



Invisible Illness

—an online resource about children and young people with chronic conditions for school communities



CANCER Entry

Organisations who wrote / approved the information

Cancer Council Victoria & Royal Children's Hospital

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A: FACTS ON THE CONDITION

1. General description, including different types, causes, prevalence, signs and symptoms

2. Treatments, including role of specialists, effects of treatments, use of devices, daily routines

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.

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.

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.

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

Rhabdomyosarcoma is a cancer of muscle, and soft tissue sarcoma is a cancer of 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 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, e.g. thyroid cancer. For more information about the specific disease, contact the haematology/oncology clinical nurse coordinators, or the Cancer Information and Support Service on 13 11 20.

B: THE CONDITION'S EFFECT ON THE CHILD/YOUNG PERSON

1. Effects on the individual

Each child and young person is unique and not everything you read here will be relevant to your situation. Openness and honesty is the best approach in disclosing and talking about a cancer diagnosis to a child, dependent upon the age and understanding of the child. When a child or young person is diagnosed with cancer, they may face intense emotion and fear from the people and community that surrounds them. Children and young people are often far less fragile than we think and open and honest communication is important.

Quite often, the child/young person is in hospital for extended periods of time for tests/treatments. They are often surrounded by strangers and separated from key family members (e.g brothers/sisters, father/mother) and friends during the duration of their hospitalisation.

Both the disease and treatment can produce physical changes in the patient, such as nausea, fatigue, decreased energy levels and reduced ability to participate in school activities. They may also have learning difficulties or decreased cognitive skills as a result of treatment. There are other possible changes that are temporary - including weight gain/loss, mood swings, hair loss, problems with coordination, body marks resembling tattoos and muscle weakness.

Any of these physical changes can result in fears of (or actual) teasing and rejection by peers and can create a reluctance to resume friendships or to return to school. The child or young person may also become concerned about missing school. They might also worry how friends are going to treat them and how they -- will catch up on all their schoolwork.

Young people with cancer also must face emotional challenges. They may fear relapse and the subsequent repetition of treatments. Emotional energy usually spent mastering basic developmental skills is now used to cope with illness. (For example, teenagers have difficulty attaining the independence so important to their development when the disease forces them to be dependent on parents and caregivers.) In addition, children and young people with cancer must learn to deal with others who treat them differently because of their disease; they may subsequently seem to withdraw, regress or become belligerent.

It is important to try and keep to the normal routines going where possible. Going to school, or staying at grandparents maybe part of a child/young person's routine. It is important to maintain the routine for both you and your child.

The health professionals involved in the patient's care as well as the school will have access to a range of good resources to assist the patient and those around her/him to manage the range of stressors that occur with the diagnosis and treatment of cancer.

2. Effects on those close to the child/young person

Parents

If parents are angry, sad, hostile or overly anxious, it is important to understand that these feelings are not necessarily directed at you. Parents that have a child with cancer face a host of emotional problems such as siblings becoming jealous of the attention lavished upon an ill child or strains associated with the child's illness being distorted within the adult relationship. The parents are placed under tremendous strain and are often in turmoil.

Continued sharing of information between parents and the school is extremely important. Most parents are willing to supply information when they realize the teacher shares their concern and wants to ensure the child's attendance at school is optimal to the child's management of the cancer diagnosis and treatment.

Siblings

Being the brother/sister of someone with cancer can be really hard. When children are diagnosed with cancer, the siblings may need to stay with friends or relatives as their mother and/or father may be living with the sick child in hospital. The siblings are often kept out of the information pathway so as not to worry them unduly. However siblings will worry enormously about their brother/sister. Siblings may feel guilty and wonder if they did something or said something to cause their brother/sister to get cancer. They may feel sad for quite a long time but this period of sadness usually goes away when the hospital stay is over and everything at home is back to normal. Siblings may also become jealous and feel left out. Being in hospital, missing school, and spending lots of time with Mum and/or Dad can look like a pretty good deal! Siblings can even think that people don't love them as much as the child with cancer. Other feelings could include anger - "how come bad things happen to my family?"; worry and fear about what is going on in the hospital; worrying that they or other family members might also get cancer; missing your parents and want their comfort. Reassurance, accurate information and comfort from trusted adults at this time is essential.

Grandparents

A grandparent may be involved with taking care of things on the homefront and so are only receiving medical information about the sick child second hand. They often worry about the effect of the grandchild's illness on their son or daughter and feel that life is very unfair putting such a burden on their child and their young family. The grandparents often put their own lives on hold so they can assist in this time of crisis. They may be tearful and angry about what is happening.

3. "In Their Shoes" - stories from children/young people with the condition

When I was told that I had cancer, I didn't know what it meant. It's not too bad but I don't like the treatments. The best thing about it is getting to tease the nurses and doctors. (Breanna, 6 yrs old)

When I was told I had cancer I was very scared because I heard from TV that cancer was a serious disease. But there was nothing I could do about it but wait to get it over with. (Jack, 9 years old)

C: STRATEGIES FOR SCHOOLS/TEACHERS

1. Overview of strategies for schools.

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

- Hair loss
- Weight changes
- Fatigue
- Limb amputations
- Change in body image
- Reduced concentration and learning difficulties
- Behavioural changes

Changes in peer relationships

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

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.

Education advisors at the Royal Children's Hospital Education Institute can provide advice on how to manage key issues relating to education faced by students.

Nominate a School Coordinator

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

Meet with the student and parents regularly to determine their needs and preferences and to monitor progress.

Be aware of any siblings that attend the school and inform relevant staff of the situation.

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.

Contact the Clinical Nurse Coordinator (03) 93455652 and Royal Children's Hospital Education Institute (03) 93225100

These people can liaise with the education advisor and provide information to teachers and classmates. In some cases they are available to visit the school if the parents agree.

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

It is important that the school maintains contact with the student through all periods of absence. This includes hospital stays and recovery time at home.

Please Note: This is only a summary of the book "When a student has cancer: A resource for teachers and school communities, (Royal Children's Hospital Education Institute & Anti-Cancer Council of Victoria, 2000)".

2. Link(s) to useful other online resources for schools on strategies in responding to a child/young person with this condition

The book "When a student has cancer: A resource for teachers and school communities, (Royal Children's Hospital Education Institute & Anti-Cancer Council of Victoria, 2000)". can be found online at the RCH website: www.rch.org.au

D: FURTHER INFORMATION

1. Organisations, including services and resources available

2. Reading, including links to downloadable documents

Royal Children's Hospital Education Institute

Phone: (03) 9322 5100

Support and information

Internet Address: www.rch.org.au

Royal Children's Hospital Multi-Disciplinary Support Staff

Phone: (03) 9345 5522

Treatment, information and support services

Monash Medical Centre Paediatric Multi-Disciplinary Support Staff

Phone: (03) 9594 6666

Treatment, information and support services

Cancer Council Victoria (CCV)

Service to metropolitan and regional Victoria

1 Rathdowne Street

Carlton VIC 3053

Phone: (03) 9635 5000

Toll Free: 13 11 20

Email Address: enquiries@accv.org.au

Internet Address: www.accv.org.au

Cancer Council Victoria Cancer Information and Support Service

Phone: 13 11 20

Hours: 9.00 a.m. - 5.30 p.m. weekdays

Nurse Counsellors provide referral to support services and resources on childhood cancer, e.g. the books and brochures:

When a student has cancer: A resource for teachers and school communities (Royal Children's Hospital Education Institute & Cancer Council Victoria, 2000).

Resources for children and adolescents who have a parent with cancer are also available.

Kids' Links at: <http://www.rch.unimelb.edu.au/gcrc/patinfo/kidslinks.htm>

Cancer Council Victoria Welfare Grants

Emergency grants are available to families. These are accessed through the Paediatric Social Worker at the Royal Children's Hospital and at Monash Medical Centre or directly through the Cancer Information and Support Service.

Network of Childhood Cancer Groups

These groups meet quarterly and the Cancer Council Victoria produces a calendar of their events to inform families and hospital staff. The Network runs a Sunday family seminar every two years.

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Camp Quality

Phone: (03) 9459 4437

Family support and activities

CanTeen

Phone: (03) 9329 5288

Teenage patients' and siblings' support and activities

Challenge Cancer Support Network

Phone: (03) 9329 8474

Patients' and siblings' support and activities

Children's Brain Tumour Association

Phone: (03) 9388 9194

Family support and information

Geelong Paediatric & Adolescent Support Service (PASS)

Phone: (03) 5226 720

Family Support and activities

The Koala Support Group

Phone: (03) 9802 2229

Family support and information

Leukaemia Foundation

Phone: (03) 9620 1815

Family support and information

Young Ostomy Support Group

Phone: (03) 9219 8597

Family support and information

Ronald McDonald House - Monash

Phone: (03) 9562 6223

Accommodation and family support during treatment

Ronald McDonald House - Parkville House Inc

Phone: (03) 9345 6300

Accommodation and family support during treatment.

The Malcolm Sargent Cancer Fund for Children (Victoria) Ltd

Phone: (03) 9345 6422

Financial assistance to families

Make A Wish Foundation of Australia Ltd

Phone: (03) 9523 2000

Special grants

Starlight Children's Foundation

Phone: (03) 9287 1399

Special grants