Returning to school

A TEACHERS GUIDE
FOR PUPILS WITH BRAIN TUMOURS

The Royal Marsden Hospital
NHS Foundation Trust
Paediatric Oncology Unit
Downs Road
Sutton
Surrey SM2 5PT
www.royalmarsden.org
bette.petersenbroyd@rmh.nhs.uk

Cerebra
Second Floor Offices
The Lyric Building
King Street
Carmarthen
SA31 1BD, Wales
Tel: +44 (0) 1267 244200
www.cerebra.org.uk

For copies please contact:
Cerebra
Second Floor Offices
The Lyric Building
King Street
Carmarthen
SA31 1BD, Wales
Tel: +44 (0) 1267 244200
www.cerebra.org.uk
Foreword

A special thanks to the staff at the Royal Marsden Hospital, the parents, and the schools who worked together to produce this excellent resource for teachers. We are proud to be able to fund such a worthwhile project.

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Susan R Walker  Educational Psychologist
Jane Hood  Consultant Paediatric Neuropsychologist
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Eltham Green School, London
Gravesend Grammar School for Girls
Harris City Technology College, Upper Norwood
Hayes School, Bromley
Hichley Wood School, Esher
Landsdowne School, Brixton
Limpstills 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 Wilfrids 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
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Note to treatment centre:
Please tick the boxes which are relevant to the particular pupil.
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.

School represents to these pupils a resumption of normal life, with an opportunity to enjoy social relationships with peers and to benefit from the stimulation and rewards of learning. It can greatly reduce the sense of isolation and loneliness which is an inevitable part of illness and hospitalisation.

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 booklet is intended to provide the guidance which teachers will need to assist them with the task of helping a young person with a brain tumour return to school. It is based on the results of interviewing teachers who have had a pupil with a brain tumour in the classroom and who have had to find ways to accommodate their special needs. Extensive classroom observations in secondary schools and parental questionnaires also formed a part of the preparation for the guidelines.

We were struck during these interviews by the teachers’ ability to find creative solutions to the problems experienced by these pupils in school. We have therefore attempted to capitalise on this by giving examples of good practice in each section.

We begin by providing some information about your pupil’s brain tumour and its treatment. We also describe the network of hospital and community professionals who will be providing medical and educational support, some of whom will be available to liaise with staff in schools. The main problems experienced by brain tumour patients will be outlined, including difficulties in learning, emotions, social relationships and behaviour. We give examples and case vignettes to illustrate these points.

Many teachers will recognise techniques and strategies they already use successfully in class. Some of the problems exhibited by pupils with brain tumours (e.g. poor concentration or disorganisation) are commonly exhibited by other pupils. However, each child is unique and techniques must be adapted to meet their needs. There is usually no one single solution and what may work with one child may not work for another.

We hope that this booklet will encourage teachers to use their creativity in finding new ways to help these pupils. Understanding and meeting the needs of a young person with a brain tumour can be frustrating, confusing and anxiety provoking even for an experienced teacher. It is certain, however, that the effort spent will bring its own rewards, and will mean a great deal to your pupil and their family while at the same time enriching the school community.
pupil details

Name ___________________________ Date of birth ___________________________

Diagnosis _________________________________________________________________

Dates treatment started:

Operations _______________________________________________________________
Radiotherapy ______________________________________________________________

Chemotherapy ____________________________________________________________

Medication _______________________________________________________________
________________________________________________________________________
________________________________________________________________________

Special concerns _________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Return to school: Part time

Full time

parent details

Parents/Guardians: __________________________________________________________

Address _________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Postal code: __________________________

Telephone: Home _________________________________________________________

Work ________________________________________________________________

Mobiles _________________________________________________________________

Sibling: ____________________________
strategies for brain tumour pupils

(Please refer to the full text in ‘RETURNING TO SCHOOL – A teachers’ guide for pupils with brain tumours’)

- Communicate any concerns to parents and relevant parties
- Place the pupil on ‘School Action’, review regularly and leave on SEN register
- Circulate letters re Measles and Chicken Pox to all parents – if relevant
- Liaise with the home tutor
- Work through a plan of action regarding SATS and public exams
- Be aware of the individual needs of the pupil and their siblings
- Support the pupil at times of change and school transition

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

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### treatment centre

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Consultant

POON
(Paediatric Oncology Outreach Nurse)

Hospital Teacher

Paediatric Clinical Psychologist

Tel

Tel

Tel

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**STRICTLY CONFIDENTIAL**

(Where parents and the pupil are in agreement, all teachers should carry a copy of this page in their planners)
Each year around 350 children and young people in the U.K. will be diagnosed with a tumour in their brain or spinal cord. Although rare, these tumours are very important as they can be difficult to treat and can cause significant disability.

The symptoms that result from a tumour can be due to a build up of pressure inside the head (raised intracranial pressure) resulting in headaches, sickness and drowsiness. Other symptoms are related to where the tumour arises.

These symptoms include:

- Seizures (fits)
- Weakness of the limbs
- Unsteadiness when walking
- Problems with speech & swallowing
- Back pain or disturbed sensation
- Behavioural or learning difficulties
- Vision or hearing problems
Main types of brain and spinal cord tumours:

- Low grade glioma (benign tumours often called astrocytomas)
- High grade glioma (cancerous tumours also called glioblastoma or anaplastic astrocytoma)
- Medulloblastoma (cancerous tumour also called a PNET)
- Ependymoma (can be benign or cancerous)
- Craniopharyngioma (benign tumour but often aggressive)
- Germ Cell Tumour (cancerous tumour also called a germinoma)
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, if 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.

Rehabilitation is essential for all children with a brain or spinal cord tumour and many therapists may be involved.

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 & Spinal Cord 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 ‘neurocognitive deficits’ (processes such as thinking and memory) is a major issue for the child and family and obviously can have a major impact on education.

The factors associated with developing brain injury include:

- Early age at diagnosis
- Tumour type, location and extent
- Raised pressure in the head (intracranial pressure or hydrocephalus)
- Surgery
- Surgical complications (bleeding, infections, etc.)
- Prolonged seizures (fits)
- Radiotherapy (dose and extent)
- Chemotherapy

However, the disability caused by a brain injury may also be modified 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.

The types of neurocognitive problems described in young people with brain tumours include:

- Non-verbal intellectual functioning
- Slowed physical functioning
- Memory deficits
- Compromise of visuo-spatial 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. This means that over a period of time, (i.e. further from time of radiation), deficits become more apparent and exaggerated. This is most likely a result of failure to learn at a rate that is appropriate for the age of the child, rather than a loss of previously acquired knowledge.

Therefore brain injury and associated neurocognitive deficits (learning difficulties) need to be continuously monitored. Appropriate learning strategies should be applied to try to reduce the impact on the performance of the developing child or adolescent.
A medulloblastoma is a malignant tumour (cancer) formed from primitive or poorly developed brain cells. These tumours commonly arise in the cerebellum, but are also found in other regions of the brain, where the name PNET (Primitive Neuro Ectodermal Tumour) is used. They 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. They can also occur in adults but are extremely rare. Like most brain tumours the cause of medulloblastoma 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 (the way they walk)

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 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 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.
Childhood optic pathway glioma is a type of brain tumor which is usually a benign slow growing tumor, also called a low grade glioma, (gliomas are a type of astrocytoma).

An optic pathway glioma occurs along the nerves that sends messages from the eye to the brain (the optic pathway) and can occur anywhere along its path. For this reason the initial problems a patient may suffer from are related mostly to vision:

- Reduced vision
- Squints
- Flickering eyes
- Eye protruding forward
- Double vision
- Head tilt
- 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 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)’ can lead to these tumours. 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. Neurofibromatosis type 1 (NF-1) can be inherited from a parent but half the time 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 (ranges from none to severe)

A child/ family with NF-1 will be offered specialist counselling and be followed up by a paediatrician with an interest 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 the only 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.

**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 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 all of the 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.

**What is the outlook (prognosis)?**
Optic pathway gliomas are usually not life threatening (aggressive tumours can be) and the aim is to preserve 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 gliomas are benign tumours that arise from brain cells called astrocytes. Gliomas originate from glial cells, also 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) 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

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 location of the tumour and the 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.

**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 is given together with surgery and/or radiotherapy to treat the tumour. Chemotherapy is usually outpatient based and lasts over a year but is quite well tolerated and pupils can usually continue to attend school. 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 to be 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.

**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 gliomas are malignant (cancer) 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

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 and their resistance to radiotherapy and chemotherapy.
As there is no ideal therapy patients are often treated on clinical trials investigating new therapies.

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.

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 (less than 3 years) radiotherapy may be avoided 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.
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 on-going 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.
An *ependymoma* is a type of brain tumour that arises from the 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. They 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 less than 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

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 at achieving 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 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 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.
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.

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

Craniopharyngiomas result from the growth of cells that early in fetal development have failed to migrate to their usual area. These tumors 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 tumors 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.
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 tumour will 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!
A child or young person who has a brain or spinal cord tumour will usually be referred urgently to a regional paediatric neurosurgical 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 neuro-surgeon 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.
The diagram below 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.

Specific areas of the brain are not separate working units but part of an inter-related system and dependent on each other. This means that if the tumour has damaged a particular part of the brain it is to be expected that certain skills may be affected. However, the inter-connection means that unexpected skills could also be affected. Similarly, damage to certain parts of the brain does not necessarily result in the same problems for each person as every brain is different.
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. 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 111.

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 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 so as 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.
Radiotherapy

Longer Term Side Effects of Radiotherapy

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 cataract 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.

It is vital to continually assess and reassess pupils as their learning difficulties and needs may change over time.
follow up
of brain & spinal cord tumours

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 vary but initially they are 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 in to 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 education 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.
returning to school

While absent from school

Few brain tumour patients spend a long time in hospital but they may still be absent from school due to the severity of the treatment and the daily practical demands of radiotherapy, etc. However, quite a lot can be done to include the pupil:

- Visit the patient – small groups are best and always check with the hospital, the pupil and parents first
- Send get well cards and letters – not just when the class finds out about the illness but at regular intervals
- Encourage individual pupils to make contact, particularly close friends
- Make a video-diary or take photographs
- Send E-mails, MSN or mobile phone texts

The recovering pupil may be too poorly to work but will still be interested in school ‘gossip’.
While Absent from School

“When Emma’s name is called during registration, someone usually provides an update.”

Send circular letters to the home; the family still want to be kept informed of activities at school and this will help them all to still feel included.

Continue to call their name on the register even if you know they are away. It helps the class to remember them.

Make contact with the parents for regular updates and keep the school informed if you have their permission to do so.

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.

Be aware that there may be changes in the ill pupil’s appearance and behaviour.

One teacher commented, “The help offered by the hospital staff was invaluable. We were all reeling from the shock of Mary’s illness and quite unable to think straight about what we should and shouldn’t do or say. Talking it through helped and instead of feeling totally helpless we suddenly had ideas of positive things to do.”
A member of the hospital staff will usually make contact with school in order to discuss the following:

- **Treatment plan** and information about a possible return to school
- **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.)
- **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
- **Supporting the family and school** is important. Immediate strategies will be shared between hospital staff and teachers
- **Home-tuition** may need to be put in place. The school will have to liaise with the parents, the LEA and possibly the hospital teacher. A pupil is entitled to a home tutor after 15 days’ absence from school. They can reasonably (and legally!) expect to receive a minimum of 5 hours tuition per week. In some education authorities or in circumstances where a pupil is due to sit public exams it is often more than 5 hours. Having a home tutor should not stop the pupil from getting into school now and then for mainly social reasons. Attendance at school is always to be encouraged and social visits should not jeopardise the arrangement for home tutoring.
- **Educational support and / or statementing issues** may have to be looked into at this very early stage
- **A part-time timetable** should be considered
- **Special considerations and arrangements regarding exams** will need to be planned

“Visiting him in hospital made it all more real.”
Returning to school can be daunting for a brain tumour pupil and also for the school itself. The pupil may feel socially isolated after a period of worry and debilitating treatment. Their sense of self will have altered as physical and psychological changes have taken place. Confidence and motivation may be at rock bottom and their energy level nonexistent. 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 treatment, even if only for a few hours or half days each week. 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.

"The pupils have actually learnt a great deal from all this. Valuable lessons for the future!"

Joe was physically and mentally unprepared for school so he and his parents came to an agreement with his Form Tutor and Head of Year. Joe was able to come and go as he felt able to until well enough to return to regular schooling.

On occasional days Joe would turn up at lunchtime to meet his friends and spend the first lesson of the afternoon in class. The teachers all knew not to expect regular attendance or work from Joe. Their sympathetic understanding of his limited energy meant that Joe’s eventual reintegration into school was easier and he experienced less social isolation, all invaluable factors in increasing Joe’s confidence and recovery.

“I dreaded going back to school – but they were all so nice about it.”
Open and frank discussion about cancer and questions answered honestly can provide a new level of awareness and learning for both staff and pupils.

Possible strategies

- At the onset of the disease 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.
- Try to meet with the pupil and his / her parents before returning to school, either in hospital or at home.
- 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.
- 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. (Discussed beforehand with the family)
Be aware of the impact of a brain tumour on siblings and their schooling

- Try to create an atmosphere of support where problems can be discussed – by the pupil, their parents, other teachers and pupils
- 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
- Re-integration 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 re-integration will vary greatly from one pupil to another
- A separate and individualised timetable to accommodate for individual circumstances may be needed at first
- 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 is used to dealing with this problem. The hospital teacher or outreach nurse can often offer helpful advice and ideas

“Brian’s teacher arranged for the outreach nurse and the hospital teacher to visit Brian’s class before his return to school. Brian was invited to be present but he decided not to. The nurse told the class about Brian’s brain tumour and the treatment and side-effects. A rag doll from the hospital was used to illustrate to the class how Brian now had no hair, had a Hickman line in the chest and could not go swimming or play rugby. The pupils were very interested and asked lots of questions to increase their understanding. The hospital teacher told them how they could be a good and supportive friend to Brian, how they might help him with work or getting around the school. They were genuinely concerned about how Brian would catch up and cope with exams and were keen to find out what to say and what not to say to Brian.”

“We had no idea what to tell the other pupils.”
Establishing open lines of communication with parents is an essential part of good educational practice. Parents are often more aware of a young person’s 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 in school. There are, however, areas of possible difficulty where parents and teachers may have a different perspective on the pupil.

Parents and teachers as well as the pupil themselves may each hold different expectations regarding academic performance. For example, teachers may feel that the parents have not adjusted their expectations sufficiently after a pupil’s 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.

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 GCSE’s. John himself was bitterly disappointed and suffered a loss of self esteem because of his lower academic achievement. 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.
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.

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 be regularly updated.

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 is hard to know what to expect. Am I too demanding or too soft?”

“The last thing they need is for school to get in touch – or so I thought!”
Returning to School

“‘ We had no idea just how supportive the school could be. They have all been brilliant!’”

Be aware that:

- The entire family is experiencing severe stress and trauma. They may feel isolated and confused and find it hard to consider plans for the future.
- Privacy and a comfortable environment can help in situations where difficult issues are discussed. Sit with rather than across from the family and include the young person as much as possible with direct and non verbal communication.
- Arrange for a sympathetic interpreter in cases where the family speak little or no English.
- Culture, religion and customs often influence the way families deal with and talk about illness. Different ways of coping all deserve respect.

“‘ As a teacher I am sometimes unsure to what extent a ‘snappy’ episode is due to the illness or medication or simply no more or less than you get from other hormonal teenagers! I would like to have direct contact with hospital staff to discuss such issues and get a more accurate picture of the pupil’s condition and ability. Mum is very supportive but I really do not want to worry her any more than necessary and her unrealistic expectations are not helpful at all.’”

“I don’t quite know why her mother tells me all the gory details! What does she expect me to say?”
Preparing and Supporting Staff

Normality, routine, achievable goals and inclusion are important for all pupils with brain tumours, even those with a poor prognosis. All staff, including dinner ladies and helpers, should be aware of the illness and consequences as long as the family have agreed to this. The school may need to temporarily review rules and procedures.

Be flexible about:
- Visits to the toilet
- Wearing a hat, cap or bandana
- Coursework deadlines
- Coming and going – attendance
- Parents or supporters in class
- Drinking or snacking
- Unusual behaviour
- Amounts of work or homework
- Attending PE and going outside at break time
- Seating plans

Communication between staff is important as is communication with the pupil, the parents and peers. How the pupil feels or is able to cope may fluctuate greatly from day to day. Some get increasingly nervous before a check-up at hospital or worry about work.

It is important to have an effective way of communicating individual pupils’ needs to all relevant staff. Often the information remains with the SENCO or Head of Year, leaving other teachers in the dark.

Display a photo of the pupil with relevant information in the staffroom for teachers’ planners, or distribute information via the school intranet. Be sure to acquaint any supply staff of the pupil’s illness and needs.

“Jane had been reassured by her Head of Year that she could wear a cap to school. She had lost all her hair as a result of the chemo and radiotherapy. She was distressed when a new teacher at the school shouted at her and insisted that she take off the cap as wearing it was against school rules.”
Integrate discussion of the illness into classroom activities, if appropriate and only with the pupil’s permission.

Make staff aware of the needs of siblings.
They commonly experience stress as a result of their sibling’s illness. There can be varied emotions of worry and concern mixed with resentment at experiencing less attention from parents and relatives. Siblings may find it hard to attend school while looked after by family and friends. Staff may notice changes in academic performance, behaviour or emotional well being.

Maintain expectations of behaviour and discipline.
Some pupils may try to exploit their situation after having been the centre of attention in hospital. They may find it difficult to readjust and are likely to be genuinely sensitive and emotional or prone to tears and tantrums.

Support the staff.
Some staff may have personal experience of cancer and this may bring up raw emotions for them. It is important to recognise 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.

One mum commented,
“ We have always found the head and the deputy head really understanding. They sympathise and are very willing for Paul to have individual arrangements. But somehow the information we keep giving them just does not filter down to the individual subject teacher. Paul is too self-conscious to keep reminding teachers of his limitations so he gets very frustrated, taking it out on himself or us.”
Preparing and Supporting Staff

Be aware that:

- Staff may find that strong emotions are being stirred in themselves or their colleagues. Support may need to be available.
- Confidentiality issues can sometimes conflict with the need for sound and practical advice.
- Some matters are outside the mandate and expertise of teachers.
- There can be potential conflicts between the values, beliefs, customs and cultures within a school.
- Bullying and teasing is always a potential problem.

“Miss Jones was so upset. A relative of hers has just been through a similar scenario with a negative outcome!”

“As soon as his mum told me he was due for a progress scan at the hospital it clicked why he had been so ‘stroppy’ lately.”
The brain tumour patient is likely keen to catch up with peers and to fit back into the group once again. 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. 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 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.”

“There was no shortage of volunteers when I asked for someone to help Richard get around the school.”

“I like to carry his bags for him. Gets me out of lessons sooner!”

“Because of the tubes we know not to wrestle with Paul. We still tease him, though.”
Points to address when talking about how to be a good friend:

- Realise that wearing a cap / hat 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 would be in order!
- Understand that mood swings are likely and not to take them personally
- Be aware that when the brain tumour pupil snaps, 'I don’t want to talk about it!' it usually means just then and not forever
- Keep in contact if the pupil is absent. If they are too poorly to chat on the phone or receive a brief visit you will be told by the parent. Try again later. A text message, MSN or Hotmail is another good way 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 the friend to parties, etc. but understand if it may only be 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 the pupil for wearing a cap or leaving the room, explain the situation so the brain tumour pupil does not have to defend themselves – again!
- The pupil could carry a note in their planner with a brief indication of the situation and special provision required
- Do not bump in to or wrestle with the pupil. 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 the pupil 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 the pupil 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 to staff

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!
The brothers and sisters of a young person diagnosed with cancer can be deeply affected in a variety of ways. Research has shown that it is common for them to experience adjustment problems.

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. Siblings may be left with an uncomfortable mixture of emotions, including anxiety, resentment and guilt. Daily routines are often disrupted. 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 who are aware of the problems a pupil may be facing during illness in the family can do a great deal to help. With parental permission all teachers should be informed of the situation. The pupil may need space or time to talk or just sympathetic handling. 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.

The sister of a patient:
“ 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.”
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. 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 which 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 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!”

“We don’t seem to have much of a family any more.”

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!”

“We don’t seem to have much of a family any more.”
If the treatment ultimately fails the sick bother 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.

Organisation offering support for brothers and sisters:
‘Siblinks’
Website: www.siblinks.org
Email: info@siblinks.org

“I can understand why everyone always asks after my brother, but I sometimes wish they would also worry a bit about me.”
All tests and exams present their own problems and difficulties for young people with a brain tumour. The pupil may fear how they will cope in an exam as well as worry about the future consequences of a poor performance. They face having to accept lower results than they might have hoped for before they were ill. This might shatter their morale.

It is important that the school or exam board gain 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 while others will breathe a sigh of relief. 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 L.E.A. 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.
School strategies for public exams:

- Reduce the number of subjects taken to the most elementary ones or those most enjoyed by the pupil. Perhaps they can re-sit at a later stage, if appropriate.
- Arrange for curriculum support lessons to enable the pupil to catch up.
- Apply to or inform awarding bodies of access arrangements well in advance of the exams if possible. The treatment centre should be able to offer assistance in the form of advice or medical documentation.
- Apply for special consideration immediately following the student’s exams.
- 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.

Access Arrangements

Access arrangements cover the entire course and should be applied for as early as possible. They are based on a history of well established need but must also 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.

There are two types of access arrangements:

1. Access arrangements delegated to the examination centre:
   - Additional or extra time - up to 25%
   - Rest breaks and food or drink
   - Separate room
   - Transcript
   - Prompter
   - Bilingual Dictionary for use by candidates whose first language is not English, Irish or Welsh and 25% extra time for pupils who arrived in Britain less than two years ago (Not for English and foreign language exams)

In one of the schools visited the teacher kept a detailed file of notes with an overview of topics, course work and assignments. The folder was geared at pupils and their learning rather than potential inspectors. If any pupil was absent or if a parent, home tutor or hospital teacher required information on work missed or planned, it was easy to photo-copy and instantly user friendly.

“...I know he would have done so much better had it not been for the illness...”
2. Access arrangements requiring application to the awarding body for approval

- Additional time over 25%
- Reader
- Modified examination question paper
- Scribe (previously known as amanuensis)
- Practical assistance
- Word Processor
- Use of British Sign Language

**Always apply for access arrangements as early as possible.** Rules and guidelines may change from one year to the next. Teachers should consult the Joint Council for Qualifications (JCQ) guidelines which are published annually in “Rules and Guidance Relating to Candidates Eligible for Reasonable Adjustments in Examinations”.

**Special consideration**
Apply for this if you consider that a ‘health crisis’, possibly caused by the long-term illness, has occurred. This must manifest itself during the assessment and relate to the specific time the exam was conducted. An allowance of marks up to a maximum of 5% may be given in exceptional cases

**Enhanced grading**
Where a candidate has missed an exam or unit of work altogether, an adjustment to the final grade can be made as long as minimum requirements have been satisfied. The minimum requirements for enhanced grading vary greatly – usually between 35 – 50%. In cases where minimum requirements are not met an exceptional circumstance award may be made.

**Transfer of candidate**
The pupil is entered for exams by their school but arrangements are made for the pupil to sit the exam elsewhere, such as in hospital.
Teacher strategies for tests and exams:

- Reassure the pupil that allowances can be made in judging their academic performance
- Encourage them to do their best and to use the test as a means to show up where the gaps are
- Adjust your marking system to allow for the gaps, only testing work covered by the pupil
- Where possible you might arrange for coursework to take the place of tests
- Help the pupil plan their revision and provide a summary of work covered
- Liaise with the hospital teachers or home tutors regarding 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 will be possible
- Do not make promises regarding grades without first having discussed the situation with the exam board.
- Make sure the pupil is familiar with any exam concessions that have been agreed. For instance working with a scribe – or being one – is a skill that needs to be developed or practised prior to a significant exam

“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.”

“I’ve realised now with Fatima that it is more important for her learning and well-being 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’.”
School Transitions

Transitions within school and between schools or college can be 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.

**Strategies:**

- Keep change to a minimum, whether classroom layout, seating plan or working patterns
- Prepare your 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

**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

Based on working with Laura during the summer before her transfer, the SENRA 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.
Treatment for a brain tumour may leave your pupil seemingly ‘cured’. However, they may well be suffering from invisible injury or subtle side effects. In many cases they improve while, sadly, in others the decline continues, often undetected. The initial elation at seeing the pupil back at school after serious and life threatening illness may mask the fact that subtle changes have occurred and may continue to manifest themselves.

For these reasons we recommend that steps are taken to place any young person returning to school after treatment for a brain tumour on ‘School Action’ level of the Special Educational Needs Code of Practice.

It is important to assess the pupil at this stage so that comparisons can be made at a later date.

‘School Action’ level of the SEN Code of Practice
The Special Educational Needs Co-ordinator, (SENCO), will take responsibility for the young person’s needs. The school provides any extra help that is necessary. An Individual Education Plan (IEP) should be drawn up. It should describe the pupil’s difficulties and the provision and strategies put in place by the school to meet identified targets and goals. Regular reviews of the IEP should reveal any late effects of treatment or delayed reaction, whether cognitive, social, physical or emotional. Parents should be given a copy of the IEP and it should be reviewed at least twice a year.
We recommend that any young person treated for a brain tumour should remain on the 'School Action' level for the duration of their school career.

“Mohammed’s LSA is superb! He is happy every morning he goes to school. That is all I want!”

'School Action Plus' of the SEN Code of Practice
When your pupil returns to school with more complex needs, does not make enough progress, or if problems show up at a later stage, they need to be put on the 'School Action Plus' level of the Code of Practice. Specialist staff from outside the school will be involved in assessing or advising the school in terms of meeting the needs of the pupil.

The Local Education Authority (LEA) or health authority is able to assist with specialist staff such as a Speech and Language Therapist, Specialist Teacher or Educational Psychologist. The SENCO must try to include parents in any discussions about how best to help the pupil.

With parental consent the school might benefit from speaking to the hospital teachers regarding educational concerns over a pupil after treatment. They may already know the pupil well and be able to offer advice and are well placed to liaise with relevant agencies.

'Statemaning' or Statutory Assessment of Special Educational Need
Your pupil may return to school with severe deficits or, over a period of time, it becomes 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. In such cases the local education authority must, with parental consent, make a statutory assessment of their needs.

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 1½ years after returning to school Sandra was offered LSA support which needed to be increased over the years.

“Finally now I am happy that the support she is getting matches her needs - finally!”

“If only we had started the process sooner!”
Statement of Special Educational Need

The LEA’s statement, agreed with the parents, describes all the pupil’s needs and the special help and support required to meet them. Speech therapy, physiotherapy, psychological support or advice and teaching from the local visually and hearing impaired units or mobility unit are all examples of help available.

In some cases the parents can express a preference to attend another school better suited to meet the specific needs of their child. The Educational Psychologist may be helpful here. (See separate section on Specialist Schooling)

The statement supports the young person’s education up to the age of 19 and is reviewed on an annual basis.

In our experience, the majority of young people with a brain tumour require specialist help within school in order for their individual needs to be met. Hospital staff will be able to provide some advice as to the level of support that will be required in school.

Given the length of time it takes to obtain specialist support and educational resources, we suggest that the LEA is informed as soon as possible in order for an IEP (Individual Education Plan) to be drawn up and backed up.

Any request for additional educational support for the pupil can be initiated either by the school, the parents or by professionals. However, it is always best if this is done in collaboration with all parties.

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, pesterling 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.”
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 non-contact 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 a 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 classwork and withhold inappropriate support at such times in order for the teacher to be able to assess the pupil fairly
- A LSA is unlikely to have experience of young people with a brain tumour. They may need additional support and supervision
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.
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.

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
- LSA support need not necessarily be provided by one person. LSAs attached to a department can provide extra subject expertise, particularly in exam classes. Various input by several LSAs may provide welcome relief for the pupil and create less dependency on the support of the LSA.
- The flipside is that an LSA will not necessarily be able to track and observe a pupil coping brilliantly in some subjects while struggling in others.
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 extra curricular 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.”
Many brain tumour patients suffer from severe fatigue, and the idea that the pupil can cope with homework after a full day at school is unrealistic. In one school the taxi pick-up time for a brain tumour pupil was set for 1 hour after school finished rather than immediately after school. This allowed the pupil to attend a drama club after school one evening a week. On the other days the pupil attended a homework club run by the LSAs. This almost entirely eliminated the battles at home over homework when much too tired.

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.

“ 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. ”

“ I try to help the others in class also. Shay hates to be singled out, and the friends are also needy in different ways. ”
Some young people returning to school after treatment for a brain or spinal cord tumour will find it difficult to take part in Physical Education (P.E.) 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). 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.

Barry fiercely resented the idea of having to return to school with restrictions on his participation in P.E. lessons. Being sporty both in and out of school, this was the worst aspect of his illness. Fortunately, Barry’s P.E. 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 pupil’s 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.”

“As soon as we all had understood about not being ‘upside down’ with a shunt we were off! Andrea is the best goal shooter we have had for years.”

“I really miss not being able to swim.”
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.

Reintroduction to swimming may need to be carefully monitored. A previously competent swimmer may have become slow or weak and so needs specialist teaching to re-gain 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 co-ordination 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, i.e. 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.

“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.”
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. 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 risk assessment can be carried out.

Useful Contacts:

London Sports Forum for Disabled People
436 Essex Road
London N1 3QP
Tel: 020 7354 8666
www.londonsportsforum.org.uk

The Local Disability Sports Organiser should be able to give teachers information on how to adapt activities.

English Federation of Disability Sport
Manchester Metropolitan University
Alsager Campus
Hassall Road
Alsager
Stoke-on-Trent ST7 2HL
Tel: 0161 247 5294
www.efds.net
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 terms they are now a different person. 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
- Small classes
- Fully differentiated curriculum
- A feeling of being valued and understood
- A sense of belonging
- Access to therapies
- Specialist facilities
- Specific preparation for practical life skills

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.
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 changes from curative to palliative. The most important focus in palliative care is to make the patient comfortable, to enable them to enjoy life as much as possible and to die peacefully.

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

Even though a young person is dying, they and their parents may wish them to attend school. The school is a familiar place where most of the young person’s relationships outside the family exist. Through these important relationships, a regular routine and normality can be maintained. With careful planning and communication the school can nurture the child’s social and emotional wellbeing. The parents and siblings may also find it comforting that their social network of support is involved and maintained.

The sick pupil may only be able to attend school part time or come in mainly for lunch 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, E-mails, videos or MSN.

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. Those who have already experienced significant loss in their lives tend to need greater support and comfort. Significant loss need not only be through the death of a loved one but can also be separation through the break-up of families. For refugees the loss of language, culture and home can be traumatising. Those who recognise similar health problems in themselves or their family may need additional understanding as will those with a particularly close relationship to the person dying or to their siblings.
Communication
A school dealing with the death of a member of their community will need to plan and set up a system of good communication.

- Who will be the key member of staff responsible for co-ordinating information and support? Do all know who it is? Do all know how to get hold of them?
- A named member of staff should keep in touch with the family. Their consent for all action or information passed around school should be sought sensitively. All preparation and support should be done in accordance with their wishes and beliefs.
- Make contact with professionals who will be able to support the school and offer advice and counselling (see below).
- Allow staff the space and time to discuss among themselves how to share information, to plan what to say to pupils and to support each other. Staff should only be asked to speak to classes if they feel able to deal with and manage pupils’ reactions and questions.
- Consider 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.
- Small groups are usually better than assembly for breaking bad news.
- Be prepared for questions, answer as directly and honestly as possible and admit to not being able to answer all questions.
- 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 in any form they find suitable. There are no ‘right words’ and any gesture of sympathy is valid.
- 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.

“Our school is huge and it was the first time I felt we were ONE community.”
Further points to consider

- 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?
- Acknowledge the powerful learning experience for pupils and teachers. Allow time for talk and reflection. Be a good listener
- Include issues in the curriculum if appropriate, particularly where pupils raise the topic. It may need revisiting again and again over time
- Are there practical ways the pupils can engage in expressions of grief and sympathy i.e. attending funeral or memorial service, creating an area of remembrance, raising money for charity, etc.?
- Should anniversaries, birthdays, etc. be marked? Experience has shown that families really appreciate the fact that their relatives are not forgotten on these special occasions

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 memories.

Please see the list at the back of the booklet of recommended books and organisations able to support the school in the bereavement process.
Adolescents and grief
Feelings seem to become more intense in adolescence, yet expressing them can be difficult. A grieving young person may be more comfortable expressing anger about death than showing sadness or hurt which they may perceive to be childish. Some try to cope by joking about death, or 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. Acknowledge that this is happening at a time of great change in a teenager’s life. 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.

Strategies for grief support
- Work out what to do if people feel upset. Where can they go?
- 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 your own grief. It will touch others affected and provides comfort to know that the sorrow is shared
- Discourage punishing oneself with notions such as ‘I should have.....’ or ‘if only I.....’
- Do not try to avoid those who grieve more than you. Isolation will only add to their pain
- Don’t change the subject when someone mentions their loss or becomes emotional
- 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

“If it is this tough for us what must it be like for his family!”
Difficulties in the Classroom

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 temperatures.

Pupils may suffer from mental / cognitive or physical fatigue which can affect everything they do.

We are used to thinking of fatigue as physical. Pupils treated for brain tumours experience this, particularly after radiotherapy. It can last for months or years.

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
- Apathetic or ‘lazy’ speech and behaviour
- Difficulty getting around school on time and arriving late for lessons
- Not interacting with peers
- Poor appetite
- Irritability
- 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
- Provide a coloured card for the pupil to indicate when they need time out – physically out of class or just ‘switching off’
- Modify time limits in tests and with coursework
- Reduce the time table or number of subjects studied
- Provide a calm and restful environment like the library
- 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

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.

I hate not being able to do the things I used to!

Simon’s biggest problem is fatigue. It stops him doing things and being part of a group.
Young people who have had a brain tumour are often faced with a major readjustment following treatment. In most cases there will be a change in intellectual capacity, with a different pattern of cognitive abilities. Sometimes subtle changes in personality are seen. The pupil may in addition have to cope with changes in physical appearance, about which teenagers in particular are likely to feel acutely sensitive.

Not only might they look different and have different capabilities – they may also feel different. They will have come through a traumatic and potentially life-threatening experience, which sets them apart from peers who do not share this background and who may have difficulty in relating to it.

All 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.

Upon returning to school the young person will need to confront the fact that their performance on a number of levels (e.g. academic, athletic) may have deteriorated. Some may be inadvertently protected by a lack of insight, but others will find each fresh realisation of a newly acquired limitation extremely disheartening. A grieving process then occurs, in which gradual acceptance of a new identity takes place. This may be a slow and painful process. It is crucial that the issue of expectations of their own performance, realistic or otherwise, is dealt with in a sensitive manner.

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.

It will help a teacher in her work with a pupil to be aware of these potential difficulties, although the teacher’s most important role may be to communicate his/her concerns to the relevant people.
Emotional Aspects

What might I see in the classroom?
Common patterns of emotional difficulties may include:

- Depressed mood, mood swings, withdrawal, lack of enjoyment or motivation (particularly in previously favoured activities) and tearfulness.
- Anxiety, agitation, worries about things such as acceptability by peers, keeping up with school work and the future. Anxieties about returning to school are common and may escalate to school refusal or truanting. Young people who are particularly worried about their work may develop a perfectionist attitude, which can make it difficult to keep up in class. Obsessional behaviour may result.
- Low self-esteem / low self-confidence, enhanced sensitivity
- Emotional immaturity, over-dependence and clinginess
- Somatisation (i.e. complaints of headaches, abdominal pain). In a child with a history of cancer it is important to firstly exclude any medical or physical cause for an ailment
- Emotional difficulties might also manifest as poor concentration in the classroom, academic underperformance and poor motivation
- Frustration, anger, aggression, irritability
- A young person with an emotional difficulty may socially isolate themselves from their peers and may also be reluctant to ask for appropriate help

Strategies
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? Long-standing 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 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 possibly professionals will need to become involved.

“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.”

“To be honest she does not make life any easier for herself or for anyone else. She whinges all the time and her classmates just get fed up with it.”

“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!”
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.

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, no disinhibition and inflexibility.

- There may have been behavioural difficulties prior to the illness. These may be exacerbated upon 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.
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
- Obsessive behaviours
- Attention-seeking
- School phobia

**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:

- 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?

"I don’t mean to be a pain but I know that I am."

“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.”
The teacher will need to consider the pupil’s behaviour in light of normal adolescent development, and in comparison to their peer group. Once there is some understanding of the nature of the problem, basic behavioural management strategies can be put in place. These may include:

- Giving praise and attention to positive and appropriate behaviours
- Ignoring difficult or inappropriate behaviour, where appropriate
- Eliminating or modifying triggers to the problematic behaviour
- Try to provide consistency and routine, especially for pupils who may find it particularly difficult to adjust to change
- Model calm behaviour

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.

“Talking things through with Simon and his parents helped such a lot. That boy has been to hell and back and he is scared.”
Important principles of good behavioural management

Good communication
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.

School refusal or phobia
This will need to be caught 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. It is a common problem following treatment for a brain tumour.

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.
Social needs

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

These children are at risk of social isolation and bullying.
Possible strategies

1. A buddy system
2. Moving quickly to intervene in situations where the pupil is becoming upset or agitated
3. Using simple, concrete language
4. Giving the pupil a clear idea of what is expected in a given situation
5. Social skills tuition, either individual or in groups
6. Classroom discussions around appropriate behaviour (e.g. PSHE)
7. A strong anti-bullying policy
8. Keeping a watchful eye on interactions in the playground
9. Avoid confrontations

Sally has visual and social problems following her treatment for a brain tumour. To reduce any problems she is allowed to stay inside her classroom at break times and for 2 of her friends to stay with her. On pleasant, sunny days she is encouraged to go to a particular bench in the playground. Pupils know to go there for a chat with Sally, duty staff can easily keep an eye on her and she is in no danger of knocking into people in the playground.

"The LSA knows just how to control the agitation before it escalates."

"Sarah cannot now read facial expressions or tone of voice. You have to be quite literal in what you do and say."

"His small group of friends at school are very patient and have learnt how to interact with him successfully – and he makes them laugh!"
A brain tumour can affect sexual development in a number of ways.

Physiological effects are due either to the location of the brain tumour or to the treatment (radiotherapy or surgery). This can create a hormonal imbalance leading to problems such as precocious puberty, sexual inhibition or heightened sexual drive. This can be treated by an endocrinologist, a doctor who specialises in hormonal problems. The young person may receive hormonal treatment in the form of tablets or injections, usually for life. Some long term complications of the cancer treatment such as infertility are permanent, and this may be very upsetting for the young person. Impulsiveness may be a side-effect of a brain tumour which can lead to problems in sexual behaviour.

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.

““In Biology Miss Jones told us about all sorts of things. I would have died of embarrassment but she was really good – despite the boys being crude – as usual!””

““They are likely to develop genuine affection for each other. All we ask is that display of such affection is kept discreet and modest and does not embarrass or offend others.””
Sexual skills difficulties can create problems in developing age appropriate 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

Maggie unexpectedly burst into tears and left the classroom during a human biology lesson. The theme of the lesson had been human reproduction. It emerged that Maggie had been told that as a result of treatment she would not be able to have children.
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.

**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 which 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 a difficulty 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.

“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.”

“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.”

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.
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 co-ordination (eyes may flicker and be slow to follow objects)

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.

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

“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.”

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.
Position in class

- Sit at the front of the class. This needs to be arrived at 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 visa 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 Over Head 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 which 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

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.”

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.
Laptop computer

- 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 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.
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 oral 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.
Difficulties in the Classroom

“Poor hearing means you can so easily become socially isolated.”

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

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

“Paul has become quite skilled at lip reading. A wonderful skill which saves a great deal of embarrassment.”
Most young people with a brain tumour make good physical recovery after treatment for a brain tumour. 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 P.E. / 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.

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.

**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 P.E. and Outings

“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.”
**Fine motor skills** are the smaller hand movements which include the ability to use tools such as pencils and scissors. 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 shoe-laces
- 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.

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

Some pupils may have to learn to use a different hand altogether!
Young people with a brain tumour can often have memory difficulties. There is substantial research documenting the effect of various brain tumours and radiotherapy upon memory. When assessing a pupil’s memory, it can be helpful to consider his/her memory for both visual and verbal information, in addition to their ability to remember information both immediately and after a delay. It is not uncommon to see strengths or weakness 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 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 co-exist. 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.*
Strategies

- 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.

- Try to minimise distractions when the pupil is trying to remember information.

- Reduce memory demands in the classroom where possible.

- Provide opportunities for repetition and over-learning, using a multi-modal learning approach. Start with the pupil’s most intact modality.

- Provide memory tools i.e. supplementary written instructions, diaries, checklists, clocks, memo board, dictaphone, personal organiser, calculator, worksheets or templates. Find out what works best for the pupil.

- 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 cannot locate the information they require. 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.

- Try to link new learning to the pupil’s previous knowledge and experience.

- Teach memory strategies i.e. mnemonics, mental imagery, mind maps. ‘Mnemonic’ strategies may help the pupil to remember common groupings of words or letters (i.e. ‘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 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.

- Specialist professionals (i.e. an Educational Psychologist) will be able to assess the pupil’s memory further and provide advice on specific memory techniques.
Further Strategies

- Use pictures or colour prompters to aid memory.
- 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 and make sure you provide the pupil with a checklist to follow.
- Use scaffolding techniques for planning and organising work.
- 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.
- Stick to routines as an aid to memory.
- 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.
- Use spider diagrams to help organise thoughts.
- Use write-on sheets for work to increase focus.

Some young people with a brain tumour may have specific difficulties recalling the events of their day, and they cannot talk about things that they have done or seen in the recent or distant past. They might require help 'selecting' which information they should be observing and remembering. By describing the pupil’s experiences and providing them with a verbal commentary, they may be able to remember a 'script' and retrieve factual information describing what they have done. Noting down the pupil’s experiences in a timetable or diary will allow them to refer back, and having brief reminders of events may help the pupil to locate memories that they are unable to retrieve without precise prompting.

“Cut! I’ve forgotten what I wanted to say!”

“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.”
Difficulties in the Classroom

concentration
and attention

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
- 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
- Work may be slow or lacking

What appears to be a behavioural problem in the classroom may have a number of different possible causes. 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:

- 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 visually and auditorily 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:

- 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 pre-occupied 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.

“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!”
If the pupil has trouble understanding 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
- Provide a written list of instructions that the pupil can refer to
- Request a language assessment to determine the child’s language level and to see whether therapy might be warranted
- Support spoken information with practical or pictorial demonstrations to assist in language understanding
- Ensure the child is seated at the front of the class where they will be best able to hear the teacher

Andrew found it difficult to concentrate in class following his radiotherapy treatment. His teacher often noted him day-dreaming, 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 discretely.

If the pupil has problems remembering what they have to do:

- Provide as much information as possible in a visual or written form to reduce the demands on the child’s memory
- Tell the pupil what to do or repeat instructions, not ‘get back to work’
- Model the activity with them to give them experience of the objectives
- 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

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

“For a while he only came to school in the morning. In the afternoon he was either too tired or too wound up.”

“Whatever a pupil’s poor behaviour is due to - there are limits.”
The cognitive changes that have occurred in a young person treated for a brain tumour can be very obvious, or subtle and hard to detect. A pupil’s performance may not be significantly different when measured as an overall IQ score. They can appear to be coping, and only gradually do the cognitive difficulties become clear. If there has been brain irradiation the decline in IQ may be progressive year on year.

Information processing, nonverbal skills, memory and attention span are often affected in young people with a brain tumour. Pupils may struggle in particular with maths and foreign languages both of which demand quick information processing 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 following treatment.

Because of this changing picture over time, continuous assessment is important. Some pupils may have had a neuropsychological assessment at their treatment centre, providing a detailed description of cognitive difficulties. The Educational Psychologist may also have a role in assessment. However, a teacher’s perceptive monitoring of a pupil’s difficulties in the classroom is an invaluable source of information.

*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.*
What might I see in the classroom?

Problems in one or more of the following areas:

- 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
- Working at a slow pace
- 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!”
How can I optimise the learning?

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 well respond 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 pupils 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 pupils 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 non-verbal to verbal
- Use signals, such as gesture and voice, to alert the pupil to key elements and issues

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“There were so many obvious difficulties at first that we were quite blind to the more invisible cognitive ones!”
Technology

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.

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 a ‘watch+’ which can be set to remind the wearer of what, when, where, who or how
- Use diagrams, graphs and pictures to illustrate information or represent ideas
- Focus on one piece of information at a time
- Encourage the pupil to express thoughts in one sentence at a time
- Encourage the use of study skills such as highlighting, colour coding and the use of stickers as well as summarising and paraphrasing

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.
Difficulties in the Classroom

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- 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
- Help the pupil to structure checklists, to tackle one item at a time and to cross them off as each step is completed

**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 for practical tasks.

**Backward chaining**

For pupils with a greater degree of learning disability, learning new tasks, particularly motor tasks, can be demanding and demoralizing. 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.”

“...In such an academic family her cognitive difficulties seem even more startling.”

“...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.”
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 organizing 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 recognize 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 3x9?’, 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, ‘3x9?’.

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 organizational 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.
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.
Photos this page:
“Over the Wall Gang Camp”
www.otw.org.uk
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

INTRAVENTOUS
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

“I noticed that Bev now uses very specific medical vocabulary with natural ease.”
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
Many of these websites have useful and informative links.

The Royal Marsden Hospital NHS Foundation Trust
Paediatric Oncology Unit
Downs Road
Sutton, Surrey SM2 5PT
Website: www.royalmarsden.org

Cerebra
Second Floor Offices
The Lyric Building, King Street
Carmarthen, SA31 1BD, Wales UK
Tel: +44 (0) 1267 244200
Website: www.cerebra.org.uk

Children’s Cancer and Leukaemia Group (CCLG)
Website: www.cclg.org.uk

Cancer Research UK
Website: www.cancerresearchuk.org

Cancer Backup
Website: www.cancerbackup.org.uk

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

Teenage Cancer Trust
Operates a schools programme to improve awareness of cancer
Website: www.teenagecancertrust.org

Brain Tumour UK
Website: www.braintumouruk.org.uk

Samantha Dickson Brain Tumour Trust
Website: www.sdrt.co.uk

Macmillan Cancer Support
Website: www.macmillan.org.uk

Brain and Spine Foundation
Website: www.brainandspine.org.uk
Interactive site for children:
www.headstrongkids.org.uk

The International Brain Tumour Alliance - IBTA
Website: www.theibta.org

The adventures of Captain Chemo And Chemo Command
By Benjamin de Garis
Website: www.royalmarsden.org/captchemo/
An interactive and educational computer game designed to inform patients, family and friends about treatment with chemotherapy
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 is having 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 is having chicken pox.

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

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
Recommended Reading for Secondary Schools -
Managing bad news

1. The Struggle To Be Strong – True Stories by Teens About Overcoming Tough Times
   Al Desetta, Sybil Wolin  ISBN 1-57542-079-1
2. Straight Talk About Death for Teenagers – How to Cope with Losing Someone You Love
   E.A. Grollman  ISBN 0-8070-2501-1
3. Chicken Soup for the Teenage Soul – Stories of life, love and learning
   J. Canfield, M.V. Hansen, K.Kirberger ISBN 009 1826403
4. Making Every Day Count – Daily Readings for Young People on Solving Problems,
   Setting Goals & Feeling Good About Yourself
5. Making the Most of Today – Daily Readings for Young People on Self Awareness, Creativity
   & Self-Esteem - ISBN0-915793-33-4
6. Two Weeks with the Queen – Twelve year old Colin finds it hard to accept that his brother
   is terminally ill. A new friend helps him to express his feelings of grief.
   Morris Gleitzman  -  ISBN-0141-303-00X
7. See Ya Simon – Nathan recounts the final year he spends with his best friend and how
   they made the best of it.
   David Hill  -  ISBN 014 036 3815
8. The Charlie Barber Treatment  -  Fifteen year old Simon initially clams up but is finally
   able to express his grief after his mother’s death.
9. I Never Told Her I Loved Her – Frankie finds it difficult to cope after her mother’s death
   and focuses on all the hard times and quarrels. Talking to her Dad eventually enables her
   to think about her future.
   S. Chick – ISBN 070  434 9477
10. The Grieving Teen - Written for and about teenagers in a wide range of grieving situations.
   Guidance and explanations are offered.
   Helen Fitzgerald – ISBN 0-684-86804-0
11. A Teenage Guide to Coping with Bereavement – Practical advice and guidance from a
   teenager who has had to cope with her confusing emotions after
   a loved one dies.

Books and information available from:

The Child Bereavement Trust  
www.childbereavement.org.uk

Winston's Wish  
www.winstonswish.org.uk

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

Cruse Bereavement Care  
www.crusebereavementcare.org.uk
Foreword

A special thanks to the staff at the Royal Marsden Hospital, the parents, and the schools who worked together to produce this excellent resource for teachers. We are proud to be able to fund such a worthwhile project.

Cerebra

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Returning to school