

Back to school for students with cancer



GUIDELINES FOR TEACHERS



www.childcancer.org.nz

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Back to School / Early Childhood Centre (ECC)

School / Early Childhood Centre (ECC) encourages the learning and intellectual growth necessary for adult life. School/ECC is also the major source of social contact for a young person.

Because of advances in the medical treatment of childhood cancers we are more concerned than ever about the quality of life for survivors of childhood cancer.

As a result the young person's adjustment to school/ECC and their academic advancement are primary concerns.

Any early return to school/ECC following diagnosis is a critical step in the rehabilitation process. Returning to school/ECC as soon as possible allows the young person to stay connected to a normal life and contributes to his/her sense of well being.

Being at school/ECC provides tangible evidence to the young person, family and classmates, that a diagnosis of cancer does not have to mean the end of a normal life.

For all these reasons young people on treatment for cancer are encouraged to attend school/ECC as soon as possible following diagnosis.

The Child Cancer Foundation hopes this resource will provide some insight into the needs of families living with childhood cancer and some ideas to assist schools to meet the educational and social needs of these families.

The bibliography provides information for further resources and the Child Cancer Foundation contact details are listed.

The health professionals at your nearest Paediatric Oncology treatment centre can also provide information and guidance.



1. Where are Children with Cancer Treated in New Zealand?

There are two major specialist child cancer service providers with shared care arrangements with other DHB's they are:

- Starship Children's Hospital at Auckland DHB
- Christchurch Hospital at Canterbury DHB

In New Zealand teenagers are treated either in paediatric or adult oncology departments.

The people the child will see most of at the treatment centre are:

- Doctor/s
- Nurse/s
- Teacher
- Play Specialist
- Social Worker



2. About Childhood Cancer

Childhood Cancer is more rare than adult cancer. In New Zealand approximately 150 children under the age of 15 are diagnosed each year with one of the childhood cancers.

It is estimated that today, one in 640 young adults in New Zealand is a survivor of childhood cancer.

The cause of most childhood cancer is unknown.

Hypothesized causes include viral agents, genetic factors, and exposure to environmental toxins.

However cancer is not infectious.

The most common childhood cancers are the leukaemias, followed by central nervous system (CNS) tumours, lymphomas, neuroblastomas, soft tissue tumours, Wilms tumours, bone tumours and eye tumours.

With advances in treatment, today more than 80%-85% of children with leukaemia and more than 75% of all children with cancer will survive five years or longer, and many will be cured.

THE LEUKAEMIAS

Acute Lymphoblastic Leukaemia (ALL)

ALL is a cancer of the blood producing tissue, originating in the bone marrow. The bone marrow begins to produce lymphoblasts (malignant cells) which often appear in the bloodstream. This results in a reduction in the normal blood cells.

Treatment for ALL is designed to return the blood picture to normal by destroying all of the cancer cells.

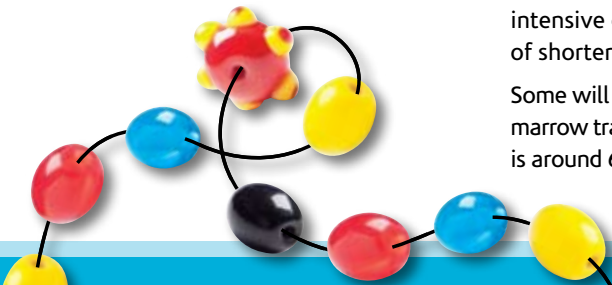
This usually involves a two-to-three year treatment plan of either combination chemotherapy and cranial irradiation, or chemotherapy alone.

The overall prognosis for children with ALL is good (80%-85% long term survival).

Acute Non Lymphoblastic Leukaemia (ANLL) or Acute Myeloid Leukaemia (AML)

ANLL includes a group of other forms of leukaemia which occur much less often than ALL. Treatment involves intensive combination chemotherapy of shorter duration than ALL therapy.

Some will also be considered for bone marrow transplantation. Overall prognosis is around 60% long term survival.



2. About Childhood Cancer continued...

BRAIN TUMOURS

Brain tumours are the most frequent solid tumours occurring in children.

Treatment may involve surgical removal of the entire tumour if possible and may also include radiation therapy and/or chemotherapy. Prognosis is dependent upon a variety of factors such as the type, location and size of the tumour.

It should be noted however that both patients and tumours tend to defy generalisation. Each progresses and reacts differently. There is still much to be learned about the treatment and prognosis of brain tumours.

The most common childhood brain tumours are briefly described below:

Medulloblastoma

A rapidly growing malignant tumour commonly occurring in the cerebellum (a region of the brain).

Treatment consists of surgical removal of as much of the tumour as possible followed by radiation of the brain and spinal cord. Most patients receive chemotherapy as well.

Astrocytoma

A tumour of the supportive (glial) tissue of the brain. It may be malignant or benign and graded I through IV.

The benign astrocytoma (grades I or II) is a slow growing tumour which may be encapsulated in a cyst. In these cases, if the location is favourable, total surgical removal may be possible, and curative.

Malignant forms of this tumour are generally treated by surgical removal followed by radiation and sometimes chemotherapy.

Glioblastoma Multiforme (GBM)

This is a grade IV astrocytoma which is the most difficult to treat because of the many cell types comprising it.

Surgery alone rarely controls GBM, because cells of the tumour frequently stray throughout the brain. Radiation therapy is almost always used following surgery, and sometimes in conjunction with aggressive chemotherapy to control new tumour growth.

Ependymoma

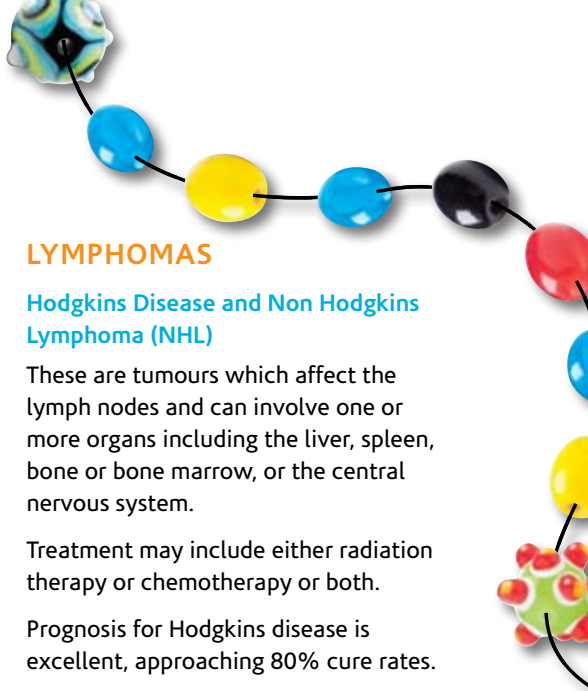
This childhood tumour may be benign or malignant, and is usually slow growing. Often these tumours cannot be totally removed by surgery because of their position in the brain. Treatment usually involves radiation and a cerebro spinal fluid shunt procedure to relieve the increased intracranial pressure that frequently accompanies this tumour. Chemotherapy may also be administered.

Craniopharyngioma

This is a benign congenital cystic tumour which involves the optic nerve and pituitary gland.

Surgery is the usual treatment for this tumour, and it may be completely removed if in a favourable location.

Radiation may be used if the tumour is not completely removed.



OTHER TUMOURS

Sarcomas

The various forms of this tumour occur throughout the body.

Osteogenic sarcoma generally shows up in the leg bones.

Ewings sarcoma develops in the spine, ribs, or pelvis.

Rhabdomyosarcoma affects muscle tissue, and usually develops in the head, neck or genital area.

Treatment usually involves a combination of surgery, radiation and chemotherapy.

Prognosis depends, as in other tumours, on the type, size and location of the tumour at diagnosis and whether it has spread to other tissues and organs (like the lungs and liver).

Wilms Tumour

These tumours develop in the kidneys, and are most often diagnosed in children between one and five years of age.

Treatment involves a combination of surgery and chemotherapy and for some radiation, dependent on stage.

Prognosis has improved dramatically over the past 20 years, and with modern treatment virtually all children with Wilms Tumour can be cured.

LYMPHOMAS

Hodgkins Disease and Non Hodgkins Lymphoma (NHL)

These are tumours which affect the lymph nodes and can involve one or more organs including the liver, spleen, bone or bone marrow, or the central nervous system.

Treatment may include either radiation therapy or chemotherapy or both.

Prognosis for Hodgkins disease is excellent, approaching 80% cure rates.

Prognosis for NHL is determined by stage of disease at diagnosis and the types of cells involved, but cure rates are still quite high.

Neuroblastomas

These are tumours of the sympathetic nerve tissue, and generally occur in the abdomen, chest, neck, or pelvic area. Treatment may involve a combination of surgery, radiation and chemotherapy. Some will require more intensive therapy such as a bone marrow or stem cell transplant. Prognosis is determined by stage of the disease, location, and age at diagnosis.

Most neuroblastomas are present in children below the age of three.

The younger the child, the better the outlook.

3. Treatment Modalities

Treatment takes various forms depending on the type of cancer and how extensively it has progressed at diagnosis. Regardless of the type of cancer, young people will receive either chemotherapy, surgery, radiation, or a combination of any of these for the purpose of destroying the cancer cells.

SURGERY

Surgery involves the actual removal of the tumour. Surgery is used when the risk of harming other vital organs is minimal or non-existent. In the case of brain tumours the neurosurgeons are very careful not to remove any part of the brain that will impair function. The option of surgery is determined by the size of the tumour, its proximity to vital organs and the potential danger for removal.

Osteosarcoma, affects the long bones of the body (most often the leg). Following chemotherapy to shrink the tumour, surgery will be performed to remove the area of disease. This usually involves a procedure called limb preservation surgery, where artificial material or a bone graft is used to replace the cancerous part. The aim is that function of the limb can be preserved. Very occasionally an amputation is performed.

RADIATION

Radiation involves using high powered radioactive particles to destroy cancer cells. Radiation may be directed at a specific tumour or may be used as a preventative measure in areas of high risk for disease spread such as the central nervous system in the case of some patients with leukaemia. Radiation therapy involves daily treatments over a period of weeks and is usually done on an outpatient basis.





CHEMOTHERAPY

Chemotherapy involves the administration of different types of drugs to destroy cancer cells. Drugs are administered in the form of pills and/or by injection through a major vein. Chemotherapy can also be administered into the spinal fluid during a lumbar puncture. Depending on the particular treatment regimen, chemotherapy may be done on an inpatient or outpatient basis. Treatment may be once per week or for several days every three or four weeks.

In addition to intravenous chemotherapy, many young people receive fluids containing nutrients, antibiotics, or blood transfusions intravenously over the course of treatment. Children's veins are small and accessing them can be difficult. Many young people now have a central venous access device – either a PORT-A-CATH or a HICKMAN LINE to simplify venous access. More information on this is available in the medical considerations section.

STEM CELL TRANSPLANTATION

A Stem Cell Transplant (SCT) is another form of therapy that is used to treat young people who suffer from a variety of blood disorders and/or cancers.

Healthy stem cells are collected (either from bone marrow peripheral blood or cord blood) from the patient while in remission, a brother or sister or an eligible donor (usually identified from International stem cell registries).

Intensive chemotherapy with or without radiotherapy is given to destroy all cancer cells within the patient. The healthy stem cells are then infused.

For a period of weeks following the SCT, the risk of infection for the patient is very high. For this reason the patient must remain in isolation for this period and will require a great deal of physical and emotional support and encouragement.

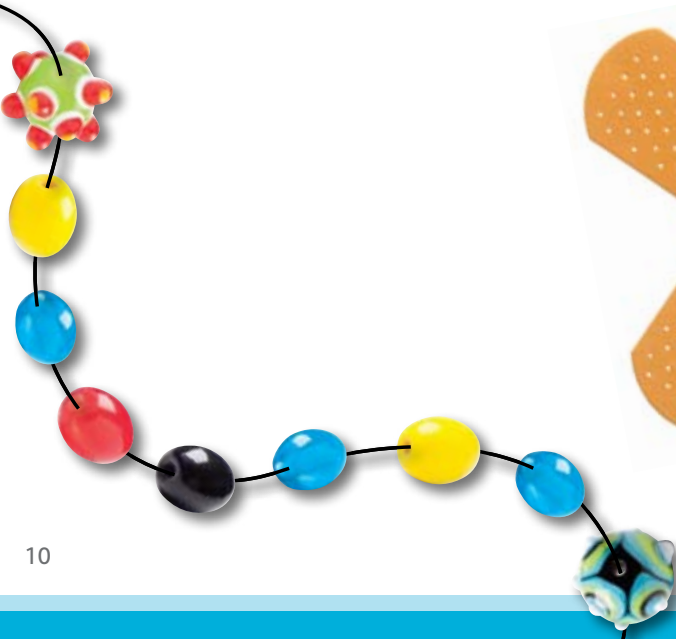
4. Side Effects of Cancer Treatment

Cancer treatment can cause nausea, vomiting and fatigue. Other changes can include hair loss, weight gain or loss, a puffy face, mood shifts, bruises, poor concentration, coordination problems and muscle weakness.

Some young people must also contend with limb salvage procedures, scars and other permanent physical changes. Young people receiving radiation may have ink marks on their body during treatment. It should be noted that a young person's response to treatment is individual, and that each one will experience side effects to a different degree.

Many side effects (e.g. nausea, vomiting and fatigue) are well managed by a combination of medications and should not seriously impair daily living.

If a student in your classroom appears to be experiencing side effects which interfere unduly with normal participation, the parents or staff at the treatment centre should be notified.



5. Coping with Childhood Cancer

Children's responses to a diagnosis of cancer can be as diverse as the young person and their families are.

THE CHILD

Generally, children respond to cancer treatment like normal children responding to a very difficult situation.

The specific responses of individual children depend on variables such as age, place in the family, pre-illness behaviour patterns, intellectual capabilities, family relationships and communication style, social and emotional support etc.

The young person with cancer will benefit from talking with teachers, parents and hospital staff, in preparation for returning to school/ECC.

He or she will cope far better knowing what to expect and how to respond.

While on treatment the physical changes resulting from the disease and its treatment can cause a reluctance to return to school/ECC because of fears of teasing and rejection.

The child with cancer must also deal with the difficult emotional experience of facing the implications of a life threatening illness.

Children with cancer may try to cope by withdrawing, regressing or by "acting out".

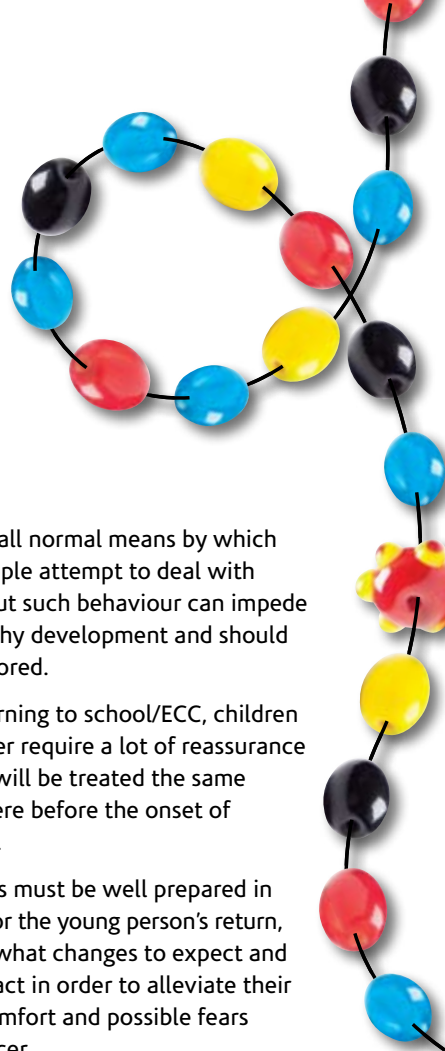
These are all normal means by which young people attempt to deal with distress, but such behaviour can impede their healthy development and should not be ignored.

Upon returning to school/ECC, children with cancer require a lot of reassurance that they will be treated the same as they were before the onset of the illness.

Classmates must be well prepared in advance for the young person's return, including what changes to expect and how to react in order to alleviate their own discomfort and possible fears about cancer.

Suggestions for preparing classmates are included in **Section 6**.

For some families, the transition to school/ECC can be difficult. Parents worry about their child's increased vulnerability to infection and fatigue. As well, there is often concern over the reaction other people will have to the obvious side effects such as hair loss, weight gain, etc.



5. Coping with Childhood Cancer continued...

BROTHERS AND SISTERS

Brothers and sisters of cancer patients can have a difficult time as well. They may experience feelings of guilt, rejection, fear, depression, or anxiety.

They may react by developing problems (academic or behavioural) or physical symptoms such as stomach pain or headaches.

As with the child with cancer, it is important to note that, although these reactions are “normal” they can impede a student’s progress and efforts should be made to help them cope in a less negative or harmful way.

BELOW IS A LIST OF COMMON REACTIONS AND PROBLEMS WHICH BROTHERS AND SISTERS MAY DISPLAY:

Worrying about their sick sibling –

The entire family will be devastated by a diagnosis of cancer and brothers and sisters often get information about their sick sibling second or third hand, from grandparents or other relatives who are caring for them while parents are at the hospital. This limits the quality and quantity of their information and often leads to misconceptions about the nature of the illness and the treatments.

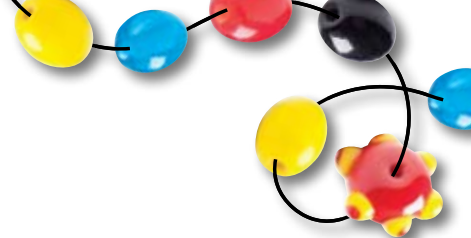
Feeling sad – Diagnosis of cancer within the family is an extremely stressful event that changes the nature of the family. Children often mirror the level of anxiety shown by other family members, including parents. Peers may need more information to understand what their friends are going through.

Feeling guilty – Some children will feel that they should have been the one to get sick, or that they somehow caused the illness. Open discussion can often alleviate misconceptions.

Feeling jealous and left out – The cancer patient gets a lot of attention from the family, community and hospital staff. Parents often have to leave other children at home or with friends/relatives while they care for the sick child. Treatment days become “special” outings for the parent and the cancer patient. School/ECC can help brothers and sisters by making them feel important too. A little extra can go a long way.

Feeling angry – As treatment progresses and the cancer patient looks and acts “healthy”, brothers and sisters can resent the continued attention given to the patient. Parents often complain of behavioural problems with siblings as treatment continues.

Worrying about what is going on at the hospital – Often inattention in class may be a result of preoccupation with what is going on at the hospital. On a “bad” treatment day the cancer patient may come home quite ill and/or the parent could be quite upset. If blood counts are low, there is always the possibility the patient will stay in hospital and the parent may not be home. Also, if the patient is sick in hospital, brothers and sisters often admit to worrying about the possibility of death.



Worrying that other family members (particularly parents) might get cancer – Despite the availability to the community of accurate information and educational resources regarding cancer, a surprising number of misconceptions still exist. Cancer is not contagious and does not necessarily end in death.

In fact many childhood cancer patients are given excellent prognoses. Also the likelihood that other family members will suffer from cancer is low.

Missing parents – Caring for a sick child takes time and energy, whether they are at home or in hospital. Unfortunately this means that well brothers and sisters often have to “make do” until the “crisis” is over.

This may mean lack of emotional support or no one to help with homework etc. As treatment for childhood cancer may continue for up to two to three years it can have a major effect on the siblings.

Worrying about parents – It is difficult to see anyone that you love upset by something that no one can control. Often older brothers and sisters feel the need to support parents during the “crisis” times, or simply feel “alone” because they don’t want to worry their parents. They often feel pressure to be good all the time or to take on much more household responsibility than is normal for their age. As a result of their parent’s energy being taken up by the sick child, siblings may have to rely on friends and teachers for support.



5. Coping with Childhood Cancer continued...

PARENTS

When talking with parents, usually a direct approach is best. Most parents want teachers to ask about their child and the disease and are willing to supply information.

If they are angry or sad (even to the point of tears), remember these feelings are not necessarily caused by, nor directed to you.

If parents are depressed, hostile, or overly anxious, a united approach by school/ECC and health professionals can be reassuring to parents which in turn will help encourage the young person's attendance at school.

TEACHERS

Planning for the student's return to class may cause you to address your feelings about life threatening illness. You might find it helpful to share your concerns with a doctor, social worker or nurse from the student's treatment centre. Your own school may have a school nurse, student counsellor or a visiting Public Health nurse, who can provide assistance. There may also be colleagues who have experiences they can share with you.

A bibliography is provided at the back of this book.

No matter how prepared you are, having a student with cancer in the class can be emotionally demanding and time consuming.

There may be times when you feel unequal to the task or depressed about your student's situation. It may help to know that health professionals who work with young patients are also vulnerable to these emotions and rely on each other and outside sources for support.

Remember that you are part of a team which includes parents, treatment centre staff, other medical personnel and other school/ECC staff members. Whether working through your own feelings, looking for advice, or sharing loss, support and guidance should be available from the other members of the team.





MISSING SCHOOL /ECC

There are many reasons why a young person with cancer will miss school.

Depending on the treatment protocol, they may need to be absent for as much as one or two days per week.

Due to the effects the treatment may have on the immune system, children on treatment are more susceptible to developing fevers and infections. Sometimes they may need to be admitted to hospital for a period of time to receive the antibiotics to help them fight the infections.

Some parents fear the risk of infection and become over protective or over indulgent as a result.

Social isolation and teasing have been reported to produce separation anxiety and school phobia in some children.

Children and parents need to be reassured that school/ECC is a safe and supportive place to be.

By being understanding and making parents aware that you understand their concerns regarding the above issues, you will be providing them with confidence and reinforcement of their efforts to come to grips with the diagnosis and the disease.

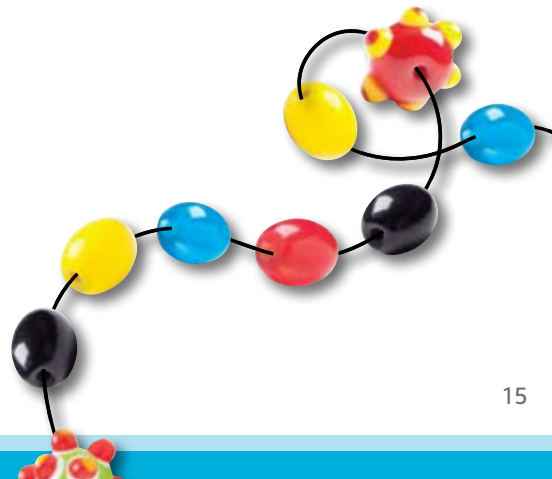
They need to know, as well, what the school is able to provide in the area of tutoring, extra help, etc to enable the student to catch up on work missed.

Parents and the student may worry about what happens if a child has missed a lot of school and is well behind the class at the end of the academic year.

Obviously, it is very hard to fail a student who has cancer. Feelings like “The poor child and family have been through so much already” are likely to surface for school teachers. Keep in mind that the majority of young people do survive cancer for many years.

When they become well and are functioning normally they may find themselves really disadvantaged if their progress has not been measured appropriately.

Although there is no sure, fast rule regarding such cases, it is important that school staff consult with parents and perhaps the health care team when faced with difficult decisions regarding academic performance and planning.



6. Planning a Return to School / ECC

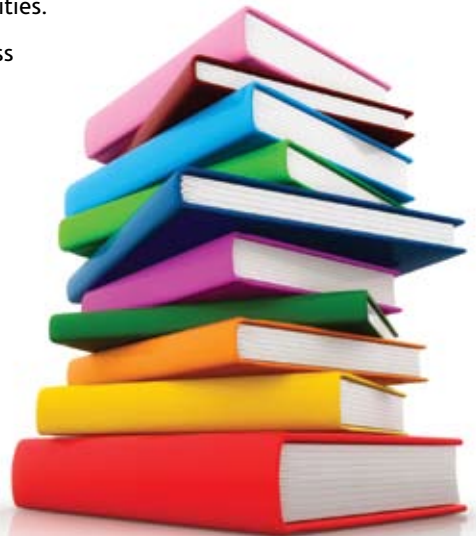
WHAT QUESTIONS TO ASK?

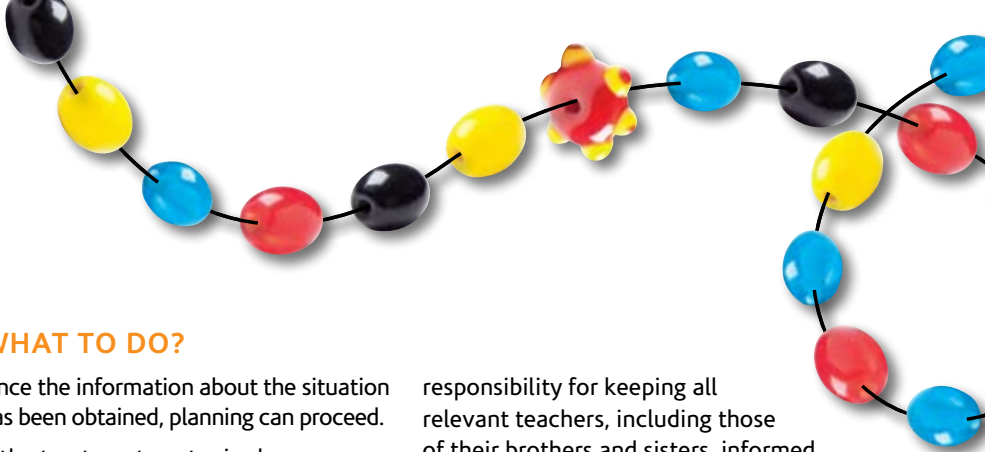
The second step in planning for the student's return is to gather information about his / her situation.

The child's parents should have all the information you need regarding the specific type of cancer and how it is being treated. Further information can be obtained from the hospital treatment centre.

It will be helpful for you to know:

- How treatment is administered, what potential side effects there are and the likely impact on appearance and behaviour.
- An approximate schedule of upcoming treatment, procedures or tests which may result in the student's absence from school.
- Limitations, if any, on the student's activities.
- What the student knows about the illness (although current policy is to be honest with young people who have cancer, there are exceptions).
- For younger children, what the family would like classmates and school/ECC staff members to know.
- For teenagers, whether the student wishes to talk directly with teachers about any of the above points.





WHAT TO DO?

Once the information about the situation has been obtained, planning can proceed.

If the treatment centre is close, doctors, nurses, social workers or Child Cancer Family Support workers along with school / ECC personnel, and parents should meet.

It is important to understand the family's right to confidentiality, so only enough information needs to be shared to allow the child to fit in to school/ECC.

Permission for any meetings must be sought from the family at the outset, in order to allow these partnerships to proceed and be maintained.

If including caregivers is not possible, a consistent approach should be developed by identifying one key person from your school to liaise with the family. The liaison person should have the time and be willing to assume

responsibility for keeping all relevant teachers, including those of their brothers and sisters, informed.

This is especially important for intermediate and secondary school students who come in daily contact with several teachers, all of whom should have accurate information on the student's condition.

Another means of ensuring good communication is to arrange a meeting at the beginning of each term between a member of the student's medical team, school/ECC staff and the parents. The liaison person will need to ensure any special needs are provided; for example, transport or a place to rest, wearing of non-uniform clothing such as a hat or footwear, time out to eat a snack or just be alone by themselves for a while.

THE CLASSROOM

Students with cancer should be accepted for who they are; children or young people with a life threatening disease who require periodic treatment.

If the cancer is ignored, a major part of that person's life is overlooked.

On the other hand, if the cancer is made the overwhelming concern, the other important aspects of the child or young person's life may be neglected.

Some concessions will be necessary, of course, but a balance must be struck between what students can reasonably do and what they must do for their own self image.

Like their peers, children with cancer need love, support, and understanding.

They should not be overprotected, rather apply the same limits on behaviour as their classmates.

6. Planning a Return to School / ECC continued...

Teachers should discipline, and hold reasonable academic expectations for the student with cancer. Doing less will rob them of their pride in learning and accomplishment and will prevent camaraderie with their peers.

Obvious special treatment will create resentment among classmates and can be devastating to the student with cancer. For example, assignment deadlines may need to be adjusted to accommodate a student's treatment schedule.

However, the completed work should be evaluated by the same criteria used for the rest of the class.

Teachers who become aware of any new learning or behavioural problems (peer fighting, hostility, irritability) should draw this to the attention of the person acting as liaison between the school, family and treatment centre.

Cancer treatment, especially cranial irradiation, has, in some children, been associated with problems in attention and concentration, performance under pressure, visual and auditory memory, and mathematical skills. This coupled with disruptions in school attendance may impact on educational achievement, see section 10: Late Effects of Treatment.

It is also important for the student with cancer to feel a part of their class, even if absences for medical reasons preclude full-time attendance. It may be helpful to send assignments to them at home or to the hospital.

Other approaches, including attending school for part of the day or arranging for extra tuition, can be used, depending on the school situation.

CLASSMATES

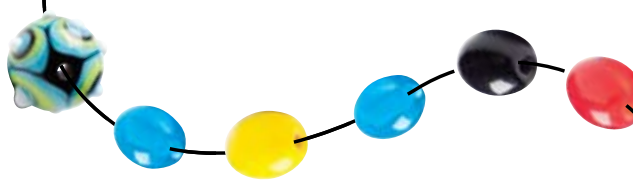
Open discussion about childhood cancer, treatment, and side effects with classmates helps to foster understanding and acceptance of the student with cancer.

It may be useful to do this in the total context of health care and chronic illness and disabilities.

The first step is to consult with the parents, (depending on the child's age) to ensure they are happy with the resources available, and your aims for the discussion. (Some children newly diagnosed with cancer may not want too much attention focused on the subject initially.)

A well planned discussion will be an excellent opportunity to reassure classmates that cancer is a serious but treatable disease, that it is not hopeless or too terrible to mention, and most importantly that it is not infectious.





Information should be geared to the students' level of understanding and aimed at minimizing perceived "differentness" in the student with cancer.

It is important to be aware that each student will have his/her own individual issues and fantasies regarding cancer. To some it may be linked to an unpleasant memory about the death of a grandparent or some other significant person or even a pet.

Therefore, it is of the utmost importance that teachers encourage students to talk about their experiences with cancer and educators have found it useful to conduct such discussions in the classroom setting. Obviously, the discussions will vary according to the student's developmental levels.



Some guidelines are suggested below:

- 1. Begin by asking the class how they like to be treated when they are ill or how they feel when around someone who is sick. Use their answers as the basis for discussing how classmates might treat their school friend with cancer.*
- 2. With the parent's permission explain to the class the type of cancer their friend has, the kind of treatment he/she is having and the ways the treatment may affect his/her appearance and behaviour. This is particularly useful in dealing with embarrassing side effects such as temporary weight gain and hair loss. Classmates who know these changes come about because of life saving therapy are less likely to tease and may even defend their friend against ill-considered remarks of others. It is also important to reassure classmates that they cannot 'catch' cancer and emphasise that the cause of cancers in children and young people is unknown.*
- 3. For older students a health or science project for the study of cancer will be useful. Assign groups to develop research reports on types of cancer, their treatment, and side effects, ensuring the source material is up to date. Reporting back to the class will increase their basic knowledge of cancer as well as their classmate's disease.*
- 4. Through the child's parents - invite staff from the treatment centre or a Child Cancer Foundation Family Support Coordinator, to make a presentation to the class. This approach should be a supplement, rather than a substitute, for class discussion led by the teacher. In the case of prolonged absence from school, continued communication with the class will provide the student with cancer with an important link to his/her "regular" life.*

6. Planning a Return to School / ECC continued...

THREE MAIN THINGS MAY BE DONE:

1. Social contact

The class could prepare “happy packages” at very little cost, which will bring more joy to a sick child than an expensive floral bouquet. Some ideas are:

- notices about class/school events
- a small souvenir from a school trip
- a large card with contributions from everyone
- a newspaper clipping about school events
- the current best classroom jokes
- the words of the current “top of the pops”
- a picture of a favourite person cut from a magazine
- a video the class has enjoyed

The child’s best friend will know what could be of most interest.

If the school has access to a DVD or video recorder, skyping or social networking sites, class news items can be recorded and sent to the child who may then be able to send a message back to the class. The hospital school also has email access and contact with the child can be done via this means as well.

2. Visiting

Children and young people often like to visit sick friends, but it can be overwhelming if too many arrive at once, so spread the visits.

Encourage classmates to contact the family to arrange visiting rosters and to make sure visiting is allowed and appreciated. This will provide very important social contact for the sick person.

“knock knock...”

Ed tis... Incipisuci blam...
Ignit, sit et lobore esecite veros nim nulla adipisuci te facit,
euismod tiumum zzril dolore modo comny non hendre mag

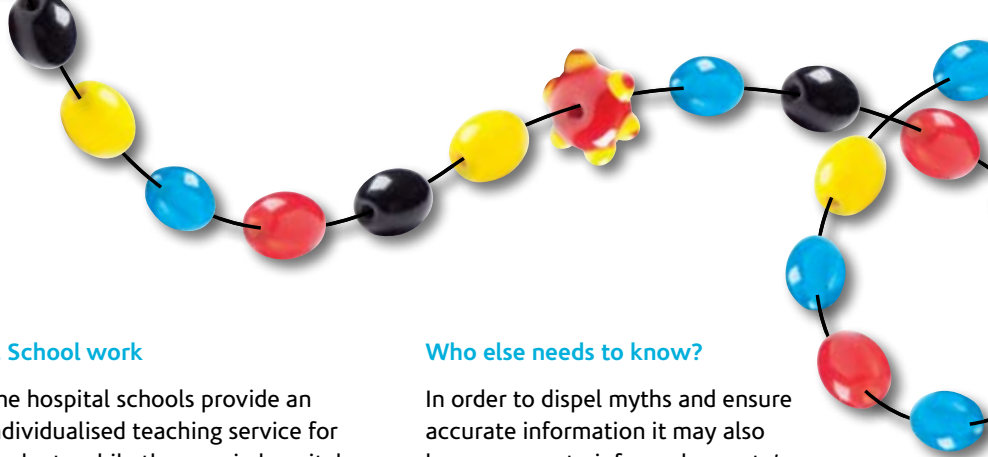
Cupcakes reign supreme at this years annual school baking competition

Bethany Smith was the overall winner of the annual baking competition this year. Her winning cupcakes were sampled by the judges and just beat out runners up Johnathon Blake and Jeremy White.

Thanks to all those who entered and all proceeds were donated to the Child Cancer Foundation.

Ed tis... dit am
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3. School work

The hospital schools provide an individualised teaching service for students while they are in hospital and during convalescence when the student is unable to attend school for extended periods.

They also help transition students back to school.

The teachers will make contact with the school when the student is first admitted to hospital to co-ordinate the student's educational programme. This may include providing a programme through The Correspondence School.

The schools can be contacted on:

Northern Health School, Auckland
0800 153 002 or (09) 520 3531

**Central Regional Health School,
Wellington** 0800 153 000 or
(04) 380 2009

**Southern Regional Health School,
Christchurch** (03) 366 6739

Who else needs to know?

In order to dispel myths and ensure accurate information it may also be necessary to inform classmate's parents of the diagnosis.

Again the family of the student with cancer must be consulted first, then the information conveyed in a simple letter such as the example shown on page 27.

If teasing occurs, find out if classmates feel the student is receiving unfair attention, pampering, or special consideration above what may be really necessary, or if perhaps students are frightened and putting distance between themselves and the patient as a defence?

Are they normally aggressive?

Through stories, discussion and role play you can help teasers understand their own motives and discover better ways to cope with the situation and the feelings which give rise to the teasing.

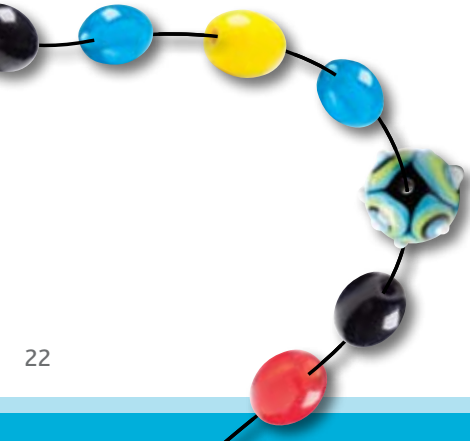
"...who's there?"

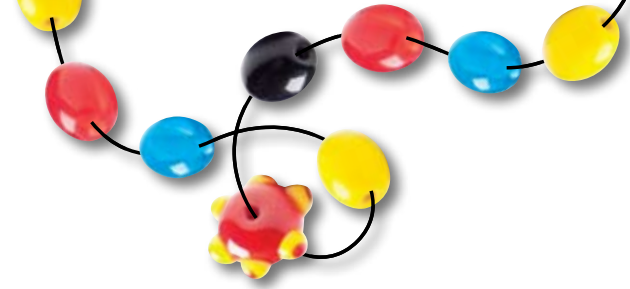


7. Special Concerns of Intermediate and High School Students

The needs and experiences of teenagers with cancer differ from those of younger children. The normal process of development for the adolescent is put at risk by virtue of their time in hospital receiving treatment - their lack of peer contact, long term removal from school, the physical changes they experience and the debilitating nature of their treatment.

These different needs reflect the developmental issues facing adolescents, for example, independence, peer acceptance, body image, and self worth, as well as the mechanics of intermediate and secondary schools as opposed to primary schools.





Having cancer often interferes with the young person's attempts to achieve independence from parents and other adults.

The illness and treatment may involve limitation of activities and temporarily place the young person in the position of being cared for like a younger child.

Since parents fear losing their daughter or son to cancer they may tighten their control even more, leading to inevitable conflict.

If you notice or suspect this situation with your student, counselling by trained professionals may help open the lines of communication.

Once the dynamics of the situation are understood by parents, counsellors can assist all concerned to allow the student more freedom of choice in his or her school and home life.

At a time when peer pressure assumes vital importance, the teenager with cancer is quickly classified as 'different' both by the fact of the illness and by the visible manifestations of treatment, such as hair loss or weight gain.

Also, certain types of cancer (such as bone cancer Osteosarcoma or Ewings Sarcoma) are more common among teenagers than younger children and treatment results in obvious body changes.

Physical limitations can interfere with participation in sport and other school activities, creating a sense of isolation.

Teasing or rejection by peers can result in varying degrees of withdrawal from extracurricular activities, or even from school. You can help by encouraging participation where possible, in social activities that foster peer acceptance and keeping alert for signs of conflict.

The student may already have made contact with CanTeen (A peer support group supporting young people living with cancer or a life threatening blood disorder, and their teenage siblings). See page 35 for details.

Simple solutions may not always be easily apparent or even workable. If, for example, the student was a 'loner' before diagnosis, the task of encouraging acceptance by classmates becomes very difficult.

The size and complexity of the school may also influence the student's ability to re-enter school successfully. Where the primary student has only one or a few teachers, secondary students must deal with many teachers and many may have no information about the illness and treatment.

While immediate classmates may be understanding and supportive, other students will be unaware of the illness.

7. Special Concerns of Intermediate and High School Students continued...

Policies necessary for the operation of a large school can create problems for the young person if communication is poor and special arrangements are not made. For instance, rules against wearing caps or scarves in class may create embarrassment for the student without hair.

Schedule changes, necessary for medical care, can sometimes be difficult to arrange.

The larger classes and greater number of teachers may make it more difficult for the young person to maintain contact with the school during periods of extended absence. This may lead to a reluctance on the student's part to return to school when well again, for fear of social awkwardness and difficulty in "catching up."

For students with physical problems (weakness, impaired coordination, or limb salvage), the size and structure of the school building may pose problems in carrying books/heavy bags from class to class and arriving at classes on time.

Part of the solution to many of these problems is communication.

As previously mentioned, one person in the school should be made responsible for making contact with the student's parents and for disseminating

information to all teachers involved with the student.

Ongoing contact between parents/medical staff, school representative, and other staff members is essential throughout the year, especially at the beginning of terms and when the student's medical condition changes, e.g. complications from treatment, relapse, or secondary illness.

A single individual who has rapport with the young person should meet frequently with her or him to discuss the student's academic progress and social interaction.


Other teachers should be made aware that this individual is the "trouble shooter" to whom problems concerning the young person should be referred.

Working on positive thinking skills and goal setting is also very necessary for teenagers with cancer. We recommend involvement from school guidance counsellors from the very beginning.

However, it may not be a totally negative experience for these young people.

They may gain useful coping skills for their adult life and an increased zest for life. Personal growth can and does come out of surviving a life-threatening experience.

7a. Special Concerns for Children Returning to Early Childhood Centres



Children returning to early childhood centres face the same potential difficulties as those returning to school. However, compared to primary and secondary schools, centres are smaller and less complex. With a higher ratio of teacher to child and fewer organisational constraints during the day, teachers in early childhood centres may be more aware of the relationships among the children.

In hospital, children may have become accustomed to interacting with many adults and few children and they will need support from the early childhood teachers. Employing inclusive strategies to support the returning child in both large and small groups and encouraging the child's inclusion in conversations and in small groups of children will be valuable. It is important to be aware of the needs of the child who avoids attention and plays unobtrusively as well as a child with a more outgoing disposition. However, teachers have reported that typically, children experience less teasing and embarrassment than in school.

Establishing a medical play area in the centre will provide the child with the opportunity to play through their experiences of illness and treatment. This can allow the child to further develop their understanding and express their emotions about the changes to

his world. Sensitivity will be needed to allow the child time and privacy if they wish to talk about or play their experiences while protecting the other children from possible intensity.

Outdoor play and physical activities may require close supervision initially as children regain their confidence. It is here, that teachers may notice fatigue.

Most early childhood centres are easily accessible to parents and they are encouraged to spend time with their child, easing separation concerns. Although parents may discuss the child's condition and any other concerns they have, with the teachers and/or other parents, their rights to privacy must be respected and given their child's vulnerability, they need early advice about any infection risks. Maintaining contact with the child and family when the child is absent is also important and will help the child to settle when he/she returns.

8. Medical Considerations and Concerns

You may have health related concerns about the young person with cancer. Some of the most common are:

ACTIVITIES

In general young people with cancer should be encouraged to undertake all activities suited to their age.

Most set a pace that is comfortable for them and do not have to be cautioned against over exertion. Do not assume what the patient can or cannot do.

Through your nominated school liaison person maintain contact with the parents.

INFECTIONS

No special precautions are necessary except with: Chickenpox, Shingles (Herpes zoster), English Measles.

Young people on chemotherapy are especially vulnerable to these diseases and measures to prevent serious complications must be taken within 96 hours (preferably 72 hours) of contact with the infection. Actual or suspected exposure to these three diseases must be immediately reported to the child's parents or the treatment centre.



A letter as outlined below is one way of ensuring that this information is passed on.

Dear Parent

A classmate of your son/daughter has recently been diagnosed with cancer. At the present time the child is back at school and doing well.

The purpose of this letter is twofold.

The first is to make you aware of his/her disease and reassure you that cancer is not contagious.

The second is to request that you please contact the principal (or school nurse or class teacher) if your child comes into contact with chickenpox or measles or develops them.

These illnesses can have serious implications for a person on treatment for cancer and we need to inform the parents so that appropriate action can be taken.

Please feel free to contact us with any questions or concerns.

Thank you for your help.

Yours sincerely
Principal

8. Medical considerations and concerns continued...

MEDICAL CRISES

It is rare for students with cancer to have a medical crisis in the classroom.

Ask the parents about potential medical problems.

Treat minor ailments just as you would for other students. However, if the problem persists seek medical attention.

HEALTH SCREENING

The student with cancer is subject to the same health concerns and maladies of any other young person. For example, vision and hearing tests are just as necessary on a routine basis.

COMMUNICABILITY OF CANCER

Cancer is not contagious.

In this respect consider your student as someone recovering from a broken bone rather than having a cold or flu.

MEDICATIONS AND IMMUNISATION

Students with cancer must not be given any medication without parental consent.

Even relatively “harmless” medications can cause problems: for example, paracetamol can mask a fever, which may be the only sign of an infection developing, and aspirin interferes with platelets in the blood which may lead to bleeding problems.

Routine immunisations must not be given without contacting the parents and/or the treatment centre.

Any student on chemotherapy should not receive any immunisation containing a live virus. To protect the child with cancer it is recommended that classmates/teachers are up-to-date with their immunisations (especially MMR, measles, mumps and rubella). In recent years children with cancer on treatment and their families have been encouraged to have annual influenza immunisations.

Always contact the parents, prior to the commencement of any immunisation programme, and alert the Public Health nurse administering the vaccine(s).





HICKMAN LINES AND PORTACATHS

A PORTACATH or port is a totally implanted device located just under the skin in the chest area. The catheter is tunnelled under the skin towards the neck where it enters a large vein. It is visible as a small raised area on the chest beneath the skin.

A port requires no home maintenance and does not interfere with a young person's day to day activities. The port is accessed during treatment by inserting a special needle through the skin into the silicon reservoir. The needle is then removed.

Contact sports such as rugby may be discouraged for young people with a portacath.

A HICKMAN LINE is a partially implanted venous access device located in the centre of the chest. Part of the catheter is tunnelled under the skin and travels towards the neck where it enters a main vein. The remaining part of the tubing exits through the skin, usually on the chest wall and requires a dressing.

The dressing must remain dry and in place. This reduces the student's ability to participate in water sports, contact sports or any other activity which could dislodge the line.

The child's parents will be very competent in the care of their child's line and should be called first if teachers suspect a problem with the line. Generally it will be hidden under the child's clothing and the teacher will have no need to be involved with it.

When the child first returns to school, have the child show it to you with the parent, who can point out the important features of it.

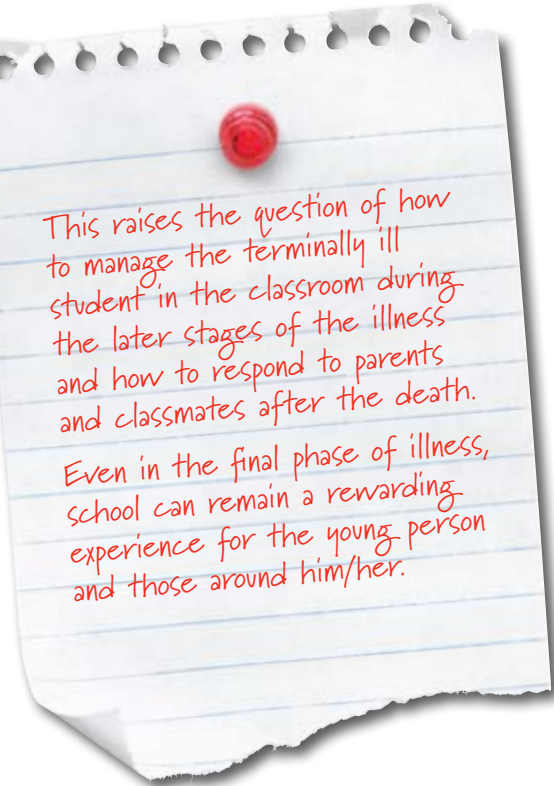
PROBLEMS THAT WOULD REQUIRE YOU TO CALL THE PARENTS INCLUDE:

- **the end plug coming off** - do not replace the one that has come off – simply put on a sterile sticking plaster and call the parents.
- **the line getting accidentally cut** - this needs urgent attention if it is below where the little clip is you will need to kink the line to stop blood coming out.
- **the line accidentally coming out** - apply pressure to the area and contact the parents.
- **if the clip comes undone** - re-clip it and let the parents know at the end of the day.

Whilst there have been very few incidences of these problems occurring at school, it is worth being aware of them and the appropriate action to take.

9. Terminal Illness

Despite improvements in survival rates for children and teenagers with cancer, in some patients the disease cannot be controlled and is ultimately fatal.



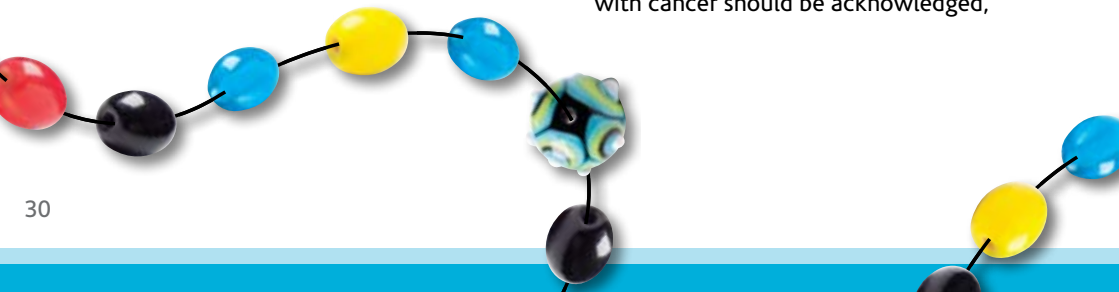
This raises the question of how to manage the terminally ill student in the classroom during the later stages of the illness and how to respond to parents and classmates after the death.

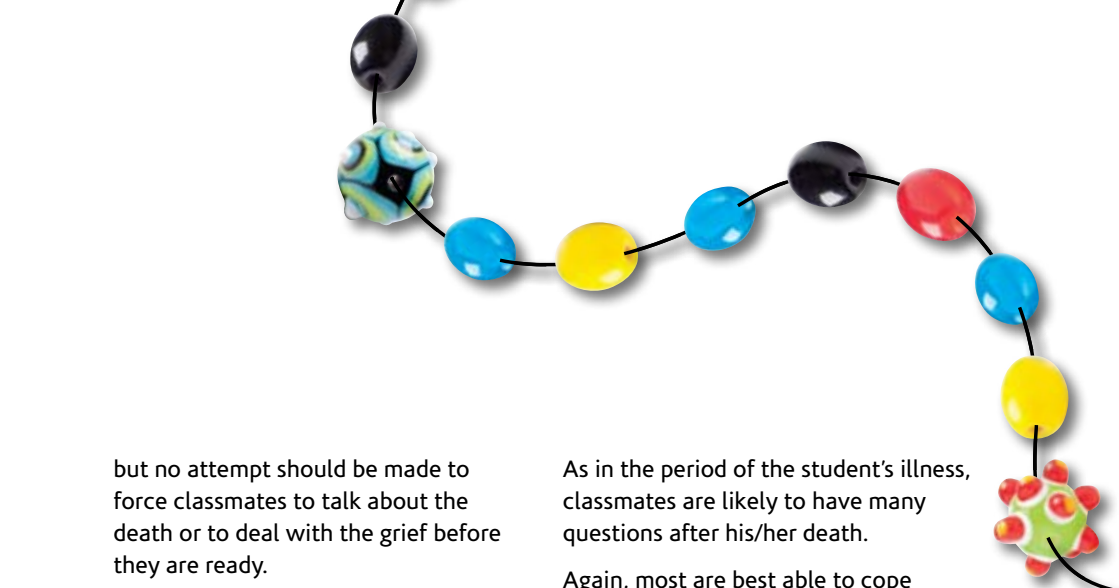
Even in the final phase of illness, school can remain a rewarding experience for the young person and those around him/her.

Often simple measures can help the student get the most from his/her remaining life. For example, those who become too fatigued to attend school for a full day will often benefit from half days or even an hour's attendance daily. As energy ebbs, assigned work should be adjusted accordingly. The young person who has lost a lot of weight may be uncomfortable sitting in a school desk chair, but may do quite well if allowed to bring a pillow or cushions to sit on.

When a student dies, classmates may express their grief in a bewildering variety of ways. Some are quite open, while others may appear almost indifferent to the loss of their classmate. Such responses are a normal variation in the gamut of young people's grief reactions. They may assimilate the information about a death gradually, as they become able to deal with the event and its implications.

Feelings of loss for the young person with cancer should be acknowledged,





but no attempt should be made to force classmates to talk about the death or to deal with the grief before they are ready.

Most young people do so in their own way and at their own pace, if they are allowed the space and not forced or hurried.

Attending the memorial service or funeral of the student is a way of helping classmates understand the meaning of death.

Even for very young children, especially if they have not seen their sick friend for some time, the service may help them realise that death is irreversible.

In addition, it provides an opportunity for saying a last goodbye and for expressing sorrow for the loss of a friend.

This is not to say every friend or classmate should attend the service. The decision to do so rests with each individual and with each student's parents. No young person should be forced to attend the funeral if he or she is reluctant.

As in the period of the student's illness, classmates are likely to have many questions after his/her death.

Again, most are best able to cope with this distressing event if they are given honest, simple, straightforward answers to their questions. Classmates may also want to create a memorial to their friend, such as a tree to be planted in the school grounds or some piece of equipment to be donated to the school.

Organising such a project and raising funds for it can be a valuable and therapeutic experience. In addition, the parents, brothers and sisters of the young person will usually be greatly comforted by the way in which others share their feelings of loss.

10. Late Effects of Treatment

Medical treatment of young people with cancer improves every year. More and more are surviving, progressing through school, and entering adulthood.

Parents, the medical team, teachers, and other educational professionals, need to be aware that there may be late effects of the medical treatment of childhood cancer and be ready to follow up with strategies to encourage the student in overcoming any learning disabilities.

Chemotherapy and radiotherapy will damage normal cells as well as cancerous ones – some children will recover all function completely but others may have problems.

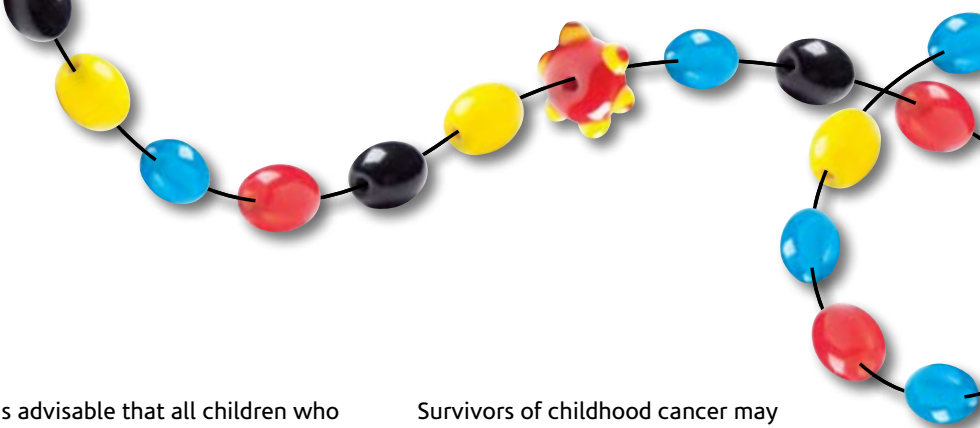
You may come across students who were treated for cancer as preschoolers or many years ago and it is important that schools are passing this knowledge on to subsequent learning institutions as the problems may not be apparent for many years.

Cranial irradiation, given for brain tumours and some high risk forms of leukaemia, carries an increased risk of learning problems. Some children have shown significant declines in IQ (10-20 points) and other academic achievement tests. Specific deficits that have been identified are in visual motor integration, memory, attention and motor skills. Nonverbal skills e.g. abstract reasoning, visual spatial skills and mathematics are especially vulnerable to cranial irradiation and intrathecal chemotherapy.

Some common learning difficulties may be expressed as problems with:

- *Reading (and comprehension)*
- *Spelling*
- *Handwriting (unable to write accurately or quickly)*
- *Mathematics with concepts requiring short-term memory such as “times tables”*
- *Attention span or concentration. Children may become hyperactive or inattentive*
- *Short term memory-storage of new information and retention of material*





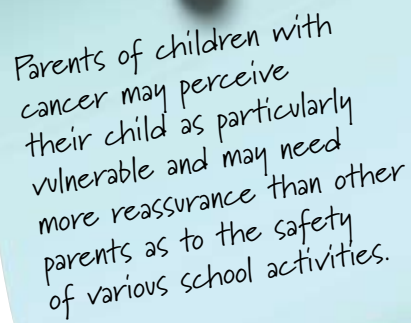
It is advisable that all children who have had these treatments have annual neuropsychological evaluations.

Often the learning deficits will increase over time but, with good assessment and appropriate intervention, the impact on learning can be minimised.

Other physical problems that may be long term side effects of treatment for childhood cancer include abnormal hormone function leading to growth retardation and early or late puberty, hearing damage, infertility, heart damage, lung problems, dental problems, kidney problems and eye problems. All of these will need monitoring and may need further treatment. It is important that if the school notices a problem this is communicated to the child's parents.

Survivors of childhood cancer may have an increased risk of having further malignancies - learning to live with the worry of disease recurrence and of developing another cancer is another burden for these children and their families.

Recent research has shown that survivors of childhood cancer are at substantially greater psychological risk than survivors of other chronic but non life-threatening illnesses. Siblings of children with cancer are also at increased risk of psychological problems. Being aware of this may alert you to any changes in behaviour. Again, early assessment and intervention may minimise these problems.



Parents of children with cancer may perceive their child as particularly vulnerable and may need more reassurance than other parents as to the safety of various school activities.

References / Bibliography / Resource List

REFERENCES

Educational Issues For The Chronically Ill Student
Author: Pat Jenner

Teaching Children With Cancer

Author: Aileen Luey and Pat Jenner

Nursing Care Of The Child With Cancer (2nd edition)

Author: Genevieve Foley, Dianne Fochtman, Kathleen Hardin Mooney
Publisher: W.B.Saunders, Philadelphia (1993)

BIBLIOGRAPHY/ RESOURCE LIST

TEACHERS

Abc Feelings Awareness
Activity/Flash cards - Available from Compassion Books**

Change, Loss And Grief: A unit for primary and intermediate schools
Author: Lois Tonkin
Publisher: Mary Potter Hospice, Wellington (1995)

Childhood Cancer And The School Handbook of Pediatric Psychology in school settings
Author: FD Armstrong, BG Briery (In press)

Death And The Classroom - A Teachers Guide (revised edition)

Author: K Cassini and J Rogers
Available from Compassion Books**

Educating The Child With Cancer

Edited by: Patricia Deasy-Spinetta MS and Elizabeth Irvin
Publisher: Candelighters*

Grief At School - A Manual for School Personnel

Author: Helen Fitzgerald
Available from Compassion Books**

Grief At School - A Training Guide

Author: Helen Fitzgerald
Available from Compassion Books**

Grieving - The Need to Know Library

Author: Karen Spies
Available from Compassion Books**

Growing Through Grief - A K-12 curriculum

Author: Donna O'Toole
Available from Compassion Books**

Helping The Grieving Student - A Guide for Teachers

Author: The Dougy Centre Staff
Available from Compassion Books**

Living With Childhood Cancer

Author: Leigh Woznick and Carol Goodheart
Available from Compassion Books**

Never Too Young To Know - Death in Children's Lives

Author: Phyllis Rolfe Silverman
Publisher: Oxford University Press (1999)

Overcoming Learning Difficulties

Author: Royal Children's Hospital, Melbourne Victoria
Producer: Anti-Cancer Council of Victoria (1993)

Something I've Never Felt Before

Author: Doris Zagdanski
Publisher: Hill of Content Pub. Melbourne Australia (1990)

Students With Cancer - A Resource for the Educator

Publisher: NIH Publications, USA (1980)

When Death Impacts Your School

The Dougy Center
Available from Compassion Books**

ADOLESCENTS

Your Adolescent

Editor: David Pruitt for the American Academy of Child and Adolescent Psychiatry
Available from
Compassion Books**

Childhood Cancer Survivors – A Practical Guide to Your Future

Author: Nancy Keene, Kathy Ruccione, Wendy L Hobbie
Publisher: O'Reilly & Associates, Sebastopol (2006)

Karen

Author: Karen Scotson & Margaret Beames
Publisher: Dunmore Press
Levin NZ (1988)

Life Is For Living

Author: Lynda Reed
Publisher: Craig Printing Co. Ltd. Invercargill NZ (1989)

Something I've Never Felt Before

Author: Doris Zagdanski
Publisher: Hill of Content Pub. Melbourne Australia (1990)

Your Cancer, Your Life

Author: Dr. Trish Reynolds
Publisher: Greenhouse Publications.
Australia (1987)

CHILDREN

Aarvy Aardvark Finds Hope

Author: Donna O'Toole
Available from
Compassion Books**

Badger's Parting Gifts

Author: Susan Varley
Publisher: Picture Lions, Collins, London UK (1985)

Barklay And Eve Explaining cancer to children

Author: Karen Varney
Available from
Compassion Books**

Because Someone I Love Has Cancer

Kids activity book
Editor: Anneke Smith
Publisher: American Cancer Society (2002)

Beyond The Rainbow

Author: Marge Eaton Heegard
Available from
Compassion Books**

Chemo, Craziness & Comfort - My book about childhood cancer

Author: Nancy Keene and Trevor Romain
Publisher: Candelighters*

Ewen's Little Brother

Sheila Lamont
Publisher: Victoria Publications
Newcastle upon Tyne.

I Have Cancer

Author: Althea Braithwaite
Publisher: Dinosaur Publications (1989)

My Book For Kids With Cancer

Author: Jason Gaes
Publisher: Meluis Publishing Corp. Aberdeen. Sth Dakota (1991)

Ribbons For Her Hair

Author: Jane Carroll & Janna Taylor
Publisher: Hyland House Publishing, Victoria, Australia

Robbie

Author: Isobel Lowe
Publisher: Shortland Publications Ltd. NZ (1988)

Simon Has Cancer

Author: Use Brazier, Avril Trapp, Nancy Yates
Publisher: Victoria Publications UK

The Amazing Hannah, Look At Everything I Can Do

Author: Amy and Dave Klett
Publisher: Candelighters*

What's Up Mate?

Author: Helen Bates
Publisher: Hodder & Stoughton NSW (1987)

When Someone Very Special Dies

Author: Marge Heegaard
Publisher: Woodland Press, USA (1998)

You And Leukaemia – A Day At A Time (2nd edition)

Author: Lynn S Baker MD.
Publisher: WB Saunders Co. Philadelphia (2002)

WEBSITES

Child Cancer Foundation Inc
www.childcancer.org.nz

CanTeen New Zealand
www.canteen.org.nz

Cancer Backup
www.canceractive.com

Childhood Cancer Guides
www.childhoodcancerguides.org

***American Childhood Cancer Organization**
www.candlelighters.org

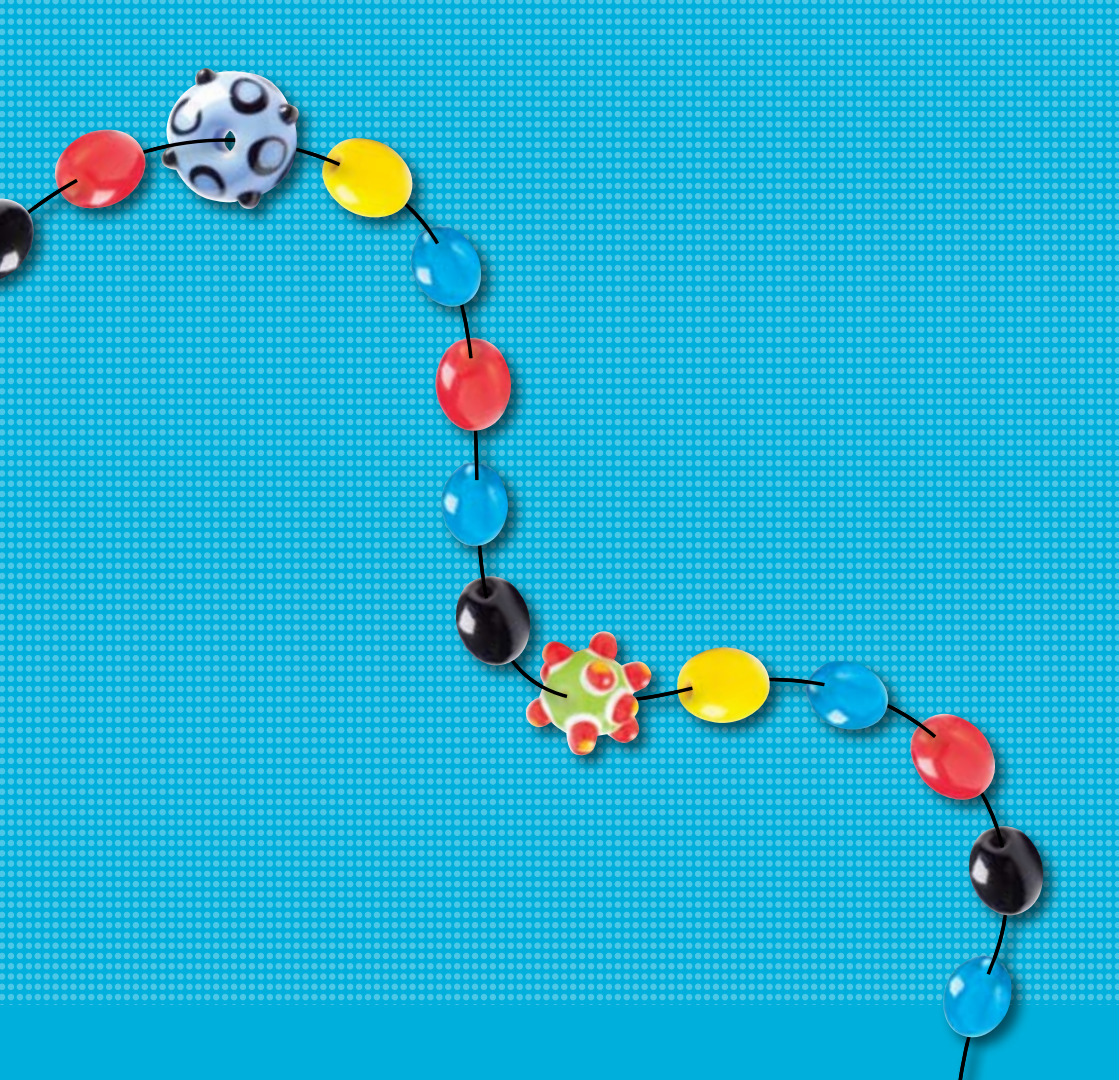
****Compassion Books**
www.compassionbooks.com

Skylight
www.skylight.org.nz

Friends of Gt Ormond St Library
www.ich.bpmf.ac.uk/library/no_frames/resource.htm

Supersibs
www.supersibs.org

Late Effects / Survivorship
www.survivorshipguidelines.org



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