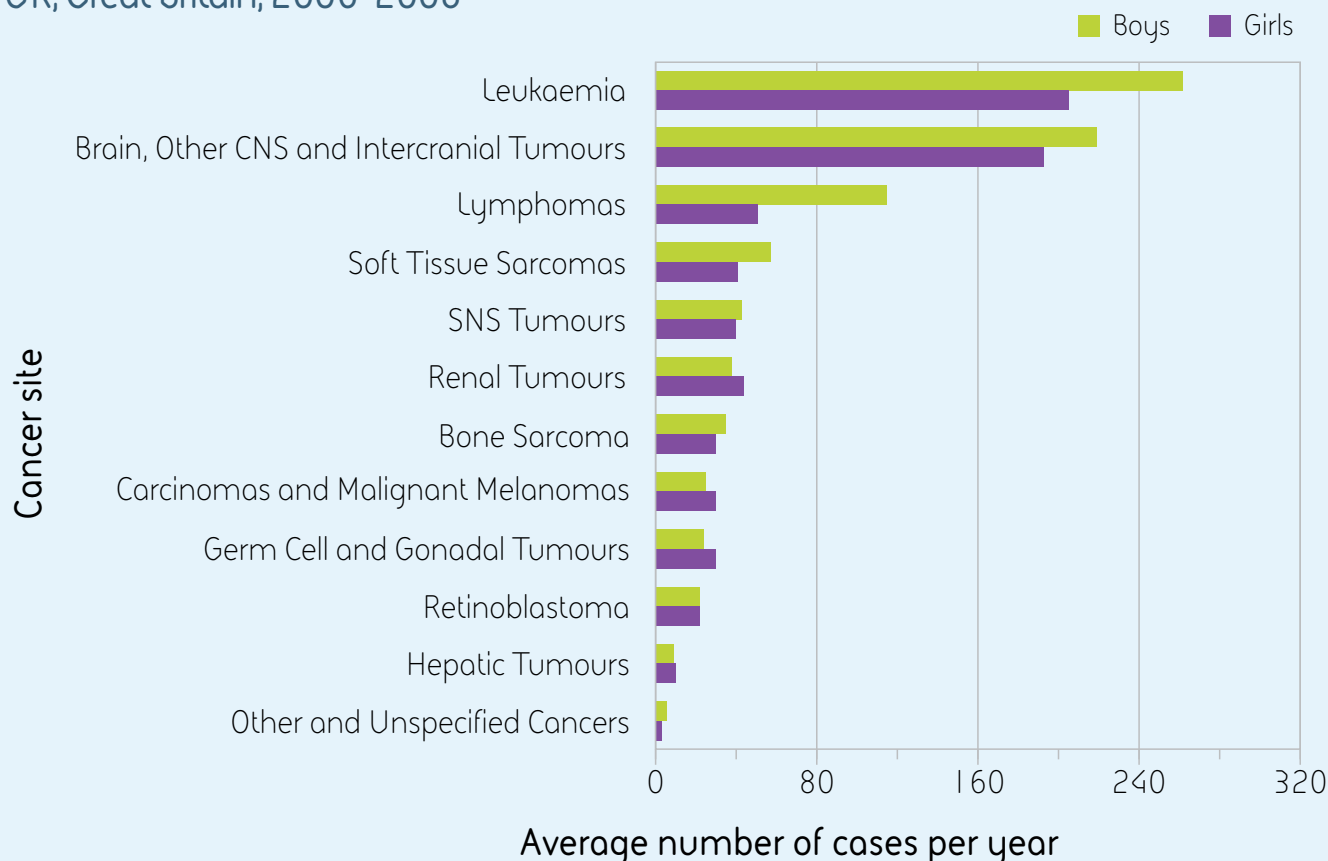
Rare tumours are not discussed individually since they together make up less than 1% of all childhood CNS tumours, and vary considerably. Specialist information should be sought on an individual basis and tailored to the child's needs.

More details on the various treatment modalities are discussed in the 'Treatment' section.

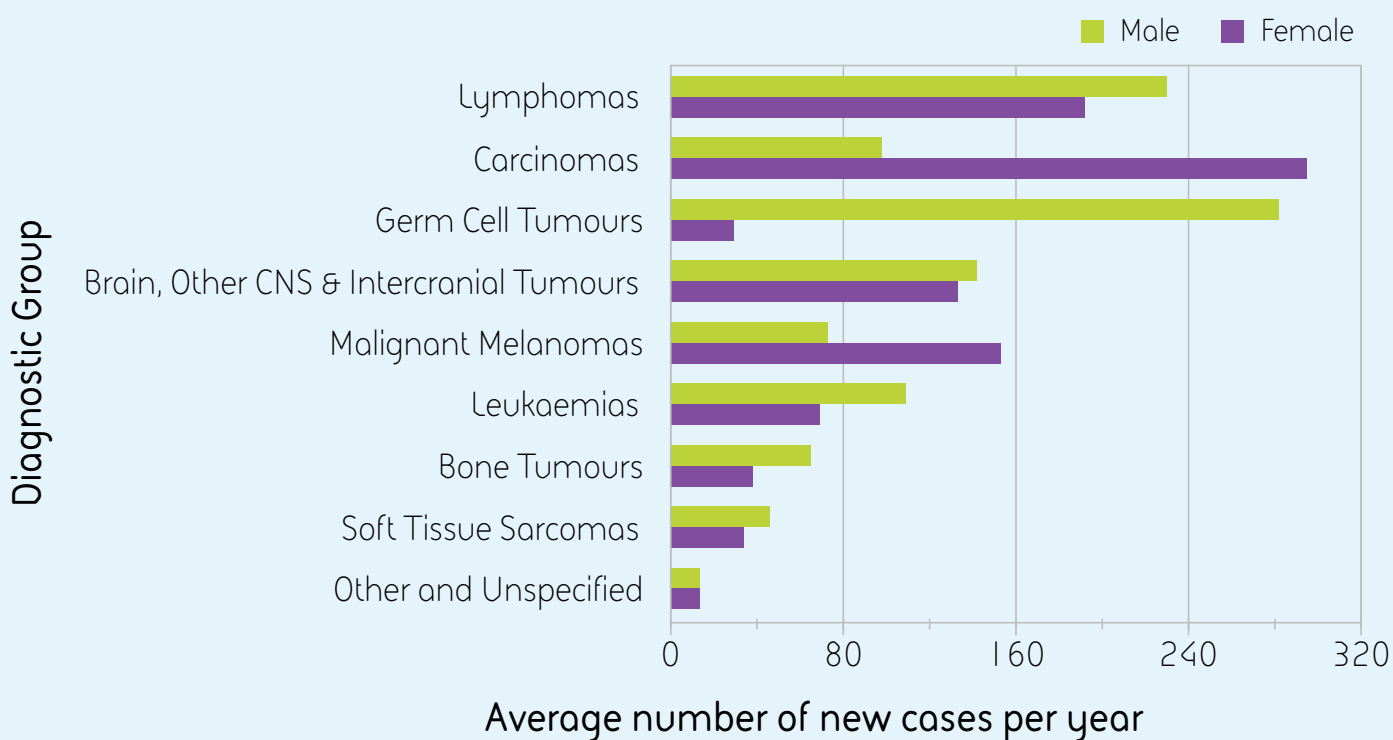
Treatment

- Surgery
- Chemotherapy
- Radiotherapy
- Follow up of brain tumour patients

Number of new cancer cases diagnosed per year, children (aged 0-14 years) by diagnostic group (Brain/CNS Tumours: boys 219, girls 193, total 412) Cancer Research UK, Great Britain, 2006-2008



Number of new cancer cases diagnosed per year, TYAs (aged 15-24 years) by diagnostic group (Brain/CNS Tumours: males 142, females 133, total 275) Cancer Research UK, Great Britain, 2000-2009





Glioma

The term 'glioma' refers to tumours arising in the supporting cells of the CNS, called glial cells, by which the neuronal cells are supported. The 'glioma' category of tumours includes both astrocytomas (which arise from astrocytes) and ependymomas (which arise from ependymal cells), although the terms 'astrocytoma' and 'glioma' are often used interchangeably.

The World Health Organisation (WHO) classifies astrocytomas from Grade I-IV, with the degree of cancerous aggression increasing with grade. Grade I (pilocytic astrocytoma) and grade II (diffuse astrocytoma) tumours are considered to be benign, slow growing tumours whilst grade III (anaplastic astrocytomas) and grade IV (glioblastoma multiforme) tumours are generally more malignant and aggressive, with poorer outcomes overall. However, low grade tumours can still cause significant difficulties for patients by virtue of their size or location in the brain or spinal cord, and the symptoms they cause. In children, 80% of astrocytomas are low grade and have a good outcome (prognosis).

Optic pathway gliomas are a specific group of gliomas which may potentially affect vision and will be considered separately.

Diffuse midline gliomas including thalamic gliomas, brainstem gliomas and diffuse intrinsic pontine gliomas, DIPG make up a special category of gliomas which may be high grade (most commonly) or low grade, and which will also be discussed separately.

Optic pathway glioma

Childhood optic pathway glioma (astrocytoma) is a type of brain tumour which is usually a benign, slow growing tumour, and thus fits into the category of low grade glioma. An optic pathway glioma occurs along the nerves that send messages from the eye to the occipital cortex at the back of the brain (the optic pathway) and can occur anywhere along its path.

What are the signs and symptoms?

Since optic pathway gliomas can occur anywhere along the optic pathway, the initial problems from which a patient may suffer are related mostly to vision:

- Reduced vision
- Squints
- Flickering eyes
- Eye protruding forward ('proptosis')
- Double vision
- Head tilt (to compensate for unequal vision in both eyes)
- Blind spots

These symptoms can manifest as problems in school, apparent clumsiness, sitting closer to watch television etc. A brain scan identifies the tumour. If the tumour is large enough it may also cause other problems such as headaches, nausea and vomiting or drowsiness if there is increased pressure in the head (raised intracranial pressure). The part of the brain that helps to control the hormones in the body, the hypothalamus, is sometimes affected by optic pathway tumours. This can lead to hormonal problems such as early puberty or weight problems (either loss or gain).

Although the cause of most brain tumours is not known, we do know that a genetic condition called 'neurofibromatosis type 1' (NF-1) can lead to these tumours, although they can also occur in children who do not have NF-1. If the child is young (<5 years) it may not be obvious to anyone that the child has this condition until the time of diagnosis of the optic pathway glioma since other signs of the condition may take several years to develop. NF-1 can be inherited from a parent but in half of cases the child will be the first affected in the family. The condition varies widely but the following problems can occur throughout life:

- Tendency to develop both benign and occasionally cancerous tumours
- Skin lesions (several types from lesions like 'freckles' to large lumps in the skin (neurofibroma)
- Skeletal bone problems (e.g. curvature of the spine, 'scoliosis')
- Behavioural and learning difficulties (ranging from none to severe)

A child/family with NF-1 will be offered specialist counselling and followed up by a paediatrician with expertise in the condition.

How do you treat an optic pathway tumour?

Observation

If a patient's symptoms are very mild (children with known NF-1 will have visual screening to pick up early problems) and the optic glioma is small and growing very slowly, observing the tumour is usually the best option. Occasionally, optic gliomas associated with NF-1 can be very benign and can stop growing or even shrink without treatment. However, regular eye checks and brain scans are necessary if observation is undertaken, so that any deterioration in vision or increase in symptoms can be picked up early.

Surgery

Surgery may be considered after the diagnosis of an optic pathway glioma. The purpose of this may be a simple biopsy to confirm the type of tumour (although this is often not necessary if the scan is typical and a tumour is seen along the optic pathway), or to try to remove part of the tumour to relieve pressure. As the prime aim is to preserve vision it is rare for a neurosurgeon to try and remove the entire tumour as this operation could damage the nerves supplying the eye.

Chemotherapy and radiotherapy

Both chemotherapy and radiotherapy can be used to treat the tumour with the aim of stopping the growth so that any further loss of vision is halted (sometimes vision is improved). The age of the child and how fast the tumour is growing are important in deciding whether the patient needs further treatment and which type of therapy will be used.

Chemotherapy is usually given as an outpatient but lasts for up to 18 months. See the chemotherapy section for details on this type of treatment.

Radiotherapy lasts up to 6 weeks as an outpatient and is very effective in controlling the tumour but does have potential significant long term side effects. Additionally, if the child has an underlying diagnosis of NF-1, the doctors will aim to avoid radiotherapy if at all possible as children with NF-1 are more likely than others to develop certain specific complications of radiotherapy, such as damage to the blood vessels in the brain (called 'moya moya' syndrome), which may lead to a higher risk of strokes.

What is the outlook (prognosis)?

Optic pathway gliomas are usually not life threatening (although aggressive tumours can be) and the aim is to preserve visual function. Some patients may become blind or visually impaired, requiring assistance for their disability including appropriate and important educational support. They may require hormone replacement therapy throughout their lifetime. They may develop learning difficulties as a result of the tumour or its treatment. Children with NF-1 may have other problems over and above those from the tumour and these can impact on schooling.

Low Grade Glioma

Low grade gliomas (astrocytomas) are benign tumours that arise from brain cells called astrocytes. You will often hear the term astrocytoma and glioma used interchangeably. In children, more than 80% of astrocytomas are low grade. Low-grade astrocytomas are usually well localised and grow slowly over a period of time.

These tumours can arise anywhere in the brain or spinal cord; the most common areas are the cerebral hemispheres (frontal, parietal, temporal lobes) and the cerebellum. They rarely spread (disseminate/metastasise) to other areas of the brain or spinal cord via the cerebrospinal fluid (CSF). Tumours can be solid or part cystic (fluid filled).

What are the signs and symptoms?

The signs and symptoms depend on the location of the tumour and age of the patient. Some symptoms result from increased pressure in the head (raised intracranial pressure).

Common symptoms include:

- Nausea and vomiting
- Lethargy and irritability
- Headaches
- Clumsiness
- Difficulty with tasks like handwriting
- Gradual decline in school performance
- Changes in personality and behaviour
- Seizures
- Abnormal gait (walking)

If the tumour spreads to the spinal cord, the signs and symptoms may include:

- Back pain
- Difficulty walking
- Problems with bowel and bladder control

How do you treat a low grade glioma?

The treatment used depends on the location of the tumour and the age of the patient.

Surgery

All patients will undergo initial surgery to confirm the diagnosis, relieve pressure and to try to remove as much of the tumour as possible.

Radiotherapy

Radiotherapy is commonly used after surgery to destroy any remaining tumour cells in patients older than 8-10 years of age. Radiotherapy is usually directed locally to where the tumour is / was. See the radiotherapy section for more details on this type of treatment.

Chemotherapy

Chemotherapy may be given after surgery to treat the tumour, with or without radiotherapy. Chemotherapy is usually outpatient-based and lasts over a year but is quite well tolerated and pupils can usually continue to attend school. Drugs that are most commonly used include drugs called vincristine and carboplatin, or vinblastine. See the chemotherapy section for more details on this type of treatment.

What is the outlook (prognosis)?

The majority of low grade gliomas are not life threatening but some inoperable tumours (often in young children) can prove difficult to treat. In up to half of the cases of low grade gliomas, despite initial control, they can re-grow and need further therapy. It is not uncommon for patients to need several lines of treatment for their tumour, sometimes separated by long periods of time (years) where the tumour does not grow at all.

What are the possible long term effects?

Low grade gliomas cause long-term problems related to where they are located. Tumours can result in growth, hormonal and behavioural changes with possible learning problems and difficulties with coordination. Hearing and visual disturbances can result from both tumour and treatments.

High Grade Glioma

High grade gliomas (astrocytomas) are malignant (cancerous) tumours that arise from brain cells called astrocytes. In children and young people only 20% of astrocytomas are high grade. High grade gliomas are classified according to the grade of aggressiveness as either anaplastic astrocytomas (grade III) or glioblastoma multiforme. These tumours often spread into the healthy tissue that surrounds the tumour, making them difficult to remove surgically. They most commonly arise in the cerebral hemispheres (frontal, parietal and temporal lobes) or centre of the brain (thalamus). The tumour can spread to other parts of the brain and spinal cord.

What are the signs and symptoms?

The signs and symptoms depend on the location of the tumour and age of the patient. Some symptoms result from increased pressure in the head (raised intracranial pressure).

Common symptoms include:

- Nausea and vomiting
- Lethargy and irritability
- Headaches
- Clumsiness
- Difficulty with tasks like handwriting
- Gradual decline in school performance
- Changes in personality and behaviour
- Seizures
- Abnormal gait (walking)

If the tumour spreads to the spinal cord, the signs and symptoms may include:

- Back pain
- Difficulty walking
- Problems with bowel and bladder control

How do you treat a high grade glioma?

These are very difficult tumours to treat due to the difficulty in completely removing the tumour, their tendency to re-grow rapidly and their resistance to radiotherapy and chemotherapy. As there is no ideal therapy patients are often treated on clinical trials investigating new therapies, especially when the tumour grows back after initial treatment.

Common treatments include:

Surgery

All patients will undergo initial surgery to confirm the diagnosis and if necessary to relieve pressure. The surgeon will try to remove as much of the tumour as possible without causing severe disability to the patient, since the degree of successful removal is known to affect the outcome.

Radiotherapy

Radiotherapy is commonly used after surgery to try to destroy any remaining tumour cells. Radiotherapy is usually directed locally to where the tumour is/was. In young children (under 3 years) radiotherapy may be avoided or at least delayed due to the potential damage on the early developing brain. See the radiotherapy section for more details on this type of treatment.

Chemotherapy

Chemotherapy has been shown to be of some benefit in the treatment of high grade gliomas but researchers are still investigating the best drugs and treatment schedules, although a drug called temozolomide is most commonly used, initially in combination with the radiotherapy. See the chemotherapy section for more details on this type of treatment.

What is the outlook (prognosis)?

Unfortunately the prognosis is poor for many patients with high grade gliomas. However, some are long-term survivors and these are usually characterised by a lower grade (anaplastic astrocytoma) and a complete removal by surgery. Clinical trials are ongoing to improve the outcome.

What are the possible long term effects?

High grade gliomas can cause long-term problems related to where they are located and the treatment received. Tumours can result in growth, hormonal and behavioural changes with possible learning problems and difficulties with coordination. Physical disabilities and seizures can be a problem, even when the tumour is controlled, and will need to be monitored.

Brain Stem Glioma and Diffuse Intrinsic Pontine Glioma (DIPG)

The brain stem acts as a transmission centre for directing messages between the brain and other parts of the body, housing functions critical for survival such as the respiratory (breathing) control centre. The brain stem is made up of three structures namely the midbrain, pons, and medulla.

Brain stem gliomas (astrocytomas) arise within the brain stem, and are either centred on the brain stem with part of the tumour protruding out into other parts of the brain, or in the case of a classical diffuse intrinsic pontine glioma (DIPG), centred in the pons, with a typical appearance on CT or MRI scan. These tumours may be either low grade or, more commonly, high grade gliomas. DIPGs tend to occur most commonly in younger children under the age of 8-10 years.

What are the signs and symptoms?

Common signs and symptoms include:

- Unsteadiness of gait (walking) and balance
- Clumsiness
- Squints and visual abnormalities
- Difficulties with speech and/or swallowing (sometimes drooling)
- Headache
- Nausea and/or vomiting

How do you treat a brain stem glioma or DIPG?

Surgery

In some cases a biopsy may be done to confirm the diagnosis or the grade of the tumour, and to remove some of the accessible part of the tumour protruding outside of the brain stem. Surgery may also be performed to reduce the intracranial pressure if possible. However, in the case of DIPG, the appearance of the tumour on the scan is very typical, and the doctors may decide not to perform a biopsy because of the potential risk to critical brain stem structures, but will treat the patient on the basis of the very typical scan appearance and the clinical signs and symptoms.

Radiotherapy

Radiotherapy is the mainstay of treatment for brain stem tumours. Most tumours respond well to radiotherapy resulting in an encouraging improvement in symptoms; however, unfortunately most of these tumours will start to grow again subsequently, causing disabling symptoms and sometimes rapid deterioration. Recent treatment strategies have included re-irradiation approaches but this is relatively new and the benefits thereof yet to be confirmed.

Chemotherapy

Various chemotherapy regimens have been used over the years with none yet proven to be of lasting benefit. It is therefore common for patients to be enrolled on clinical trials of new drugs.

What is the outlook (prognosis)?

Unfortunately the prognosis for most brain stem gliomas and especially DIPGs is very poor, and patients may deteriorate rapidly following an initial apparent response to treatment. This is particularly true of patients whose tumours have certain aggressive mutations (abnormalities in the genetic code of the tumour). Many patients may be treated on clinical trials of new drugs in an attempt to improve survival.

In some rarer instances where the tumour is low grade, the disease may stabilise, even for years, and these children are likely to need additional support in school because of difficulties with balance, coordination, speech, vision (they may have squints) and learning difficulties.

Ependymoma

An ependymoma is a type of brain tumour that arises from the ependymal cells that line the brain's fluid spaces, known as the ventricles. It can be classified as either malignant (cancer) or benign (non-cancerous) depending on how aggressive the tumour is. Ependymomas have the potential to spread (disseminate or metastasise) to the spinal cord via the cerebrospinal fluid (CSF).

Approximately 60% of all patients diagnosed with this tumour type are under 5 years of age. Ependymomas are twice as likely to occur in the posterior fossa region of the brain (this is the area at the lower back of the head). Like most brain tumours the cause of ependymoma is unknown.

What are the signs and symptoms?

The symptoms are usually due to increased pressure in the head (raised intracranial pressure).

Common symptoms include:

- Nausea and vomiting (most common)
- Lethargy and irritability
- Headaches
- Clumsiness
- Difficulty with tasks like handwriting
- Gradual decline in school performance
- Changes in personality and behaviour
- Abnormal gait (walking)

If the tumour spreads to the spinal cord, the signs and symptoms may include:

- Back pain
- Difficulty walking
- Problems with bowel and bladder control

How do you treat an ependymoma?

Current treatment aims to achieve a complete surgical removal of the tumour. However, this is only possible in approximately 30-50% of cases, as these tumours have a tendency to infiltrate or spread into healthy brain tissue that surrounds the tumour. In addition, further treatment is usually required and varies according to location of the tumour and age of the patient.

Common treatments include:

Surgery

All patients will undergo initial surgery to confirm the diagnosis, relieve pressure and to try to remove as much of the tumour as possible. Sometimes multiple operations will be needed.

Radiotherapy

Radiotherapy is commonly used after surgery to destroy any remaining tumour cells. Radiotherapy is usually directed locally to the area of the tumour. However, in young children (especially under the age of 3 years), radiotherapy will be delayed, reduced or possibly avoided due to the significant effects of radiotherapy on a young child's brain. See the radiotherapy section (on page 153) for more details on this type of treatment.

Chemotherapy

Chemotherapy is usually given to either facilitate further surgery by shrinking any remaining tumour or to avoid/delay radiotherapy in young children. The type of chemotherapy varies in intensity and duration according to the age of the child. See the chemotherapy section (on page 151) for more details on this type of treatment.



What is the outlook (prognosis)?

This is very closely related to whether the neurosurgeon can remove all of the tumour, its spread and aggressiveness. Patients who have had an incomplete removal of tumour at initial surgery, or evidence of tumour spread, have a reduced survival rate. The treatment of infants is difficult but results with intensive chemotherapy have been very encouraging.

What are the possible long term effects?

As ependymomas can occur in young children and the treatment is given at an important time of the child's development there may be some long-term effects of treatment. These could include growth and hormonal changes, behavioural changes, possible learning problems and difficulties with coordination. Hearing and visual disturbances can result from both tumour and treatments.

Medulloblastoma

A medulloblastoma is a malignant tumour (cancer) formed from primitive or poorly developed brain cells. These tumours most commonly arise in the cerebellum, but are also found in other regions of the brain e.g. the cerebral hemispheres, where the name SPNET (Supratentorial Primitive Neuro Ectodermal Tumour) has historically been used instead. When they arise in the pineal gland, the term pineoblastoma is used. These tumours have the potential to spread (disseminate or metastasise) to the spinal cord via the cerebrospinal fluid (CSF), but rarely spread to other organs of the body.

Medulloblastoma is the most common malignant brain tumour of childhood, representing 20% of all childhood brain tumours. It is most common in children between the ages of three and eight, and slightly more common in boys than girls. SPNETs tend to occur in older children. Both can also occur in adults but are rare. Like most brain tumours the cause of medulloblastoma/SPNET is unknown in the majority of cases.

What are the signs and symptoms?

The symptoms are usually due to increased pressure in the head (raised intracranial pressure). Common symptoms include:

- Nausea and vomiting (most common)
- Lethargy and irritability
- Headaches
- Clumsiness
- Difficulty with tasks like handwriting
- Gradual decline in school performance
- Changes in personality and behaviour
- Abnormal gait (walking)

If the tumour occurs in one of the cerebral hemispheres it may cause weakness in arms or legs (usually one-sided) or may cause seizures (fits).

If the tumour spreads to the spinal cord, the signs and symptoms may include:

- Back pain
- Difficulty walking
- Problems with bowel and bladder control.

How do you treat medulloblastoma?

The treatment used depends on location and spread of the tumour and the age of the patient. The child or young person will have a treatment plan developed according to all of these factors.

Common treatments include:

Surgery

All patients will undergo initial surgery to confirm the diagnosis, to relieve pressure and to try and remove as much of the tumour as possible.

Radiotherapy

Radiotherapy is commonly used after surgery to destroy any remaining malignant cells. As medulloblastoma may spread through the CSF to the spinal cord, radiotherapy is given to the brain and spinal cord. However, in young children radiotherapy will be delayed, reduced or possibly avoided due to the significant effects of radiotherapy on a young child's brain.

Chemotherapy

Chemotherapy is given together with surgery and/or radiotherapy to treat the tumour. The type of chemotherapy varies in intensity according to whether the tumour has spread, whether radiotherapy will be used and the age of the patient.

What is the outlook (prognosis)?

Significant progress has been made in the management of children and young people with medulloblastoma/SPNET over the last 10 years. Intensive chemotherapy and reduced dose radiation to the brain and spine has resulted in a cure for the majority of patients with a localised tumour, which a surgeon is able to remove. Patients who have had an incomplete removal of tumour at initial surgery, or evidence of tumour spread, have a reduced survival rate. The treatment of infants continues to be difficult. This is because of the desired delay in delivering radiation to the entire brain and spine.

What are the possible long-term effects?

As medulloblastomas are more common in young children and the treatment is given at an important time of the child's development there may be some long-term effects of treatment. These could include growth and hormonal changes, behavioural changes, possible learning problems and difficulties with coordination. Hearing and visual disturbances can result from both tumour and treatments. The same long-term effects may occur in children and young people with SPNETs but are likely to be less severe if treated at an older age.

Craniopharyngiomas

Craniopharyngiomas result from the growth of cells that, early in fetal development, have failed to migrate to their usual area. These tumours generally occur just above the pituitary gland. Located at the bottom of the brain, the pituitary gland is about the size of a pea and controls many vital functions.

Craniopharyngiomas are benign tumours that do not spread, but may interfere with important structures near them, causing serious problems. Craniopharyngiomas represent 5-10 percent of childhood brain tumours and can be solid, cystic (full of fluid), calcified, or full of debris. They are slow-growing tumours that can take 2-3 years (or longer) to manifest themselves before a diagnosis is made.

What are the signs and symptoms?

Symptoms result either from the tumour causing blockage of the flow of fluid surrounding the brain, resulting in increased intracranial pressure, or from direct pressure and damage to the pituitary gland, or nerves from the eyes.

- Headaches (sometimes accompanied by nausea or vomiting)
- Hormone disturbances
- Disturbed sleep patterns
- Visual disturbance
- Behavioural changes
- Increased sensitivity to cold or heat
- Early or delayed puberty
- Appetite and weight variations

How do you treat a craniopharyngioma?

Surgery is the main treatment strategy and if possible the neurosurgeon will try to cure the patient by completely removing the tumour. However, surgery can cause significant damage to the surrounding brain and often some parts of the tumour may be left behind to avoid further damage to the patient. Radiotherapy may be administered to stop the tumour from growing.

What is the outlook (prognosis)?

Most children and young people are cured from their tumour by surgery and radiotherapy but many suffer from serious long-term problems, some of which can be life threatening.

What are the possible long-term effects?

Craniopharyngiomas, although benign, have many potential serious effects on a child and young person's health and development. These include growth, hormonal and behavioural changes as well as learning difficulties. Visual disturbances can result from the tumour and are sometimes severe.

An endocrinologist (specialist hormone doctor) will need to be involved in the long-term care of patients to replace hormones that are deficient (either in the form of tablets or injections). The patient may need urgent medical attention if they become unwell as they may not be able to control fluid balance and blood pressure normally. Children and young people can develop severe obesity problems due to hormone problems and damage to the hypothalamus of the brain, which is the region controlling appetite. This needs complex multi-disciplinary management and can be very difficult to control. Behavioural problems and educational difficulties can be severe.



Germ Cell Tumours

Germ cell tumours are tumours arising from primitive germ cells and may arise either inside the head ('intracranial' germ cell tumours) or outside of the head in various locations of the body including ovary, testis, abdomen or chest ('extracranial' germ cell tumours). There are different types of germ cell tumours and these can be differentiated when the tumour cells are examined under a microscope by a pathologist. They may be either malignant (cancerous) or benign (non-cancerous).

Intracranial germ cell tumours most commonly arise in the midline structures of the brain such as the pineal gland or in an area called the suprasellar fossa near the pituitary gland. Sometimes they secrete hormones which can be measured in the blood, or in the cerebrospinal fluid by means of a procedure called a lumbar puncture. More than two thirds of germ cell tumours arise in older children and adolescents, especially around puberty. Rarely they can spread from the central nervous system to other organ systems.

What are the signs and symptoms?

Symptoms result either from the tumour causing blockage of the flow of fluid surrounding the brain, resulting in increased intracranial pressure, or from direct pressure from the tumour mass. Symptoms depend on the location of the tumour but most commonly include:

- Headaches (sometimes accompanied by nausea or vomiting)
- Hormone disturbances (which may include severe thirst related to an inability to regulate fluid balance, a condition known as 'diabetes insipidus')
- Early or delayed puberty
- Visual disturbance
- Appetite and weight variations

How do you treat a germ cell tumour?

Treatment usually depends on the location, size and type of germ cell tumour but may include surgery, radiotherapy and chemotherapy. The neurosurgeon may perform just a biopsy, or may try to remove that part of the tumour that can be safely removed without causing damage to critical structures. Radiotherapy and chemotherapy will then be used to kill the remaining tumour cells.

What is the outlook (prognosis)?

This depends slightly on the type of germ cell tumour; however, most are curable although patients may have long-term side effects.

What are the possible long-term effects?

These include growth, hormonal and behavioural changes as well as learning difficulties, although the severity of these may vary. Many young people will need ongoing support, in terms of follow up by an endocrine (hormone) specialist, and educationally.

Spinal cord tumours

Spinal cord tumours are very rare in children and adolescents overall; however, the most frequently occurring are gliomas (either astrocytomas or ependymomas).

Symptoms and signs usually depend on the level of the spinal cord involved but may include back pain, limb weakness, abnormalities of gait (walking), bladder or bowel weakness.

Treatment depends on the tumour type but usually consists of surgery +/- radiotherapy +/- chemotherapy. Long-term effects may include ongoing difficulties with mobility (including paraplegia or quadriplegia), bladder and bowel weakness. Educational, social and psychological support will need to be tailored around the patient's specific disability.

Treatment of brain and spinal cord tumours:

Surgery for brain and spinal cord tumours

A child or young person who has a brain or spinal cord tumour will usually be referred urgently to a regional paediatric neuro-surgical centre. At these centres specialist teams will review the patient and stabilise their condition whilst making a decision on whether the patient requires surgery. If the child has a build up of pressure in the head (raised intracranial pressure or hydrocephalus) a preliminary operation may be required to relieve this pressure before any attempt to remove the tumour. This pressure can be relieved by:

- Giving steroid drugs
- Removing the tumour, if possible
- Insertion of a shunt (this is a mechanical device that drains excess fluid from the brain to the abdomen). This can be temporary or permanent
- Making a new pathway for fluid to flow in the brain without a shunt (3rd ventriculostomy)

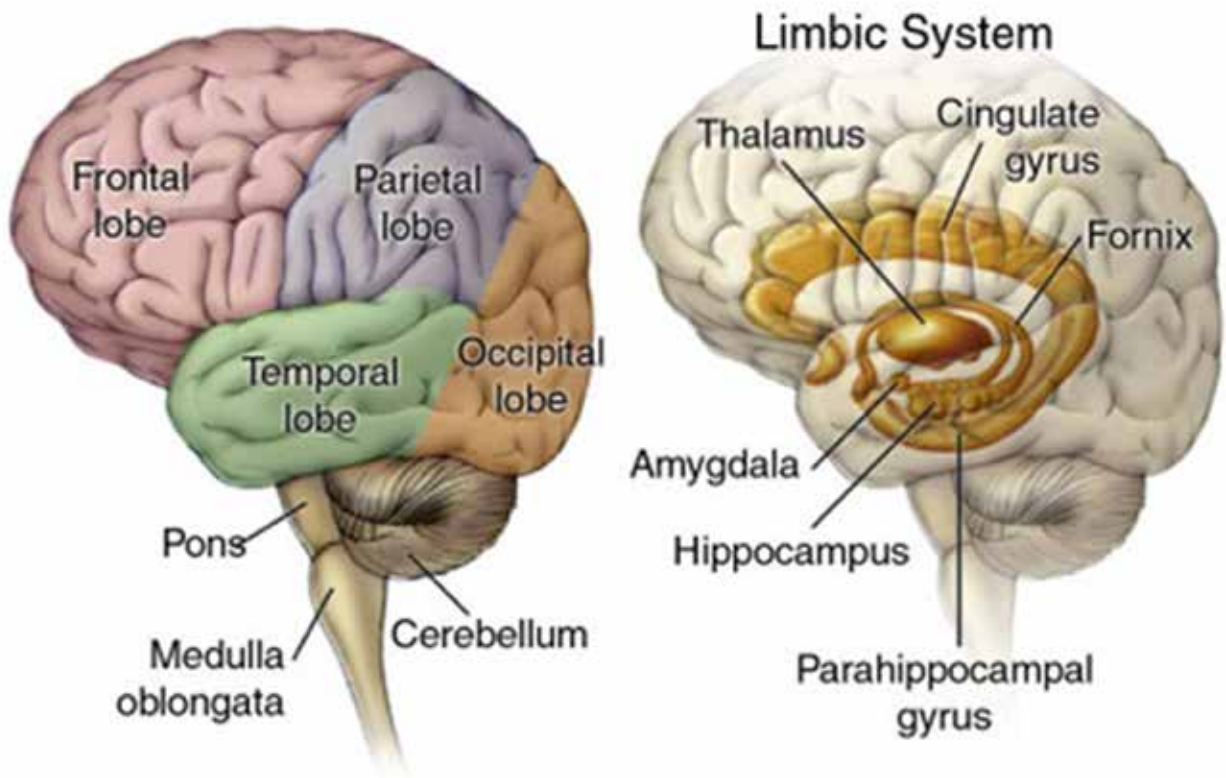
A biopsy may be performed to find out exactly which type of tumour it is. In some cases this is all that is possible or required. However, in many cases of childhood brain or spinal cord tumour the neurosurgeon will attempt to remove all or part of the tumour. The skull is opened (craniotomy) to allow access to the tumour and after the operation the bone is usually replaced.

The length of time spent in hospital after the operation depends on the extent of surgery and the condition of the patient. If a pupil has a shunt inserted, teachers should be aware of signs of acute shunt malfunction or blockage and if concerned inform the parents:

- Vomiting or nausea
- Photophobia (sensitivity to light)
- Dizziness
- Fits
- Headache
- Other visual disturbances
- Drowsiness
- Abdominal pain

In many cases the neurosurgeon will attempt to remove the brain or spinal cord tumour entirely, or at least as much as possible. Whether this is achievable and what damage may be caused depends on the area of the brain the tumour is located in and also whether it is in the dominant hemisphere or not. The dominant hemisphere is the side of the brain that is more important for higher functions such as speech and is usually the opposite side to the handedness (i.e. left if right handed) of the patient.

Anatomy of the Brain



The diagram above shows the areas of the brain with their associated functions.

- Frontal lobe – reasoning, planning, parts of speech, movement, emotions and problem solving
- Parietal lobe – movement, orientation, recognition, perception of stimuli
- Temporal lobe – perception and recognition of auditory stimuli, memory and speech
- Occipital lobe – visual processing
- Cerebellum – regulation and coordination of movement, posture and balance
- Pons and medulla – motor control, sensory analysis, level of consciousness, vital body functions, such as breathing and heart rate

Chemotherapy for brain and spinal cord tumours

Chemotherapy drugs work by interfering with the ability of a tumour (cancer) cell to divide and reproduce itself. The cancer cells become damaged and eventually die. As the drugs are carried in the blood, they can reach tumour cells within the brain.

Chemotherapy can be given in different ways, either by mouth or intravenously. Treatment has to be carefully planned so that it progressively destroys the tumour during the course of treatment, but not the normal cells and tissues. The duration of chemotherapy varies from as little as eight weeks to as long as two years.

Children and young people undergoing treatment for tumours (cancer) will often require repeated blood tests and insertion of needles to enable chemotherapy and other drug treatment to be given. Many patients therefore have 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 or platelet transfusions.

A central line is a fine plastic tube, which is inserted into a vein in the patient's chest. This 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).

In the treatment of aggressive brain tumours higher doses of chemotherapy are sometimes given to improve the chances of completely curing the disease. As chemotherapy interferes with the production of the blood (in the bone marrow), very high doses can only be used if the bone marrow and blood are supported by initially collecting and then giving back 'stem cells' to rescue the patient from the effects of high dose treatment. This is called 'autologous stem cell rescue' or 'autologous stem cell transplant'. High dose chemotherapy requires the patient to stay in hospital for several weeks to receive supportive care.

Side effects of chemotherapy

Since chemotherapy works by killing dividing cells, they will affect normally dividing cells as well as tumour cells. The normal cells which divide most rapidly in the body are those in the bone marrow, the gut and the hair follicles. The following are the main temporary side effects which may be experienced as a result of treatment.

Bone marrow suppression (Low blood count)

Almost all chemotherapy causes bone marrow suppression. This means that the bone marrow cannot make the usual number of cells and a blood or platelet transfusion may be necessary. When the white cell count is low, infections are quite common.

Risk of infection

All through chemotherapy the child or young person will be more at risk of infection. When the white cell count is low (neutropenic) the patient may absorb germs from his or her own skin or gut. In spite of this they will be able to cope with most minor infections perfectly normally and if the child or young person is well he/she can attend school. However, some infections that usually cause little trouble may prove more serious. Measles and chicken pox can be particularly serious if the patient is not immune. If they are exposed to either of these (this means close contact e.g. in the same class or playing directly with an infected person), let the parents know straight away so that a protective injection or medication can be given. If the pupil is generally unwell or has a fever, inform the parents immediately. See Measles and Chicken Pox Letter on page 164.

Hair loss

Many of the drugs used in chemotherapy make the pupil's hair fall out. It usually grows again quite normally within a few months of stopping treatment. This can be an upsetting problem and the pupil may wish to wear a wig, baseball cap, hat or scarf. School rules may have to be modified for that particular pupil.

Loss of appetite and weight

Chemotherapy may make the pupil feel sick and directly affect the lining of his gut so that he will not want to eat and will lose weight. Modern anti-sickness drugs are now very effective. Their weight will be checked regularly. If he/she is losing too much weight he may need to be fed through a naso-gastric tube or a gastrostomy (tubes passing into the stomach). The weight usually returns to normal when treatment is over.

Fatigue

The majority of patients being treated for a brain or spinal cord tumour will suffer from fatigue at some point. Chemotherapy will result in them tiring more easily, both physically and mentally. Therefore school attendance and activities may need to be modified to allow for this.



Radiotherapy for brain and spinal cord tumours

Radiotherapy uses high energy x-rays which destroy tumour cells. It is used to treat the site of the brain or spinal cord where the tumour is located but sometimes the whole brain and spine is treated to prevent the tumour from spreading to these sites. Radiotherapy is given each day Monday to Friday with weekends off. How long a course of treatment lasts is variable, but it may be anything up to six weeks.

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 place each time.

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. In order to facilitate this, a "mask" is often made by a mould which the patient wears during treatment and this fixes their position to the radiotherapy machine. 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. The immediate side effects of radiation are usually mild and include:

- The skin may become sore as if it were sunburnt
- Hair loss which can be permanent
- Nausea and sickness
- Sore mouth and diarrhoea
- Headache
- Fatigue
- 'Somnolence syndrome' develops 6-8 weeks after radiotherapy to the brain, resulting in irritability, fatigue, mild headache and high temperatures

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

There are newer types of radiotherapy which aim to give a much more targeted dose of radiotherapy with the aim of sparing the surrounding normal tissue. This has meant that sometimes much younger children can be given radiotherapy than was done historically, although doctors would still aim to delay or avoid this if possible. Newer forms of radiotherapy include stereotactic radiotherapy, cyberknife and proton therapy (although the latter is not yet widely available and long-term data on its benefits not yet clear).

Longer-term side effects of radiotherapy

It is vital to continually assess and reassess pupils as their learning difficulties and needs may change over time.

After treatment for a brain or spinal cord tumour children and young people will attend a follow up clinic to monitor their health and identify long-term effects resulting from the tumour and its treatment. Long-term side effects which can result from the tumour and particularly radiotherapy include:

Endocrine and growth problems

Radiotherapy can have important effects on growth and development.

It may affect growing bones: for example, if radiotherapy is given to the spine, the child or young person may not grow quite as tall as expected.

Radiotherapy to the brain may affect production of growth hormone in the pituitary gland. The pituitary gland helps regulate growth and development from childhood to adulthood. It does this by producing hormones. If a young person does not produce enough growth hormone from the pituitary gland he/she will not grow normally and may need treatment with synthetic growth hormone in the form of daily injections.

Other hormones can be affected including thyroid, cortisol and the hormones controlling puberty and the kidneys. These may also need replacing and may require tablets to be taken regularly.

Sensory impairment

Occasionally radiotherapy can lead to the development of visual problems, either from damage to the optic nerves or cataracts forming. However, this is unusual. Hearing can be impaired by a combination of the tumour, chemotherapy and radiotherapy. Regular vision and hearing checks are performed.

Intellectual development and education

Children treated for brain tumours may develop learning difficulties and may require special help at school. The extent of these difficulties will depend on the type of brain tumour, the age of the child, when they were treated, and the treatment dose and volume they received. It is thought that the damage caused by radiation leads to a decrease in the ability of the child to learn new tasks compared to healthy peers. Thus the effects on intellect are not static but gradually become more prominent over time. The gap between the child with a brain tumour and his or her peers may therefore widen (see chapter 5 on page 67).

Targeted therapy and Immunotherapy for CNS tumours

At present there are a lot of clinical trials testing new therapies such as targeted anti-cancer drugs which act against certain cancer cell signalling pathways or mutations, and immunotherapy drugs which allow the body's own immune system to recognise the cancer cells as foreign and attack and kill them.

At present some of these may seem promising strategies, and children may be enrolled in clinical trials of these, but most are not yet of sufficient proven benefit to be used as standard treatments for children with brain tumours, although our knowledge of the science is emerging and growing continuously. These drugs are not without side effects but they may differ from those caused by typical chemotherapy drugs.

Follow up of brain tumour patients

The end of treatment is obviously a time of mixed emotions for the patient and their family. On the one hand is the delight of finishing treatment and on the other, the uncertainty of the future and the reality of further struggles to achieve a normal family life.

Unfortunately many children and young people with a brain or spinal cord tumour will relapse with re-growth of the tumour. Therefore they require regular follow up visits to the oncologist (tumour specialist), and often regular brain scans are required. These visits can create stress in the patient and their family. The timing of follow up visits varies but initially they are usually every 3 months.

With time, the focus of follow up becomes less on trying to detect tumour relapse and more on addressing the side effects of the tumour and its treatment. This means that the child may come into contact with even more health care professionals than during treatment, including:

- Oncologist
- Endocrinologist
- Community Paediatrician
- Ophthalmologist
- Audiologist
- Child Psychiatrist
- Social Worker
- Clinical Psychologist
- Physiotherapist
- Speech & Language Therapist
- Occupational Therapist
- Outreach Nurse
- Hospital Teacher

To ensure co-ordinated clinical supervision patients are often seen in a special clinic known as a 'long term' or 'late effects' clinic. Here they are periodically assessed for health, growth, development and behavioural, emotional or educational problems.

The child or young person will usually be followed up in this clinic until adulthood (18-19 years of age) when their follow up will be transferred to a specialist clinic for adult survivors of childhood brain and spinal cord tumours. After a period of time (often 10 years or more) it may be appropriate for patients to be followed up by the general practitioner.

9

Medical terms,
contacts, and resources

Recommended reading

There is a reference list at the end of each chapter for each specific subject. They can be found on the following pages.

Section 1: Introduction	17
Section 2: When first diagnosed with cancer: what to do, what to expect	35
Section 3: Getting back to school	52
Section 4: SEN, statementing and the Education, Health and Care plan (EHC)	65
Section 5: Cognitive and learning issues in the classroom: recommended teaching strategies	87
Section 6: Other social, behavioural and disability issues in the classroom	113
Section 7: What to do if the pupil becomes palliative and may die	127

Medical terms

Audiologist

A specialist in diagnosing and treating hearing defects

Astrocyte

A type of cell in the central nervous system

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. Is involved in 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. Used for diagnosis and for monitoring the effects of treatment

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

Central Nervous System

Consists of the brain and spinal cord

Cerebrum

The largest part of the brain. Consists of two cerebral hemispheres (see below)

Cerebral Hemispheres

Consists of a right hemisphere, which controls the muscles on the left side of the body, and a left hemisphere, which controls the right side of the body and is also involved in emotion and language. Together the hemispheres form the cerebrum.

Cerebellum

Coordinates muscle movements for balance and complex actions

Cerebrospinal Fluid (CSF)

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

Chemotherapy

Treatment using one or more cancer drugs

Endocrinologist

A medical specialist who treats hormonal and growth problems

High Grade

Malignant

Hydrocephalus

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

Intracranial Pressure

Increased pressure in the head

Intravenous

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

Low Grade

Classified as a benign tumour. However, low grade tumours can be locally aggressive and life threatening

Malignant

Cancerous

Metastases

Cancer which has spread from the place where it started

MRI Scan

Magnetic Resonance Imaging – Magnetic waves, rather than radiation, used to produce a picture for diagnosis or for monitoring treatment

Neurosurgical

Specialising in operations on the brain

Neutropenic

Having less than the normal number of 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 option of curative treatment does not exist

Primary

Original site of cancer

Prognosis

The outlook or expected outcome of a disease and its treatment

Radiotherapy

The use of radiation to treat the cancer

Relapse

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

Remission

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

Seizure

A sudden and intense fit with convulsions where the person may fall, breathe heavily and become incontinent (tonic-clonic seizure or 'generalized') OR an interruption of consciousness where the person becomes unresponsive and appears 'blank' or 'staring' (absence seizure or 'partial')

Shunt

A long thin tube threaded under the skin, usually from the brain to the abdomen, in order for excess fluid to drain away

Tumour

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

Ultrasound Scan

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

Useful contacts and websites

Many of these websites have useful and informative links.

The Royal Marsden NHS Foundation Trust

Paediatric Oncology Unit
Downs Road
Sutton, Surrey SM2 5PT

Website: <http://www.royalmarsden.org>

Email for more information: lesley.edwards@rmh.nhs.uk

Tel: 0208 661 3676

Cerebra

Second Floor Offices
The Lyric Building, King Street
Carmarthen
SA31 1BD

Tel: 01267 244200

Website: <http://www.cerebra.org.uk>

Brain and Spine Foundation

Website: <http://www.brainandspine.org.uk>
provides medical information

Cancer Research UK (2013) CRUK

Website: <http://www.cancerresearchuk.org>

The Child Bereavement Trust

Website: <http://www.childbereavement.org.uk>

The Child Bereavement Trust offers support to grieving children and excellent training, information and advice for professionals.

The Child Brain Injury Trust

The Child Brain Injury Trust is the charity that supports children, young people, their families and professionals and helps them come to terms with what has happened and how to deal with the consequences. The Child Brain Injury Trust has produced a number of factsheets about acquired brain injury, including some on memory, learning and behaviour, and you can access these by visiting the site.

Website: <http://childbraininjurytrust.org.uk/>

Children's Cancer and Leukaemia Group (CCLG)

Website: <http://www.cclg.org.uk>

The CCLG is a national professional body responsible for the organisation of treatment and management of children with cancer in the United Kingdom. They produce information leaflets on all aspects of childhood cancer including siblings, which might be of particular interest to school staff if the child with cancer also has a sibling in the school. These can be downloaded from their website. They also produce a list of books and videos. These are listed in their resource directory, which also mentions over 100 parent support groups, charities, hospices and related organisations of potential interest to families and professionals.

They have a long list of downloadable resources and publications including: Bereavement: where to go for help – a guide for families, health care professionals and schools, when a young person has died from cancer.

CLIC Sargent: Caring for Children with Cancer

Helpline 0300 330 0803 (Mon–Fri, 8.30am–5.30pm)

Email: info@clicsargent.org.uk

Website: <http://www.clicsargent.org.uk>

Provides a variety of support to children with cancer. Also supports families and carers both during and after treatment, in hospital and at home. Produces excellent booklets for children and families.

Council for Disabled Children

Website: www.councilfordisabledchildren.org.uk

Tel: 0207 843 1900

Email: cdc@ncb.org.uk

The Council for Disabled Children (CDC) is the umbrella body for the disabled children's sector in England, with links to other UK nations. They list local independent supporters who help parents access up to 8 hours of free support with EHC plans.

Cruse Bereavement Care

Website: <https://www.cruse.org.uk/>

Cruse Bereavement Care offers support to those affected by the death of someone close to them. Face-to-face and group support is delivered by trained bereavement support volunteers across the UK. They also offer information, publications, and support for children.

Tel: 0844 477 9400

Email: helpline@cruse.org.uk

Website: <https://www.hopeagain.org.uk/> – designed by young people to help other young people through bereavement (Cruse)

Department for Education

Website: <http://www.dfes.gov.uk/sen>

In collaboration with the Department of Health, the DfEs have produced a document entitled, 'Access to Education for Children and Young People with Medical Needs'. This is not specifically for pupils with cancer, but it provides advice for local authorities, schools, hospital and home teaching services, hospital and health trust managers, and social services departments. It gives guidance to ensure that these establishments have in place arrangements to enable the continuance of pupils' learning.

Website: <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>.

EHC plans <http://www.ehcplans.co.uk>

Headway: coping with memory problems after brain injury, practical strategies

Website: <https://www.headway.org.uk>

An excellent charity that provides information, support and services to people affected by brain injury (including cancer), their family and carers.

JTV Cancer Support

Website: <https://jtvancersupport.com/>

Offers a valuable resource of short films from young people with cancer and organisations and is supported by the Teenage Cancer Trust.

Macmillan Cancer Support

Website: <http://www.macmillan.org.uk>

The Macmillan website contains expert, accurate and up-to-date information on cancer and its treatments. Offers support and advice and information to those affected by cancer.

Macmillan has a website for teachers at www.macmillan.org.uk/information-and-support/resources-and-publications/information-for-teachers-and-schools/teaching-about-cancer.

This contains a support section for teachers that offers advice and information on dealing with specific situations that might arise when a pupil returns to school following treatment.

Macmillan also produces free curriculum-based teaching packs for Primary and Secondary Schools called 'Cancertalk'. This helps teachers talk about cancer with their pupils and educate them as to what cancer is. It helps dispel any myths and helps to make pupils aware of how best to support their returning classmate.

Details of this and other helpful resources are obtainable on the Cancertalk website, or by emailing cancertalk@mktpoint.com. They can also be ordered directly by calling 0845 601 1716. The Schools and Youth Coordinator is contactable for advice on 020 7840 7805.

The National Autistic Society

Website: <http://www.autism.org.uk>

The leading UK charity for people with autism (including Asperger Syndrome) and their families. They provide information, support and pioneering services, and campaign for a better world for people with autism.

Royal National Institute for the Blind

Website: <http://www.rnib.org.uk/Pages/Home.aspx>

RNIB offers support and advice to blind and partially sighted people, including advice for children with impaired vision.

SEN Code of Practice

Website: <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>

Guidance on the special educational needs and disability (SEND) system for children and young people aged 0 to 25, from 1st September 2014.

Teenage Cancer Trust

Website: <http://www.teenagecancertrust.org>

Operates a schools programme to improve awareness of cancer.

Winston's Wish:

Website: <http://www.winstonswish.org.uk>

Information for schools, downloadable lesson plans, message board for young people, booklists, general information about grief and bereavement.

Teachers TV

Website: <http://www.teachers.tv>

School Matters – Coping with bereavement –
video about two schools managing a death

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Appendix

Measles and chicken pox letter

This is an example of a letter to send to all parents in the school:

Dear Parents

MEASLES, CHICKEN POX AND SHINGLES

We are asking 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 our pupil from measles is for all pupils to be immunised against measles. Please discuss measles immunisation with your GP if your child has not already been 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 3 days of contact. Please let us know immediately if you suspect that your child has chicken pox or shingles.

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

Many thanks.

Yours sincerely,

Head Teacher

Sibling letter example

This is an example of a letter to send to teachers of siblings of an ill child.

Dear [name of teacher]

Re [name of pupil [siblings name]]

This is to inform you that [sibling] has a brother/sister [name of pupil being treated] aged [age] who is currently being treated for [use wording agreed by family].

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

It may be useful to keep an eye on [sibling] over the coming weeks and months in case this has an effect on either behaviour or performance at school. You may wish to give them an opportunity to talk about it on a regular basis with someone they trust. It might also be prudent to have additional contact details for alternative carers in case at some point the parents may be in hospital with their sick child.

During this time, particularly when your pupil may be being cared for away from the family home, there may be understandable reasons why they might turn up in the wrong uniform or have incomplete or missing homework or missing equipment. Please inform relevant subject teachers sensitively. If your pupil is about to sit exams, you may wish to speak to the examination officer if a special consideration letter is needed from the hospital.

For more information about strategies for siblings do get in touch with me and/or the parents.

Yours sincerely

Teacher/head of house

(I also enclose agreed details about their brother or sister who is being treated)

Pupil details

Name _____ Date of birth _____

Diagnosis _____

Date treatment started _____

Operations _____

Radiotherapy _____

Chemotherapy _____

Radiotherapy _____

Medication _____

Special concerns _____

Return to school:

Part time _____ Full time _____

Parent details

Parents/Guardians _____

Address _____

Telephone:

Home _____ Work _____

Mobile _____

Siblings _____

STRICTLY CONFIDENTIAL

(Where parents and the pupil are in agreement, all teachers should carry a copy in their planners)

Treatment Centre

Name and address _____

Consultant _____

CYPOON (Child/Young Person Paediatric Oncology Outreach Nurse):

_____ Tel _____

Hospital teacher _____ Tel _____

Paediatric Clinical Psychologist _____ Tel _____

CLIC Sargent Social Worker _____ Tel _____

STRICTLY CONFIDENTIAL

(Where parents and the pupil are in agreement, all teachers should carry a copy in their planners)

Checklist for schools

Immediately

- Identify and name a contact teacher or member of staff, eg a teaching assistant or learning mentor
- Inform staff and pupils according to family wishes
- Place the pupil on 'school action' (now called SEN support)
- Draw up an individual education plan (or equivalent)
- Provide suitable work and materials for the pupil
- Provide information about pupil capability and a programme of work
- Notify the Local Authority or Educational Welfare Officer of prolonged absence for medical reasons
- Liaise with home and hospital teaching services
- Ensure sibling needs are considered and their teachers are informed
- Arrange home tuition and liaise with the home tutor
- Ensure the school has a clear policy for pupils with medical needs

Exams

- Ask the examinations officer to make special arrangements
- Inform the pupil of changes to procedures in public exams

Ongoing

- Keep in regular contact with the pupil and family
- Ensure suitable work from individual subject teachers is provided
- Encourage fellow pupils to maintain contact with their sick friend
- Circulate letters about infection risks/measles when requested by the family or health professionals
- Inform staff and pupils sensitively about developments and changes
- Invite a nurse and other professionals to speak to staff and pupils
- Arrange for special educational support and staff training
- Agree changes to school rules and circulate arrangements to all staff and pupils
- Prepare for transitions – inform new teachers, school and support staff
- Regularly revise the pupil's timetable and school day as necessary
- Teach the class general awareness of illness and supportive strategies
- Prevent teasing and bullying through teaching strategies, clear communication and sanctions
- Arrange for ease of movement around the school
- Follow up signs of distress, poor performance or school phobia
- Provide opportunities for extra support and catching up with work

- Include the sick pupil as far as possible in all activities
- Inform staff about long term effects such as fatigue
- Adjust expectations of academic performance
- Provide strategies for improved learning, concentration and memory

Areas of particular concern

- Fatigue
- Emotional Aspects
- Behaviour
- Social Needs
- Sexuality
- Cognitive Difficulties
- Concentration and Attention
- Memory
- Speech, Language and Communication
- Vision
- Hearing
- Mobility and Motor Skills

Thank you

Grateful thanks to the staff and pupils from the following secondary schools:

- Ashburton Community School, Croydon
- The Ashcombe School, Dorking
- Bennett Memorial School, Tunbridge Wells
- Carwarden House School, Camberley
- Cheam High School, Sutton
- The City of London Academy, Southwark
- Court Moor School, Fleet
- Central Sussex College
- Dorothy Stringer High School, Brighton
- Dover Grammar School for Girls
- Eltham Green School, London
- Gravesend Grammar School for Girls
- Harris City Technology College, Upper Norwood
- Hayes School, Bromley
- Hinchley Wood School, Esher
- Lansdowne School, Brixton
- Limpsfield Grange School, Oxted
- Treloar College, Alton
- Oxted School
- Reigate Secondary School
- SEEVIC College, Benfleet
- Spelthorne College, Ashford
- St Andrews CE High School, Croydon
- St Andrews RC School, Leatherhead
- St Luke's School, Redbourn
- St Paul's RC Secondary School, Abbey Wood
- St Richard's Catholic College, Bexhill-on-Sea
- St Simon Stock School, Maidstone
- St Wilfrid's Catholic School, Crawley
- Thomas Bennett Community College, Crawley
- Ursuline College, Westgate-on-Sea
- Walthamstow School for Girls
- Walton Leigh School, Walton-on-Thames
- Warlingham School, Warlingham
- Wilmington Grammar School for Girls, Dartford

For further copies please contact:

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The findings of this report are those of the author, not necessarily those of Cerebra.

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Working wonders for children with brain conditions

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