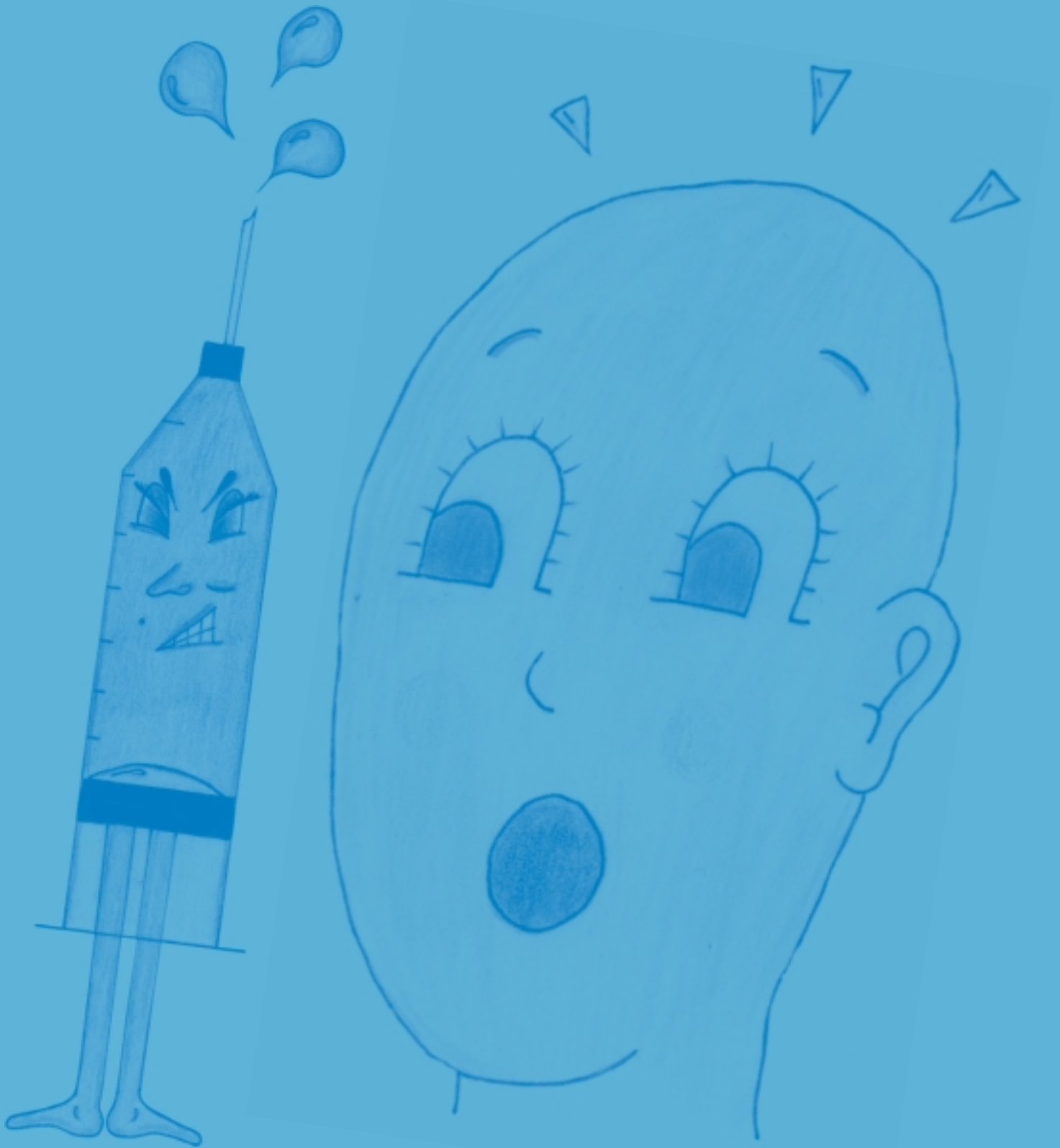


# When a student has cancer



A RESOURCE FOR TEACHERS AND SCHOOL COMMUNITIES

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# WHAT IS CANCER?

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In general, cancer occurs when cells in the body multiply in an uncontrolled way. As their numbers increase, they form a mass that affects the normal functioning of the surrounding tissue. If cancer is not successfully treated at this stage, cancer cells can break away and spread through the bloodstream or lymphatic system to other parts of the body. This process is called metastasis.

The cells in almost any part of the body can become cancerous. There are many different types of cancer. The extent and nature of cancer in children and young people differ from adult cancers and therefore require different treatments.

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## WHAT CAUSES CANCER?

Cancer is caused by a disruption to a cell's genes. In many adult cancers, this is clearly due to a carcinogen (an agent that causes cancer, like ultraviolet radiation or some of the substances in cigarettes). In most childhood cancers, the factors that cause cells' genes to become abnormal have not been identified. Certain medical conditions and rare inherited disorders have been linked to cancer, but the causes of most childhood cancers are not known.

Although it is rare, two or three children/young people from the same school or community may develop cancer, causing local concern. Scientists continue to study lifestyle and environmental factors in their search for a cause, but have found none. **We do know that cancer is NOT contagious.**

## SURVIVAL RATES FOR CHILDREN AND YOUNG PEOPLE WITH CANCER

The cure rates of cancer in children and young people have improved substantially over the last two decades. Today, more than 70 per cent of children/young people with cancer will be cured and this rate is expected to increase. This is largely due to improved treatment.

Other cancers affecting children and young people may be controlled or go into remission for a time (remission is when the symptoms and signs disappear).

Survival rates depend on the type of cancer, the extent of the disease at the diagnosis stage, and the child's/young person's age.

# COMMON FORMS OF CANCER IN CHILDREN AND YOUNG PEOPLE

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## BRAIN TUMOURS

Brain tumours are the second most common form of cancer in children and young people and, because they are more difficult to cure, account for more cancer-related deaths than any other individual tumour type in childhood or young adulthood. The treatment of brain tumours in childhood will vary according to the type of tumour and its exact location in the central nervous system. Most brain tumours are treated by surgery and the majority also require the addition of radiation and chemotherapy. Survival rates for brain tumours vary according to diagnosis. The most common type of malignant brain tumour, known as a medulloblastoma, has an 80–90 per cent survival rate if treated appropriately with a combination of surgery, radiation and chemotherapy.

## LEUKAEMIA

Leukaemia is the most common form of cancer in children/young people, accounting for 30 per cent of childhood cancer. It is a cancer of the white blood cells. In leukaemia, the primitive blood cells begin to multiply before reaching maturity. The rapid growth of the 'leukaemic' or abnormal cells causes them to outnumber the normal blood cells.

Acute lymphoblastic leukaemia (ALL) is the most common form of leukaemia in children and young people and accounts for 80 per cent of childhood leukaemia. It commences in the bone marrow, the 'factory' where blood cells are made. Treatment is with chemotherapy and in a small number of cases, radiotherapy to the brain. The cure rate is greater than 75 per cent.

Acute myeloid leukaemia is a less common form of leukaemia in children/young people. It also occurs in the bone marrow. Treatment involves initial chemotherapy and, sometimes, stem cell transplantation. The cure rate is 50–60 per cent.

## LYMPHOMA

Lymphoma is cancer of the tissue of the lymphatic system. (The lymphatic system is the network of lymph nodes connected by lymph vessels, which branch into every part of the body except the brain and spinal cord.) There are two types, Hodgkin's disease and non-Hodgkin's lymphoma. The prognosis (assessment of the likely course and outcome of the disease) is very favourable for both, but this depends on the extent of the disease at diagnosis. Treatment is primarily with chemotherapy.

## NEUROBLASTOMA

Neuroblastoma arises in the adrenal glands: the small glands just above each kidney. It may also arise in nerve tissue in the neck, chest, abdomen or pelvis. Neuroblastoma generally occurs in children aged younger than five years and is a serious cancer, particularly if it spreads through the bloodstream to the bone marrow. Treatment generally includes surgery, chemotherapy, radiotherapy and sometimes stem cell transplantation.

## OSTEOSARCOMA AND EWING'S SARCOMA

Bone tumours occur most often in adolescence, but can occur in younger children. The two most common types are osteosarcoma and Ewing's sarcoma. They can arise in the pelvis, ribs or long bones of the arms or legs. Treatment is generally chemotherapy and surgery or occasionally radiotherapy (mainly for Ewing's sarcoma). Where long bones are involved, amputation of the limb may be required. However, limb salvage surgery is now commonly possible.

## RETINOBLASTOMA

This is a rare malignant tumour of the retina of the eye. It accounts for around 5 per cent of childhood blindness. Treatment is aimed at preserving vision if possible.

## RHABDOMYOSARCOMA AND SOFT TISSUE SARCOMA

Rhabdomyosarcoma is a cancer of the muscle, and soft tissue sarcoma is a cancer of the connective tissues. These cancers can form anywhere in the body and may spread through the bloodstream to the lungs, making the prognosis less hopeful. Treatment is by surgery, chemotherapy and sometimes radiotherapy.

## WILMS' TUMOUR

Wilms' tumour is a cancer of the kidney that occurs most often in children aged younger than five years. It was one of the first childhood cancers that could be cured. Even if the tumour has spread through the bloodstream to the lungs, the outlook is extremely favourable. Treatment is by surgical removal of the affected kidney, chemotherapy and sometimes radiotherapy. It is possible to live a normal life with one kidney.

*There are many other forms of cancers that affect children and young people. For more information about the specific disease, contact the haematology/oncology clinical nurse coordinators at the student's hospital, or the Cancer Information and Support Service on 13 11 20.*



# TREATMENT

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A team approach is essential in the treatment of all cancers affecting children/young people. The multidisciplinary team includes paediatric oncologists (specialists in children's cancer), nursing staff, radiation oncologists, surgeons, pharmacists, medical social workers, education advisors and other allied health and support professionals. The child/young person and family are the focus and often the vital link between the school community and hospital during the child's/young person's illness.

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## SURGERY

Surgery plays an important role in the management of most tumours in children and young people. The types of surgery may include:

- tissue biopsy (removal of a sample of tissue for examination under a microscope), to determine the type and nature of the tumour
- surgical removal of the tumour (and sometimes the organ of origin), either initially or after some chemotherapy
- limb salvage, which allows the affected bone to be replaced by a prosthetic (artificial) bone or with bone from another part of the body
- amputation, required for some bone tumours
- placement of a central venous catheter (used for delivery of chemotherapy, fluids, antibiotics, etc)
- placement of a cerebrospinal fluid (CSF) drainage device (shunt system).

## RADIOTHERAPY

Radiotherapy (or irradiation therapy) is an effective treatment for some cancers. Radiotherapy is the use of radiation, usually gamma rays, to kill cancer cells or injure them so they cannot grow and multiply. Radiotherapy treatment can also harm normal cells, but they are better able to repair themselves.

Radiotherapy is directed to the specific area of the body where the tumour resides. To spare the normal healthy tissue surrounding these areas as much as possible, detailed and precise planning is necessary.

A course of daily treatment usually over 2–6 weeks is required. This may vary depending on the type and nature of the tumour. It is not painful and takes only a short period of time, however there are associated side effects.

### Possible side effects of radiotherapy

SHORT TERM	LONG TERM
<ul style="list-style-type: none"> <li>• reddening of the skin and/or skin rashes</li> <li>• hair loss (where radiotherapy is directed at the brain)</li> <li>• sleepiness, usually starting several weeks after radiation to the brain is completed</li> <li>• vomiting (if the brain or abdomen is irradiated)</li> <li>• diarrhoea (if the abdomen is irradiated).</li> </ul>	<ul style="list-style-type: none"> <li>• impaired growth in the radiated area</li> <li>• abnormal hormonal function may affect growth after radiotherapy to the brain causing: <ul style="list-style-type: none"> <li>– shortness of stature</li> <li>– early or late puberty</li> <li>– learning difficulties (these may be general or subject specific)</li> <li>– fertility issues (also if the testes or ovaries are directly irradiated).</li> </ul> </li> </ul>

*Not all children/young people will experience all of the above side effects. The reaction will depend on the individual, the area being treated and the dose of radiation.*

## CHEMOTHERAPY

Chemotherapy is the treatment of cancer using drugs. Chemotherapy drugs are often called cytotoxic drugs, meaning poisonous to cells. Chemotherapy is the treatment of choice in the majority of cancers affecting children/young people. It is largely through advances in chemotherapy that survival rates for cancer in children and young people have improved in recent decades.

Chemotherapy drugs may be taken orally (tablets or liquids) or given by injection into a vein (intravenously), under the skin (subcutaneously), or into a muscle, artery or the spinal fluid.

Blood cells are made in the bone marrow, in the hollow centres of bone and released into the bloodstream. There are **red blood cells**, which carry oxygen around the body, **platelets**, which help the blood clot normally and **white cells**, which fight infection. Almost all chemotherapy, and some radiotherapy, suppresses the function of the bone marrow. This means that the bone marrow cannot make the required number of cells.

Chemotherapy is effective against cancer cells because it interferes with the growth of cancer cells, causing them to die. The advantage is that the drugs

travel around the body via the bloodstream and can attack cancer cells in different parts of the body even though the cancer cells may be too few or too small to be seen. Unfortunately, this process can also affect normal cells, especially rapidly dividing cells, such hair cells. This can result in side effects such as hair loss.

The duration and intensity of chemotherapy varies, according to the disease being treated and the treatment protocol.

**Possible side effects of chemotherapy**

SHORT TERM	LONG TERM
<ul style="list-style-type: none"><li>• increased risk of infection (including measles/chickenpox), due to low white blood cell count</li><li>• anaemia and lethargy</li><li>• bruising and easy bleeding</li><li>• nausea and vomiting</li><li>• loss of appetite and weight</li><li>• hair loss (regrowth usually occurs)</li><li>• mouth ulcers</li><li>• loss of self-esteem.</li></ul>	<ul style="list-style-type: none"><li>• hearing damage (related to some chemotherapy drugs)</li><li>• less common outcomes are reduced fertility, heart damage and possibly increased risk of cancers later in life</li><li>• learning difficulties (these may be general or subject specific).</li></ul>

*Not all children/young people will experience all of the above side effects. The reaction will depend on the individual and the type and dose of chemotherapy.*

**Measles and chickenpox:** chemotherapy can decrease the body’s ability to fight infection. Patients undergoing chemotherapy are susceptible to viral infections, notably measles and chickenpox, and in some cases these infections could be potentially lethal for the child/young person. **All parents at the school should be told to keep students home if they have measles or chickenpox and to notify the school as soon as possible.** If the school is notified of a case, the school should contact the parents of the student with cancer so they can discuss the circumstances with the doctor. (See Sample letter, Appendix two.)

## STEM CELL TRANSPLANTATION

A stem cell transplant is a major procedure. It is used in situations where the child's/young person's prognosis would be very poor with conventional therapy. A stem cell transplant involves the administration of very high doses of chemotherapy and in some cases total body irradiation. This is followed by the infusion of stem cells collected from blood, bone marrow or umbilical cords (in some cases, they are collected from the child/young person before the chemotherapy is given). Stem cells are the most primitive blood cells, capable of reproducing themselves or developing into red blood cells, white blood cells or platelets.

There are two main types of stem cell transplants:

- **autologous:** where the child's/young person's own stem cells are used.
- **allogeneic:** where a person other than the child/young person donates the stem cells. The donor may be a relative or from a bone marrow or cord blood registry.

Possible complications following an **autologous** stem cell transplant are similar to the side effects of chemotherapy, however, the side effects will be more severe due to the higher doses of chemotherapy given. A child or young person receiving an **allogeneic** stem cell transplant will also experience the severe side effects of chemotherapy and possibly radiotherapy. In addition, his/her immune system is suppressed to reduce the risk of his/her body rejecting the donor stem cells, and he/she will therefore be at risk of infection and other complications for some time following discharge from hospital.

## CENTRAL VENOUS CATHETERS

Central venous catheters are often used in the treatment of cancer in children and young people. They are a type of tubing that is inserted into a large vein which leads to the heart. This allows for the administration of chemotherapy, the taking of blood samples and the administration of blood products and fluids when required. These lines eliminate the need for continual insertions of intravenous 'drips', and stay in place for the duration of the treatment.

Several types of long-term access devices are available. The child's/young person's age and type of treatment determines the type of device that is used. While the person is under anaesthetic, a surgeon implants the device. They may remain in place for prolonged periods of time, often a year or more.

There are two basic types of central venous catheter:

- **Infusaports** are completely contained beneath the skin. When the port is used, a special needle is inserted through the skin into a rubber disc (around the size of a 20-cent coin), that connects with the tubing/catheter that leads to a vessel entering the heart. At the completion of therapy, the needle is removed. No care is required for ports in the school setting.
- **Hickman catheters** are external devices. They are thin, flexible tubes, with one, two or three barrels, that exit the chest wall near the nipple line. The exit site requires a dressing that is changed regularly to prevent infections. In the school setting, the care of a Hickman catheter differs from that of an infusaport.

*Bleeding may occur in relation to a Hickman catheter: either because the cap at the end of the line becomes detached or because a crack occurs along the wall of the line. If bleeding occurs, the central line should be **clamped or compressed** with the fingers between the bleeding site and where the line exits the skin while medical assistance is sought. Cotton wool or a clean cloth should be placed over the site that is bleeding. If the cap falls off, it may become dirty and should **not** be inserted back into the line.*

A central catheter needs to be kept meticulously clean. They will rarely cause problems in the classroom although some students may be self-conscious about them. Some doctors prefer patients with central catheters not to swim or to participate in body contact sports. Discuss such restrictions with the parents and medical team.

## STEROID THERAPY

Steroids are drugs used to reduce the swelling (oedema) that is often associated with brain tumours. Swelling may occur before or after surgery and during a course of radiotherapy. Short-term use of steroids may temporarily relieve symptoms and significantly reduce the swelling. Long-term use is for symptom relief.

Children/young people may be given steroids (for example, dexamethasone) before, during and following surgery for removal of their tumour. These are slowly tapered until they are discontinued during the week following surgery, or later if necessary. It is important that steroids are weaned slowly, to allow time for the body to readjust.

Children/young people undergoing radiotherapy may require a course of steroids at some stage. These help to reduce the swelling that is associated with receiving radiation to the brain.

Steroids are also used in the treatment of acute lymphoblastic leukaemia and lymphoma, usually in intermittent courses. Either prednisolone or dexamethasone is used.

### **Possible side effects of steroid therapy**

Children/young people may experience side effects from steroids. The side effects usually disappear several months after the treatment is stopped. Side effects may include:

- increased appetite
- fluid retention
- weight gain due to fluid retention (particularly in the face and abdomen)
- mood fluctuations, including irritability, depression, mood swings and sleep difficulties
- heartburn.

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# THE IMPACT OF CANCER ON THE STUDENT AND THEIR FAMILY

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## FINDING OUT

Detecting cancer is often difficult and there may be a time lag between the initial symptoms and diagnosis. This places the child/young person and the family under considerable stress, which may intensify with diagnosis.

Individuals react to cancer in different ways depending on age, development, personality and support networks. Some may show distress or they may ask many questions and appear preoccupied with the issues surrounding cancer. These reactions may appear immediately or may not show until weeks or even months later. There is no typical reaction and some children/young people may be more distressed than others.

When a child or young person is diagnosed with cancer the following reactions can be common.

### **The child/young person with cancer may feel:**

- scared, insecure and lonely
- concerned about dying
- angry that this has happened to them
- confused about the diagnosis and their parents' reaction to it
- resentful about the disruption treatment causes to their normal activities
- frightened and angry about losing control over some areas of their life
- denial—this can't be happening to me.

**Parents may experience:**

- shock, disbelief, confusion, anger or guilt about the diagnosis
- fear and an increased sense of protectiveness towards their children
- feelings of being overwhelmed and unable to cope
- added financial strain
- feelings that education is not a priority in the initial stages.

While parents need time to adjust, it is essential that the school community maintains contact (see section titled Strategies for school coordinators).

**Siblings may feel:**

- as if they have been forgotten and overlooked
- guilty that they have done something to cause the illness
- uninformed about what is happening
- frightened and worried for their brother or sister and parents
- angry and jealous of the attention the parents are giving their brother or sister
- afraid that they may also get cancer
- resentful of being questioned about their sibling's illness
- additional concern if they are identified as a suitable donor for stem cell transplantation.

As a result siblings at school may be disruptive and unable to cope with school work. They may need extra time away from school, flexibility with assignments and deadlines and extra support from welfare staff (see section titled Resource people in school education).

Because of these effects, all families (child/young person, parents and siblings) are routinely referred to a social worker or other appropriate specialist.

**Friends:**

- provide invaluable support and it is important that they maintain contact with the student with cancer. They should not feel hurt if there are times when the student is not 'up to' seeing them—it is very important that friends continue to offer support
- often find it difficult to cope with the idea of a friend being seriously ill
- may be afraid to visit or keep in touch because they don't know what to expect, what to say or how to act
- may question whether their friend will live and if they too may get cancer.



## BEING IN HOSPITAL

The child/young person will often spend a few days in hospital until a diagnosis is made. Once treatment begins they are required to spend more time at the hospital and for some this may involve long periods of time.

Specialist treatment centres for children/young people with cancer (paediatric oncology units) are based in Melbourne. This means that parents or families may be required to travel long distances and stay at the hospital for extended periods of time while the child/young person receives treatment. For country families in particular the disruption to family life is compounded by problems of isolation, long-term separation from partners and family and added financial burdens brought about by extra travel, accommodation and telephone costs.

It is important for the school to keep informed while the student is in hospital. Depending on the individual family situation, contact may be made with the parents (or their nominated representative), the clinical nurse coordinator or the social worker from the cancer treatment centre. Education advisors (Royal Children's Hospital) and school teachers (Monash Medical Centre), after consultation with the parents, student and medical staff, will contact the school of origin to provide support and links between the hospital, school, family and the community. Contact with hospital staff can also help prevent myths or rumours about the student.

## GOING HOME

It may not be until the child/young person returns home from hospital that the full impact of the diagnosis is felt. Their team of health carers will often play an important role in assisting families to cope; they work closely with the student, parents and siblings and are aware of the family's needs. With the parents' permission, the clinical nurse coordinator, education advisors and/or social worker can contact the school and arrange an appointment to discuss the student's diagnosis and treatment.

If amputation has been necessary, physical adjustments will be required both at home and at school and the student will also have to learn how to manage with a prosthesis, crutches or wheelchair. Modifications to the school can be arranged through the Department of Education & Training regional offices, the Catholic Education Office or the school itself in the case of independent schools.

## BACK TO SCHOOL

School is a major part of a student's life, and an important part of their socialisation. Being at school is the best way for students with cancer to maintain a sense of normality, and for this reason, acceptance by peers is regarded as paramount. **Children/young people with cancer do not like to be treated differently, so the aim is to treat them like other students as much as possible.**

Both the student and their parents may be nervous about the return to school and may be keen for a clinical nurse coordinator and education officer to visit. The parents may worry about their son/daughter being rejected or teased and will often need reassurance from the school that he/she is settling back into the classroom.

Regular Program Support Group (PSG) meetings are recommended for the sharing of information and planning for individual needs at the school level. These meetings involving parents, a parent advocate (optional), class teacher(s), principal (or nominee) and the student (where appropriate), aim to establish appropriate goals and strategies and maximise a student's participation in school life. PSG meetings also provide support for teachers, parents and the student, and monitor and evaluate student progress. PSG meetings are the most appropriate forum for parents to explore anxieties, concerns and issues. It is very important that parents are given the opportunity to do so.

The student may be worrying about the response of their friends and other students in the school. It is helpful if some close friends have made earlier contact, as they will alleviate the stress and provide initial support on the return to school.

*In general, most students look forward to returning to school. However, it should be remembered that each student will respond differently. Each situation should be assessed and dealt with on an individual basis.*

## RELAPSE

Relapse is the return of a disease after a time when there has been no evidence of disease. It is the greatest fear for the student and his or her family because the whole process of treatment, anxiety and family stress starts again and, most importantly, the prospect for cure is reduced. If a relapse occurs the family will require increased support.

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# THE STUDENT WITH CANCER AND THE SCHOOL COMMUNITY

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When a student is diagnosed with cancer, the news affects not only their class but also the school community as a whole. The ways in which the school is affected may vary depending on factors such as the size and location of the school, how long the student has been attending that school, proximity to the hospital and the attitudes and cohesion of the school community.

Principals and teachers can obtain more detailed information about dealing with specific problems from the Royal Children's Hospital support staff.

*The Department of Education & Training Victorian Schools Reference Guide should be consulted when a student is diagnosed with cancer, as the intervention needs to be applied across the school.*

## WHAT THE SCHOOL CAN DO

The news of a student with cancer in the school can evoke strong reactions and emotions, and is best handled by a systematic team approach. For this reason, it is essential to appoint a coordinator to liaise with the family and to manage all the activities and crises that may arise during and after treatment (for example, school nurse, student welfare coordinator, chaplain).

It is important that any misunderstandings about cancer are dealt with in the early stages to avoid unnecessary fear, hurt and disruption. The way a diagnosis is explained and interpreted is critical in determining the wider effect on the school community. Directing teachers and other parents to one coordinator on the staff will ensure that a consistent and appropriate message is given.

Remember that a student diagnosed with cancer will have unique needs that may vary as he or she moves about the school. For example, the playground (as opposed to the classroom) may present very different issues for them in terms of support.

Some of the key issues that schools may need to deal with include:

- reduced concentration and learning difficulties
- fatigue
- behavioural changes
- changes in peer relationships
- change in body image (for example, hair loss, weight changes, limb amputation).

*Giving the student the option of wearing a cap indoors can assist their return to school. It is very important that all staff, including casual relief teachers are informed of this.*

## SPECIAL PROVISION IN THE VICTORIAN CERTIFICATE OF EDUCATION (VCE)

In some cases, students may be eligible for special provisions when undertaking their VCE. These provisions are available to assist students to undertake coursework tasks, sit exams or meet the requirements for unit outcomes. Other provisions allow students to follow a different pattern in achieving the VCE. For example, a student may interrupt their studies so that results achieved prior to becoming ill may be retained and combined with results achieved in the following year when the student returns to school. This allows a study score to be calculated over two years.

In other cases, workload may be reduced by withdrawing from some or all studies. The use of technology, scribes, readers or extra time are all special examination arrangements which may also be used for coursework tasks. There are many ways in which a student may be assisted.

Consideration of Disadvantage allows a student's record to be annotated so that a reader of the results would know that those results which are printed with an asterisk (\*) have been achieved under adverse circumstances. Consideration of Disadvantage only applies to Graded Assessments and should be used when other special provisions have not adequately compensated the student's disadvantage.

## PROVISION FOR STUDENTS WITH PHYSICAL DISABILITIES

In some cases students with cancer can suffer a physical disability due to their treatment, for example where amputation has been necessary. Adjustments may be necessary to ensure the student has physical access around the school. Examples include making timetable adjustments, allocating the student's classes to ground floor rooms and building wheelchair ramps at the entrance to buildings. Enquire about the possibility of integration support from the regional coordinator of student welfare and support/disabilities and impairments or Catholic education officer.

## THE ROLE OF THE SCHOOL COORDINATOR

It is recommended that the school nominates a staff member to be the school coordinator. The school coordinator will liaise with others on behalf of the student and their family.

In secondary schools, the school coordinator may have the title 'student welfare coordinator' or 'year level coordinator'. In primary schools, he or she may be the child's classroom teacher or principal.

The main role of the school coordinator is to:

- facilitate the student's return to school
- be informed about the student's disease and maintain contact with the family and the hospital
- assist the school in becoming informed (as much as the parents and the student agree is relevant). In particular, the relevant staff need to understand the likely nature and extent of physical, intellectual and emotional needs and the implications in terms of the student's adjustment
- inform other parents of the need to contact the school immediately if their son/daughter has measles or chickenpox as these pose serious threats to the child/young person undergoing cancer treatment (see pro forma letter Appendix one)
- ensure that staff monitor interactions between the student and other students, both in class and in the school grounds, and inform the coordinator of any problems as soon as possible
- encourage classmates to maintain contact with the student while he/she is absent from school
- act quickly to dispel any myths, misunderstandings and fears about cancer
- be aware of the family's need for practical assistance

- be aware of any siblings that attend the school and inform relevant staff of the situation
- ensure modifications are made to the curriculum where needed, for example in sport and extensions for assignments
- remind teachers to consider and be aware of potentially sensitive content areas in the curriculum
- remind staff members that there needs to be a balance between realistic expectations of what the student can do and the possibility that they may try to avoid tasks which are possible for them to attempt.

## THE SCHOOL COORDINATOR, EDUCATION ADVISORS, CLINICAL NURSE COORDINATORS AND SOCIAL WORKERS

Education advisors from the Royal Children's Hospital (RCH) Education Institute, RCH clinical nurse coordinators and/or social workers from the Oncology Department can assist with the student's return to school.

The role of the **education advisors** is to liaise with the clinical nurse coordinator and social worker and provide information to teachers and classmates. In some cases they are available to visit the school if the parents agree. They will assist the school by visiting with an education advisor and providing information to class and peer groups about:

- the student's illness and treatment
- changes in the student's appearance
- the importance of peer support for the student
- the danger of exposure to infections, particularly chickenpox and measles
- the possible need for adjustments to the classroom and to the school environment
- sibling support.

**Clinical nurse coordinators** support and work with teachers and the school coordinator by:

- arranging for the hospital occupational therapist to visit if special classroom adaptations are required
- stressing the need to notify parents if exposure to chickenpox or measles is suspected

- letting teachers know the importance of providing feedback to the parents about any behavioural changes or learning difficulties the student may be having
- informing them about the variety of support services and resource materials available.

The role of the **social worker** is to assist with the social and emotional impact of cancer on the child/young person with cancer, their school friends, siblings and the school staff. Families are routinely referred to a social worker when the child/young person is diagnosed, however, not all families make use of this service.

A social worker can talk to the students or staff at school or consult by telephone. Special programs for siblings are available. Enquire at the Royal Children's Hospital or treatment centre.

## STRATEGIES FOR SCHOOL COORDINATORS

- Meet with the student and parents regularly to determine their needs and preferences and to monitor progress.
- Establish a consistent and clear policy at the school level to assist with communication, curriculum and welfare issues that may arise and ensure that parents, teachers and health/education professionals at the hospital are aware of these procedures and practices.
- Inform school friends and peers about the student's diagnosis or arrange a school visit by staff from the hospital where the student is receiving treatment.
- Act as a liaison person between school staff and the support services, for example social worker, clinical nurse coordinator and education officer.
- Organise visiting teachers to liaise with the school/family and hospital, to assist with the maintenance of school of origin program and the student's re-entry/transition to school.
- Keep in touch with hospital education officer/teacher to maximise the student's educational opportunities.
- Set up professional development activities so that information can be shared and plans made.
- Enquire about the possibility of integration support from the regional disability and welfare coordinator or the Catholic Education Office.
- Ensure staff and casual relief teachers know about special requirements and concessions for the student with cancer. A letter or card outlining special needs may be helpful for the student to have on hand, particularly in secondary schools.

- Organise for relevant teachers to have access to a completed pro forma of relevant information and support contacts and ensure that this is kept up to date.
- Create a space in the classroom for a beanbag or cushions so that the student can still participate when they're feeling tired.
- Provide unobtrusive support for the student with cancer in the playground and encourage other staff and peers to do the same.
- If the family approves, co-opt a parent who is a friend of the family to give suggestions about how other parents can give practical assistance, for example by providing child minding and transport for siblings.
- Maintain regular contact with siblings and their teachers to monitor their needs.
- Coordinate Program Support Group Meetings.

## COLLEGIAL SUPPORT

Having a student with cancer in the classroom presents new challenges to the teacher. **It is important that all teachers are aware of their own feelings in dealing with a student's diagnosis of cancer.** Assistance can be sought from the student welfare coordinator and/or other people as listed in the section titled Resources for teachers of students with cancer.

For the teachers involved, extra time and attention is often required to meet the emotional, social and educational needs of the student, and the class as a whole. During this time teachers can feel unsure and emotionally drained with the added stress of the situation. Teachers can also be distressed by news of their student and should consider taking a little time (if possible) to adjust before attempting to assist students. It is important for the wider school community to offer support to teachers who are closely involved with the student.

## INFORMATION FOR CLASS ACTIVITIES

It is important to consider that the student with cancer will operate in a range of school settings and with a variety of personnel who each have a special role. Teachers need to be aware that, in a classroom or small group setting, students may need to discuss:

- what cancer is
- myths and facts surrounding cancer
- that cancer is not contagious or infectious and that it cannot be spread or caught by bodily contact
- treatment and side effects of treatment



- feelings and concerns of both the student with cancer and his/her peers
- how patients may deal with a diagnosis of cancer
- how siblings may deal with a diagnosis of cancer
- how they (the friend/classmate) can deal with it
- how they can help as a friend or classmate
- grief and loss.

*More information and assistance with these issues can be obtained from the clinical nurse coordinators, social workers or other support staff at the Royal Children's Hospital Paediatric Oncology Centre, or the Cancer Information and Support Service.*

## MAINTAINING CONTACT WITH THE STUDENT WITH CANCER

It is important that the school maintains regular contact with the student through **all periods of absence**. This includes hospital stays and recovery time at home. Ways in which schools/teachers can maintain contact include:

- visits to hospital and home
- telephone calls
- cards/letters
- faxes
- emails
- school newsletters
- video tapes, for example of special school events
- audiotapes
- diary entries
- desktop video conferencing through the Royal Children's Hospital Education Institute
- Internet chat programs.

## POSSIBLE LONG-TERM EFFECTS ON LEARNING

As cure and survival rates for cancers affecting children/young people improve more attention is being paid to quality of life issues. Greater emphasis is being placed on the possible long-term effects of treatment, and treatment protocols are being modified and developed to address issues resulting from cancer and its treatment.

Some of the long-term effects of cancer have the potential to interfere with a student's ability to process, learn and retain information. It is important for teachers to be aware that students who are survivors of cancer could have long-term side effects, including learning difficulties, resulting from their treatment.

Effects on learning may include:

**Learning difficulties:** although these can occur after radiotherapy to the head, not all students receiving such radiation experience learning problems. Learning difficulties may also arise in other circumstances, for example after surgery to the brain. If teachers suspect that a student is experiencing difficulties with learning, assessments may be useful. This should be done by an educational psychologist who is experienced in working with students with medical problems.

**Hearing loss and visual impairment:** can occur with some treatments. Be on the look out for these and consider placing the student towards the front of the class.

**Prolonged school absences:** may have occurred over several years and may mean the student has a lot of work to catch up on and also have missed significant stages in their learning.

Where there are difficulties, parents and teachers should have frequent contact and can work together to make the necessary adjustments in the classroom and modifications to the curriculum and assessment tasks: for example seating the student towards the front of the class, allowing extra time for assignments and varying the nature of set tasks, for example Individual Learning Improvement Plans.

Teachers and parents need to remember that students who have undergone cancer treatment can have learning problems that are quite different from other children/young people. Learning problems can be caused by behavioural and emotional problems, or by decreased school attendance due to illness or poor motivation.

The Royal Children's Hospital has a follow-up clinic. As changes in functioning can occur several years after cancer treatment has ended, such a clinic monitors student progress over time. The clinic also makes appropriate referrals to other allied health professionals.

## A STUDENT IN OUR SCHOOL HAS CANCER—WHAT SHOULD I LOOK FOR? A CHECKLIST FOR TEACHERS

At times the student will feel quite well. If there are problems the following points need to be remembered:

**Fever:** if the student's temperature is over 38°C, notify the parents immediately, even if the student appears perfectly well otherwise. If serious, infections may be life threatening to the student with cancer. The student must go to hospital as soon as possible.

**Measles and chickenpox:** report all students with measles or chickenpox in the school to the student's parents that day. All parents should be told to keep their son/daughter home if he or she has measles or chickenpox and to notify the school as soon as possible (see Pro forma letter, Appendix two).

**Fatigue:** often these students suffer from a lack of energy and tiredness, with reduced or poor concentration levels. A short break from class work, or resting on the classroom bean bag, may be useful in the short term. Often it is suggested that, in periods of low energy, the student attend school for short periods, for example for morning lessons only.

If anaemia—a condition in which insufficient oxygen is available in the blood for the body's needs—is suspected, the family should liaise with the medical team.

**Bleeding:** a student on chemotherapy may have a low level of platelets in the blood. (Platelets are parts of the blood that assist with coagulation.) This may result in a tendency to bleed easily. Mild bruising is usually not a concern but if any other bleeding occurs, including nosebleeds, perform simple first aid to stop the bleeding. Notify the parents if bleeding continues.

**Hair loss:** the student's hair may fall out. It will probably grow back, but in the meantime the student may feel self-conscious, be teased and may be more prone to sunburn and feeling the cold. Wearing a hat should be encouraged and accepted, and is essential when the student is outside.

**Central venous catheters:** the student may have a central venous catheter. If bleeding occurs in relation to a central line, the line should be compressed with the fingers between the bleeding site and where the line exits the skin. Cotton wool or a clean cloth should be placed over the site that is bleeding. If the cap falls off, it will probably become dirty and should not be put back into the end of the line. Make sure the clamp is on the catheter (tube). Parents should be notified immediately if there is a problem with the central line.

**Falls/cuts/abrasions:** if this occurs do not panic, apply simple first aid and inform the parents.

**Sporting activities:** some students with central venous catheters will have restrictions placed upon their activities; some doctors prefer patients *not* to swim or to participate in body contact sports. The nature of any such restrictions needs to be clarified with the parents and medical team.

## SUPPORT BY OTHER FAMILIES

Teachers are often asked by other parents in the school community how they can help the family of a child/young person with cancer. These enquiries should be directed to the school coordinator to ensure maintenance of accurate, relevant and consistent information.

It is important that the family's wishes for privacy are respected. Some parents prefer one person, perhaps a close family friend who has students at the school, to liaise on their behalf between the school community and the family. The need for some form of practical assistance can be particularly important for country families.

*Treat students like everyone else. The vast majority of students treated for cancer would like most of all to be treated like all the other students and not receive any special or undue attention. Where possible avoid singling out students for special attention.*

Families may be able to offer assistance in some of the following areas:

- transporting/collecting siblings from school
- childminding
- cleaning, ironing, etc
- care of pets
- providing meals.

The type of assistance offered will depend on the family's needs and the level of privacy they desire. It is essential that the school coordinator consult with the family before arranging any form of assistance.

## WHEN A STUDENT DIES FROM CANCER

Over 70 per cent of children and young people with cancer will be cured, however, some will die.

All children/young people need information about death as part of their education in natural life cycles, before they can be expected to deal with the emotional impact of the death of someone close to them.

A child's/young person's understanding of death varies with their development. When a class member dies, students need the opportunity to express their feelings, including fears, and to have these acknowledged.

*Assistance can be sought from the guidance officer and/or other people as listed in the section titled Resources for teachers of students with cancer. The grief and loss resources listed in this booklet may also be of assistance when discussing issues of death with students. The Department of Education & Training has guidelines to support the school community throughout this time.*

There are some specific concerns that may need to be dealt with. These include:

**Siblings:** school communities need to be aware of the effects of a child's/young person's death on their family, especially siblings. The effects of the death will last long after the funeral and siblings may require extra assistance and understanding to re-adjust to school life.

**Sadness at the loss of a friend:** talk about the child/young person who is dying or has died. Let students cry and accept their expression of emotion.

**Fear of death and the unknown:** provide opportunities for students to talk about death and any fears they may have.

**Fear of getting the same illness and dying:** discuss what cancer is and ensure students understand that it is not a contagious disease and that cancer is rare in children/young people.

**Attendance at the funeral:** this should be discussed, and the wishes of the family need to be taken into account. Consider whether peers might sing at a funeral, make a tape to be played and/or form a guard of honour.

**Memorial:** when a student dies, the school community often feels it would like to do something in his or her memory. It is important that the family's wishes are respected. School communities may like to remember a student by naming a memorial garden after them, planting a tree, donating a painting or book, or being involved in a fundraising event for cancer.

**Anniversaries:** the anniversary of the death of a school friend may also provide a school community with an opportunity to remember someone special. Once again the family's wishes need to be respected.

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# HOSPITAL- BASED SUPPORT SERVICES

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## **HOSPITALS WITH CANCER CARE SERVICES AND ONCOLOGY STAFF**

### **Main paediatric oncology centres in Victoria**

Ask to speak with a clinical nurse coordinator, social worker, hospital education officer/teacher, or paediatric oncologist.

#### **Royal Children's Hospital**

Flemington Road

Parkville Vic 3052

Telephone (03) 9345 5522

#### **Royal Children's Hospital Education Institute**

159 Flemington Road

North Melbourne Vic 3051

Telephone (03) 9345 5100

Internet [www.rchmelb.org/edinst](http://www.rchmelb.org/edinst)

#### **Monash Medical Centre**

246 Clayton Road

Clayton Vic 3168

Telephone (03) 9594 6666

These hospitals are listed in the *Yellow Pages* under Hospitals—Public and Private.

## ■ SUPPORT STAFF

### **Oncologists**

The oncologist is the student's specialist doctor—he or she can be contacted through the hospital where the student is being treated.

### **Oncology nurse coordinators**

The Royal Children's Hospital has oncology nurse coordinators. This role covers the aspects of liaison, research and education in the care of the child/young person with cancer and their family. The nurse assists in the integrating of care of the child/young person and their family with the oncologist and many other health professionals. This nurse can also liaise with the education officer and visit the school if necessary, once a student has been diagnosed or upon their return to school. They can assist the teaching staff and students

at the school with information, in understanding and coping with the issues related to a student with a diagnosis of cancer. In some country areas, a community nurse from the community health centre will be able to offer support.

### **Education advisors (Royal Children's Hospital Education Institute)**

The Royal Children's Hospital Education Institute is in a unique position to provide educational services to school-aged patients (Prep–Year 12) attending the Royal Children's Hospital whose educational progress has been compromised by periods of hospitalisation and continued impact of health impairment or developmental problems. Educational services are provided across a range of hospital wards as well as an adolescent program. Services offered include:

- providing opportunities for students to link with their school via mediums such as desktop video conferencing and email
- facilitating re-entry and transitions back to school
- developing information packages on the educational management and support of students
- providing strategic advice for system policies, protocols and practice, using evidence-based data
- providing school-based professional development.

### **School teacher (Monash Medical Centre)**

Monash Medical Centre has a Department of Education and Training part-time teacher, who can help to maintain the student's school program during hospital admissions.

### **Social workers**

Social workers are trained to help with psychosocial/practical issues. Social workers are attached to the main treatment hospitals. They see all families at the time of diagnosis and provide support and assistance throughout the course of treatment. Social workers help families adjust to and live with cancer and its treatment. At times of crisis more intensive services are provided. These times include diagnosis, relapse, bone marrow transplantation, return to school, termination of curative treatment and death.

### **Physiotherapists, occupational therapists and speech pathologists**

Physiotherapists, occupational therapists and speech pathologists may also play an important role in the child's/young person's treatment. They may be contacted through the hospital where the child/young person is being treated.

### **School guidance officers, psychologists and social workers**

A school guidance officer, psychologist and/or social worker may be able to assist both teacher and student in making the transition back into the classroom. They should also be aware of any special resources available through the Department of Education and Training, Catholic Education Office and the Association of Independent Schools.

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# HELPFUL COMMUNITY ORGANISATIONS

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## ■ CANCER-SPECIFIC ORGANISATIONS

### **The Cancer Council Victoria**

1 Rathdowne Street  
Carlton Vic 3053  
Telephone 13 11 20

Provides a variety of resources that may assist, including information booklets on specific types of cancer.

**Cancer Information and Support Service** staff can speak to you about many different aspects of cancer.

### **Children's Brain Tumour Association**

PO Box 12067  
A'Beckett Street  
Melbourne Vic 8006  
Telephone (03) 9388 9194

Formed by parents of children/young people with a tumour of the brain or spinal cord, this group provides parent support. Parents can meet via the members-link program. An informative newsletter is published four times a year.

### **Very Special Kids House**

321 Glenferrie Road  
Malvern Vic 3144  
Telephone (03) 9804 6222

Offers support to families of children/young people suffering from a life-threatening illness. Services include matching trained volunteers with families to provide support and practical assistance at home, volunteers who visit children/young people in hospital, a respite and hospice facility and access to a holiday house. Bereavement counselling, parent support groups, a resource library and newsletter are also offered.



## **Challenge Cancer Support Network**

1/491 King Street  
West Melbourne Vic 3003  
Telephone (03) 9329 8474

Provides ongoing support for children aged 4–18 years receiving treatment for cancers, and their families. Activities include week and weekend camps for parents and siblings, family reunion days, celebrity visits and newsletters.

## **Chronic Illness Peer Support (CHIPS)**

Centre for Adolescent Health  
Royal Children's Hospital  
2 Gatehouse Street  
Parkville Vic 3052  
Telephone (03) 9345 6616

Provides regular sessions for young people (13–24 years) to discuss issues related to living with a chronic illness and ongoing peer support. Also provides monthly information and support evenings for parents of young people living with a chronic illness.

## **■ ADOLESCENT SUPPORT GROUPS**

### **CanTeen Australia**

161 Flemington Road  
North Melbourne Vic 3051  
Telephone (03) 9329 5288

Offers support, information, education and recreation (through camps, outings and peer support) for teenagers with cancer and other life-threatening blood disorders, and their teenage brothers and sisters (12–24 years).

### **Camp Quality**

19 Graham Road  
Rosanna Vic 3084  
Telephone (03) 9459 4437

Offers week and weekend camps, ongoing contact and support, newsletter and weekend family camps for people with cancer aged 5–18 years. Is developing educational programs for schools. When a child/young person registers, he or she is assigned a camp to go on and a volunteer whose support continues throughout the year. A free puppet show is available for school performances, suitable for Prep to Year 6.

## **■ GRIEF SUPPORT SERVICES**

### **Family Bereavement Support Program**

C/- Royal Children's Hospital  
Social Work Department  
Flemington Road  
Parkville Vic 3052  
Telephone (03) 9345 6111

Offers a monthly parent group run by hospital social workers, monthly newsletter and sibling groups.

### **Compassionate Friends Bereaved Parent Centre**

267 Canterbury Road  
Canterbury Vic 3126  
Telephone (03) 9888 4944

Offers information and support through a newsletter, lending library and parent support groups. A self-help organisation for parents who have suffered the death of a child.

## ■ DISABILITY AND RELATED GROUPS

### **Association for Children with a Disability**

590 Orrong Road  
Armada Vic 3143  
Telephone (03) 9500 1232

Provides information, advocacy and support to parents and carers of children/young people with a disability. Produces a newsletter.

### **Headway Victoria**

2/212 King Street  
Melbourne Vic 3000  
Telephone (03) 9642 2411

Provides advocacy and information services for people living with an acquired brain injury. Provides useful information about respite care, training, support groups and entitlements.

### **Interchange Victoria Respite Care Association**

41 Somerville Road  
Yarraville 3013  
Telephone (03) 9687 0366

Arranges respite one weekend a month with a host family for children/young people with a disability, to give parents a break. Youth groups and holiday programs are also run by the organisation.

## **Department of Human Services**

Specialist Children's Services (under 6)  
Client Services (school age onwards)  
555 Collins Street  
Melbourne Vic 3000  
Telephone (03) 9616 7777 (or check the *White Pages* for your local office)

Offers a range of therapy and case management services. Also offers specialist programs such as the Behaviour Intervention Support Team, to support families who are having difficulty managing their child's/young person's challenging behaviours.

### **Noah's Ark Family Resource and Toy Library**

28 The Avenue  
Windsor Vic 3181  
Telephone (03) 9529 1466

Provides toys and equipment of therapeutic value for children with special needs. Includes toy lending services, family support, playgroups, camping programs and sibling support. Has outreach services in other localities.

## ■ SPECIALIST COUNSELLING SERVICES

### **Kids Help Line**

3/875 Glenhuntly Road  
Caulfield South Vic 3162  
Telephone 1800 551 800

Offers confidential telephone counselling 24 hours per day for children or young people aged 5–18 years.

### **The Bouverie Centre**

50 Flemington Road  
Flemington Vic 3031  
Telephone (03) 9376 9844

Offers a free specialist family counselling service for people affected by acquired brain injury.

## ■ FINANCIAL ASSISTANCE

### **Malcolm Sargent Cancer Fund for Children in Victoria**

C/- Royal Children's Hospital  
Flemington Road  
Parkville Vic 3052  
Telephone (03) 9345 6422

Provides emergency financial and emotional support to children/young people with cancer and their families during treatment for and recovery from cancer. Provides grants for tutoring for students who, as a result of their illness, have missed significant periods of schooling. Education officers can assist with these applications. The fund also supports social work positions at the Royal Children's Hospital and Monash Medical Centre.

## ■ RESOURCE PEOPLE IN SCHOOL EDUCATION

### **School guidance officers, psychologists, social workers and visiting teachers**

All students have access to the services of student support services officers including guidance officers, psychologists, social workers, speech pathologists, curriculum consultants and generic school support officers.

Visiting teachers are teachers with special training in physical or sensory impairment.

All of these officers can assist schools and parents with student management and educational programming.

### **Student welfare coordinators, year level coordinators, pastoral care coordinators**

These coordinators promote the welfare of all students, but particularly students with special needs, including cancer. This might involve the coordination of programs, activities or meetings to best meet their needs.

### **Regional coordinators, diocesan special education advisers**

These officers are located in the region/diocesan office of the Department of Education & Training/Catholic Education Office. They can assist in accessing additional resources to facilitate the successful integration of students with disabilities and special needs.

## **Victorian Curriculum and Assessment Authority**

Schools are authorised to apply Special Provision where a student undertaking the VCE is suffering illness or other serious cause. Students who are absent from school for prolonged periods of time may be able to continue their study at home and special arrangements may be made to allow the student to sit coursework tests or exams at home or in hospital. A number of other provisions are available—each case is assessed individually.

Schools and parents should contact the Student Records and Results Unit at VCAA on (03) 9651 4300 or email the unit on [student.records@edumail.vic.gov.au](mailto:student.records@edumail.vic.gov.au). It is important to get the correct advice as early as possible.

## **Centacare**

Each Catholic diocese has a Centacare office providing counselling services for student and community welfare issues. This service is available to all members of the community.

Telephone (03) 9287 5555 for referral to your local Centacare office.

## **Catholic Education Officers**

For information, contact:  
Catholic Education Office  
228 Victoria Parade  
East Melbourne Vic 3002  
Telephone (03) 9267 0228  
Email: [director@ceo.melb.catholic.edu.au](mailto:director@ceo.melb.catholic.edu.au)

## **Independent schools**

Independent schools vary in relation to how student welfare issues are handled. It is usual for a school counsellor to assist with student welfare policies and practices. It is the responsibility of each school to meet the needs of its students.

## **Association of Independent Schools of Victoria**

20 Garden Street  
South Yarra Vic 3141  
Telephone (03) 9826 6011

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# RESOURCES FOR TEACHERS OF STUDENTS WITH CANCER

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The following resources may be available from your local library. If you wish to buy copies, try [www.amazon.com](http://www.amazon.com) for the more difficult to obtain books. Some are available for sale from the Royal Children's Hospital's Child Health Information Centre: telephone (03) 9345 6429.

The Royal Children's Hospital Education Institute has a series of tip sheets relating to the re-entry process, self-esteem, body image, etc. These can be accessed from the website [www.rchmelb.org/edinst](http://www.rchmelb.org/edinst)

## ■ FOR TEACHERS

### ***Body and Soul—Children, Teenagers and Cancer***

M Ragg 1994, Hill of Content, Melbourne

A book about the experience of cancer. Provides information for the entire family to help deal with the illness and its consequences.

### ***Bone Marrow Transplants—A Book of Basics for Patients***

SK Stewart 1992, Bone Marrow Transplant Newsletter, Illinois

Written by patients for patients. Covers physical and emotional effects of bone marrow transplantation.

### ***Coping with Childhood Cancer***

DW Adams and EJ Deveau 1993, Kinbridge Publications, Ontario

Covers all aspects of coping with childhood cancer and diagnosis, treatment, remission, family, long-term survival, relapse, death and grief for survivors. Includes information for single parents. Has an excellent bibliography and glossary and is written in concise short chapters.

### ***Cancer Help—An Australian Source Book for Patients, Helpers, Family and Friends***

C Henderson and A Raymond 1988, Simon and Schuster, NSW

Provides details of Australia-wide government and support groups, books and tapes, and diet and nutritional advice.

### ***It Isn't Fair—Siblings of Children with Disabilities***

S Klein and M Schleifer (eds) 1993, Bergin and Garvey, Connecticut

First-hand accounts from brothers and sisters, discussing how they learned to deal with their feelings towards their 'special sibling'.

### ***Long-term Effects of Cancer Treatment—A Guide for Patients and Families***

M Zacharin, K Tiedmann & M Sexton 2001, Miranova Publishers, Melbourne

## **■ FOR STUDENTS (ALSO GOOD TEACHER RESOURCES)**

### ***You and Leukaemia—A Day at a Time***

LS Baker 1988, Harcourt, Philadelphia

A handbook on childhood leukaemia, written for children nine years and older. Also provides parents and carers with many insights into the disease and its management. Is an excellent resource for adults with low literacy.

### ***What's Up, Mate?***

H Bales 1987, Hodder and Stoughton, NSW

Written with the help of staff and doctors at Camperdown Children's Hospital, for children 5–12 years, to help them learn about their illness and treatment.

### ***Little Tree—A Story for Children with Serious Medical Problems***

JC Mills 1992, Magination Press, New York

Uses a healing metaphor to bring children comfort, inspiration and a sense of well-being. It includes an easy-to-learn relaxation technique, which helps children feel comfortable, reduce stress and fear and draw on their inner strength.

### ***What About Me? When Brothers and Sisters Get Sick***

A Peterkin 1992, Magination Press, New York

About a little girl's attempt to cope with her brother's illness. The story deals with the complicated feelings a child can experience in such situations: guilt about somehow having caused the illness, anxiety about catching it, and longing for life to return to the way it was.

### ***When Someone Has a Very Serious Illness—Children Learn to Cope with Loss and Change***

M Heegaard 1992, Woodland Press, Minneapolis

Designed to help children understand and express feelings when someone in their family has a serious illness. Educational concepts are presented in six units.

### ***Two Weeks with the Queen***

Morris Gleitzman 1990, Pan Books, Sydney

Deals with a country family coping with childhood cancer. Suitable for children Year 5 and older.

## **Videos (available for loan from The Cancer Council Victoria Resource Centre)**

### ***Been There Done That***

CanTeen (Australia) 1990, 30 minutes

A dramatisation of the situations that some teenage cancer patients have experienced, including returning to school after chemotherapy, dealing with hair loss and remaking friendships after long periods of hospitalisation. CanTeen members share their experiences and offer advice on how to cope.

### ***Young People Can(cer) Talk***

The Cancer Council Victoria 1998, 18 minutes

Five young people talk openly about the changes that occurred in their lives after they or a sibling were diagnosed with cancer. We hear about their diagnosis, different forms of treatment, how friends and families reacted to the news, boyfriends and girlfriends and some advice to viewers.

## ■ **GRIEF AND LOSS**

### ***Coping with Grief in My Own Way: The Bereavement Journal***

M McKissock and D McKissock 1996, ABC Books, NSW

Deals with the emotions and feelings experienced with the loss of a loved one.

### ***The Grief of Our Children***

D McKissock 1998, ABC Books, NSW

Explores the grief of children of all ages, and highlights aspects of grief at each stage of psychosocial development. Provides useful suggestions to empower grieving children, and provides hope, understanding and support for those who care for them.

### ***Something I've Never Felt Before***

D Zagdanski 1990, Hill of Content, Melbourne

Designed to help teenagers cope with grief, this book covers understanding grief, coping, acceptance and how friends, parents and teachers can help.

## ■ **INTERNET SITES**

Below is a list of websites that you might find helpful:

### **The Cancer Council Victoria**

[www.cancervic.org.au](http://www.cancervic.org.au)

### **Royal Children's Hospital Education Institute**

[www.rchmelb.org/edinst](http://www.rchmelb.org/edinst)

### **Leukaemia Foundation of Australia**

[www.leukaemia.com](http://www.leukaemia.com)

### **CanTeen**

[www.canteen.com.au](http://www.canteen.com.au)

### **The Never-Ending Squirrel Tale**

[www.squirreltales.com](http://www.squirreltales.com)

### **Cancer Help (UK)**

[medweb.bham.ac.uk/cancerhelp](http://medweb.bham.ac.uk/cancerhelp)

### **American Cancer Society (US)**

[www.cancer.org](http://www.cancer.org)

### **National Cancer Institute (US)**

[www.nci.nih.gov](http://www.nci.nih.gov)

### **BC Cancer Agency (Canada)**

[www.bccancer.bc.ca/uctm](http://www.bccancer.bc.ca/uctm)

### **Oncolink University of Pennsylvania Cancer Centre (US)**

[oncolink.upenn.edu](http://oncolink.upenn.edu)

### **Candlelighters Childhood Cancer Foundation (US)**

[www.candlelighters.org](http://www.candlelighters.org)

### **American Brain Tumor Association (US)**

[www.abta.org](http://www.abta.org)

### **The John Hopkins Oncology Centre (US)**

[www.med.jhu.edu/cancerctr/peds/cantype.htm](http://www.med.jhu.edu/cancerctr/peds/cantype.htm)

### **North of England Children's Cancer Research Fund. Children's Cancer Web (UK)**

[www.ncl.ac.uk/child-health/neccr/index.htm](http://www.ncl.ac.uk/child-health/neccr/index.htm)

# APPENDICES

## APPENDIX ONE:

## INFORMATION PRO FORMA ABOUT A STUDENT WHO HAS CANCER

<p>Student name: _____</p> <p>Year/class: _____</p> <p>Type of cancer: _____</p> <p>Parent(s): _____</p>	<div style="border: 1px solid black; width: 100px; height: 100px; margin: 0 auto; display: flex; align-items: center; justify-content: center;">             Photograph of student           </div>
<p style="text-align: right;">W</p> <p style="text-align: right;">H</p>	<p>_____</p> <p>_____</p>

Name:	Contact Numbers:
Doctor: _____	_____
Hospital: _____	_____
Social worker: _____	_____
Clinical nurse coordinator: _____	_____
Education advisors: _____	_____
Visiting teacher: _____	_____
School coordinator: _____	_____

## APPENDIX TWO: SAMPLE LETTER REGARDING NOTIFICATION OF MEASLES AND CHICKENPOX

School Name

Dear Parent/Carer

I write to inform you that a student in our school community is currently receiving medical treatment. He/she participates actively in the normal school program without any major limitations. A major concern, however, is if this student develops measles or chickenpox, he/she can become seriously ill. I seek your cooperation in preventing this situation.

If your son/daughter has or may have measles or chickenpox, I request that you do not send them to school during this period and notify the class teacher as soon as possible.

Yours sincerely

signed (Principal)



As survival rates for children and young people with cancer improve, more attention is being paid to the child's/young person's quality of life and to minimising adverse after-effects wherever possible.

School education is an important area of the student's life and disruptions to school life brought about by cancer and its treatment can leave an effect long after the illness has been cured.

Depending on the severity of the disease and the schedule of treatment, the amount of time a student might be absent from school can range from a short period of time to many months. The student may return to school, but can still require frequent periods of absence as treatment continues.

This resource aims to provide useful information for teachers and school communities who have a student with cancer. It is suitable for primary and secondary schools. It includes information on cancers that affect children and young people and their treatment, the impact of cancer on the child/young person and family, practical points for school staff to help them support students with cancer, and support services and resources.

The whole school community can participate and play a role in supporting a student with cancer, and the experience can contribute to learning and be positive and empowering for all involved.

Cover illustration by Bethany Higgerson

*Hi! My name is Bethany Higgerson. My nickname is BJ. I had Hodgkin's and was bored at the hospital. I was asked if I wanted to design a front cover for a book about kids and cancer.*

*I'm in Year 8 and my sister Rosemary is in Year 9. I'm 13 and Rosemary is 15. The other members of our family are Mum (Vicki), Dad (Graham) and Poss (our dog). I enjoy walking Poss and having fun with my friends! I'm in remission at the moment and enjoying my hair!*