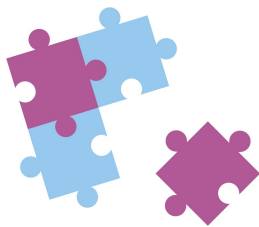


Childhood Cancer:

**Funding Priorities in Paediatric Oncology
and the Associated Areas of Support.**

Produced by

KIDS CANCER RESEARCH TRUST



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1 Introduction

In Australia in 2001, 603 children under the age of 15 were diagnosed with cancer, while in the same year 113 died from their disease. 35% of these children died from a brain cancer and 32% from leukaemia.¹

Although cancer is considered rare in children, it is still the leading cause of disease related death in children aged 1 to 14 and second only to poisons and injury related fatalities.

The most concerning aspect of the previous statistics is that the cause of these cancers in children remains uncertain. Certain chemicals and viruses may foster the onset of some cancers, while hereditary factors may also play a role. However, one thing proves to be abundantly clear, the causes of these cancers need to be found. It is often said that *an ounce of prevention is worth a pound of cure* and the weight of this statement finds added meaning in this area. The emotional, physical and economic toll that cancer wreaks on not only the child but the entire family is profound.

To add insult to injury, a child who has been cured of their initial cancer has an increased risk of developing second cancer in later life. The level of the risk depends on the type of cancer and how it is treated. Family history and the age of a child when first treated have also been suggested as important factors. Long-term follow-up health assessments are vital to these children; so is counselling and support groups because they assess a child's coping abilities and help the family readjust to a new lifestyle.²

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2 Major Types of Childhood Cancers

2.1 Leukaemia

Leukaemia is a cancer of the blood cells. It is the most common childhood cancer accounting for 32% of cancer related child deaths in 2001.

Types of Leukaemia include:

- Acute Lymphoblastic Leukaemia (ALL) – also known as “childhood Leukaemia” because it is the most common childhood cancer. Up to four fifths of children with Leukaemia have this type of cancer. (www.cancerindex.org/ccw/guide2c.htm)
- Acute Myelogenous Leukaemia (AML) – cancer of the bone marrow.
- Chronic Myelogenous Leukaemia (CML) – rare in children accounting for less than 5% of all childhood Leukaemia.

2.2 Lymphoma

Lymphoma is a tumour of the lymphocyte (lymph) tissue. These tissues are wide spread throughout the body and, among other places, exist in the stomach, intestines and skin.

Types of Lymphoma include:

- Non-Hodgkin’s Lymphoma – There are two main categories of non-Hodgkin’s Lymphoma, B-cell and T-cell Lymphomas with the B-cell type being to most common ³⁷. This cancer is most common in children between the age of 2 and 10 and it is more common in boys than girls.
- Hodgkin’s disease or Hodgkin’s lymphoma – is a cancer that affects the lymph nodes that are closer to the body’s surface, such as neck, armpit and groin area. This type of cancer commonly affects children aged 15 and over ³⁸.

2.3 Sarcomas

Cancerous tumours developed in the bodies connective tissue (muscle, tendons, fat, nerves, blood vessels, fibrous tissues) are classified as sarcomas ³⁹.

Bone Sarcomas include:

- Osteosarcoma – is the most common type of bone sarcomas in children and the sixth most common malignancy in children ³⁸. The cancer is most common between the ages of 10 and 25.
- Ewing’s Sarcoma – Common sites include the hipbones, thighs, upper arms and ribs. This cancer occurs most commonly between the ages of 10 and 25.
- Chondrosarcoma – is the second most common primary bone cancer and is formed in the cartilage. Although this type of cancer is most common in adults in can also occur in children ³⁸.

2.4 Soft Tissue Sarcomas

- Rhabdomyosarcoma – is the most common soft tissue sarcoma in children and develops in muscles ³⁸. It is often found in the neck, kidneys, bladder, arms and legs and occurs most commonly in children aged 2 to 6 years of age ³⁸.

2.5 Liver Cancer

Liver cancer is relatively uncommon accounts for less than 5% of all childhood cancers. Most frequent forms of liver cancer in children are:

- Hepatoblastoma – is very rare and can be hereditary. It mostly affects children under the age of three years.
- Hepatocellular cancer – has been associated with viral infections of the liver including hepatitis B or C. Children infected with these conditions are more susceptible to this type of cancer. This cancer occurs most often in children under the age of 4 and those aged between 12 and 15 years ³⁸.

2.6 Other Cancers

- Brain and Spinal Cord Tumours – are the most common forms of solid tumours in children with spinal cord tumours being the less frequent of the two. Gliomas account for the majority of diagnoses, most often in children from birth to 15 years of age ³⁸.
- Wilms' Tumour – is the second most common type of solid tumour found in children. It begins in the kidney and can affect both simultaneously ³⁸.
- Neuroblastoma – mostly occurs in children under the age of five. It is a cancer of the sympathetic nervous system and the most common tumour outside of the brain ³⁸.
- Retinoblastoma – is a common malignant tumour of the retina. The tumour can appear in one eye or both and is mostly found in children less than 5 years of age ³⁸.

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3 Childhood Cancer Statistics

3.1 Australia

According to the Australian Institute of Health and Welfare (AIHW) in their publication 'Australia's Children: Their Health and Wellbeing 2002'³², childhood cancer accounts for only 2% of all cancers occurrences in this country. The yearly incidence rates between 1991 and 1998 show very little change in the numbers of newly diagnosed cancers per 100,000 children (figure 1). This static trend has been apparent over the last two decades.³³

	Age (years)	1991	1992	1993	1994	1995	1996	1997	1998
Males	0-4	22.1	20.8	24.1	23.6	24.0	23.3	21.6	21.3
	5-9	11.6	13.9	10.4	13.2	13.6	10.9	12.8	13.3
	10-14	11.4	11.4	14.6	13.9	11.9	15.8	13.8	13.7
	0-14	15.1	15.4	16.4	16.9	16.5	16.7	16.1	16.1
Females	0-4	17.8	19.3	19.1	17.1	18.6	19.2	20.7	19.4
	5-9	9.5	10.4	8.3	10.9	9.5	12.1	7.0	11.2
	10-14	12.4	11.2	13.0	10.4	9.8	14.3	11.9	12.5
	0-14	13.2	13.7	13.5	12.8	12.7	15.2	13.2	14.4
Persons	0-14	14.2	14.5	15.0	14.9	14.7	15.9	14.7	15.2

Note: ICD-9 codes 140-208 (excluding 173).

Source: AIHW National Cancer Statistics Clearing House.

Figure 1: Incidence rates of cancer in children aged 0-14 years, 1991-98

In 2003, 99 children, 60 males and 39 females, died nationally with neoplasm listed as their cause of death. This equated to a rate of 2.7 children per 100,000 for all states combined.¹

At a state level, in New South Wales children, there were 201 cancers diagnosed (112 males and 89 females) in 2002 with the most common cancers being leukaemia (35%) and cancers of the central nervous system (15%). These two cancers also proved to be the most common malignancies in children aged 0-14 years.³

Cancer affects approximately 1 in 7,000 children up to 14 years of age. Without medical treatment most childhood cancers are fatal.⁴

In 1960 only one child in 25 with Leukaemia survived. Now 18 in 25 survive.³⁴

3.2 Other Nations

Statistics show that 1 in every 200 cancers, or 0.5%, diagnosed in Great Britain occurred in a patient under 15 years of age. In 2000, this equated to approximately 1400 new cases of cancer in children being reported. Like Australia, the incidence rate has not changed significantly over the last few decades however cancer accounted for almost 20 percent of all deaths in children.⁵ A child in the UK has a 1 in 500 chance of being diagnosed with cancer before their fifteenth birthday³⁵

In the United States of America, it is estimated that over 9500 children under the age of 15 years will be diagnosed with cancer and almost 1600 will die from the disease in 2005 alone. Of these 1600, 33 percent are expected to be as a result of leukaemia. ⁶

The childhood cancer incidence rate for the US in 2002 was 14.6 children per 100,000 ²⁹ which is very similar to the figures obtained for Australia and the UK.

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4 Treating Paediatric Cancer

4.1 Types of Treatment

The exact type of treatment a child receives will obviously depend heavily on the type of cancer they have been diagnosed with. Most children with cancer will receive either;

- Surgery
- Radiation therapy
- Chemotherapy

In some cases a combination of these three treatments will be used ³⁰.

4.1.1 Surgery

The primary goal of most surgery is to remove the cancerous tumour. This is usually done on an inpatient basis in most hospitals by a paediatric surgeon while recovery time can understandably vary greatly. The surgery may be followed by radiation therapy and/or chemotherapy to further the patient's treatment depending on the size and location of the tumour. However, this order is not necessarily adhered to in each case. These treatments may be used before surgery to shrink tumours and make them easier to remove ³⁰.

4.1.2 Radiation therapy

Radiation therapy can be used alone or in combination with other therapies. This type of therapy, which is most commonly done on an outpatient basis in hospitals, uses high energy X-rays to destroy cancer cells while attempting to minimise damage to healthy tissues surrounding to site of interest. The treatment may take several weeks to complete.

Side effects of this particular treatment depend on where the radiation is aimed and what types of tissue surround the site. Side effects may include, but are not limited too;

- Damage to skin. Treated areas should be protected from sunlight and irradiation.
- Sore mouth when the head and neck area is included in the treatment.
- Temporary hair loss from the area receiving radiation.
- Diarrhoea, nausea, vomiting or headaches. Medication given before or following the treatment can alleviate some of these side effects.

(as taken from the Yale New-Haven Children's Hospital Website ²⁹)

4.1.3 Chemotherapy

Chemotherapy is the use of special drugs to stop the growth of cancer cells. Each drug often kills cancer cells in a different way and sometimes several drugs are given simultaneously.

Chemotherapy medications can be delivered in a variety of ways including;

- Orally
- Intramuscularly
- Intravenously
- Directly into the spinal fluid

Like all treatments, chemotherapy can produce side effects. Just as a course of chemotherapy medication kills cancer cells, it also kills healthy cells in the body, such as bone marrow cells that would otherwise mature into blood cells. Consequently chemotherapy can reduce the numbers of blood cells in the body, which can create additional problems for the patient. As a result, children who receive this therapy must be watched for signs of infection. Additionally, because the numbers of red blood cells and platelets are reduced, blood transfusions may be required in order to stabilise a weak system³⁰.

Other side effects may include:

- Nausea and vomiting
- Pain
- Mouth sores
- Hair loss
- Constipation
- Mental or nervous system changes (lethargy, tiredness, lack of coordination)³⁰

In the United States of America, leukaemia treatments are one of the most expensive and prolonged treatments used for children. Furthermore, chemotherapy treatments are often not successful the first time. Additional treatments may be necessary if the patient does not go into remission or upon a relapse of the cancer. Other options include bone marrow transplants which can add further stress and discomfort to all involved. In the US chemotherapy programs often cost in excess of \$150,000US and bone marrow transplants cost in excess of \$250,000US.³¹

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5 Areas for Research in Cancer Treatment

5.1 Finding the Causes of Cancer in Children

Investigate the causes of cancer so that the exposure can be minimised and the development of cancers prevented.

The causes of childhood cancers are largely unknown. A few conditions, such as Down syndrome, other specific chromosomal and genetic abnormalities as well as ionising radiation exposures, explain a small percentage of cases, however, this is unlikely to be sufficient to successfully implement prevention initiatives ²⁹.

Environmental causes of childhood cancer have long been suspected by many scientists but have been difficult to conclusively identify, partly because cancer in children is rare, and partly because it is so difficult to isolate past exposure levels in children. These exposures may occur during potentially important periods such as pregnancy or even prior to conception. In addition, each of the distinct types of childhood cancer develops differently – with a potentially wide variety of causes and a unique clinical course in terms of age, race, gender, and many other determining factors... It is expected that identifying environmental factors that impact on cancer risks will be a slow and tedious worldwide research project. ²⁹

Environmental agents have been linked to cancer in children by researchers in the past. X-rays and certain chemicals used for chemotherapy have provided evidence that their use can cause leukaemia and that exposure to DES (diethylstilbestrol), a synthetic chemical hormone, prior to birth can cause vaginal cancers in young women ³⁶. It is often assumed that susceptibility to cancer begins at birth however this is not always the case. A great deal of evidence suggests that the precursors for cancer in a child may develop before that child is even conceived. With this in mind it may be important for research to take place into factors that increase the risk of cancer in children so that people can make informed decisions when exposing their children and themselves to known risks. ³⁶

5.2 Understanding Cancer

Increasing our understanding of this disease should allow us to improve diagnosis and treatment strategies.

There are many different directions cancer research can take, however, it is primarily governed by our existing knowledge of cancer and the way it affects the body. Future directions need to be focused on 'completing the picture' of cancer to develop the knowledge base required to provide the best possible medical care at the cellular level.

These directions could include;

- Investigating the formation and progression of each cancer type
- Developing a greater understanding of the unique nature of childhood cancers
- Understanding how a cancer occurs hopefully leading to better treatments
- Understanding why current therapies are not always effective, hopefully allowing for better initial treatment selection
- Identifying new anti-cancer therapies
- Following up cancer survivors to determine the long term effects of childhood cancer

5.3 Improving Diagnosis

The key to effective treatment of childhood cancer is early and accurate diagnosis.

Childhood cancers progress rapidly, often assisted by the natural speed of growth inherent in a child's tissues. A quick diagnosis greatly enhances the chance that the child will survive cancer to live a long life. Treated properly, the majority of children diagnosed with cancer have a good chance of being cured.

Symptoms which can indicate a developing cancer in a child include unexplained weight loss, headaches often with early morning vomiting, swelling or persistent pain in bones, joints, back or legs, mass in abdomen, neck, chest, pelvis or armpit, development of excessive bruising, bleeding or a rash, constant infections, whitish colour behind the pupil, constant tiredness or paleness. To exacerbate the problem, most of these symptoms can also be attributed to common benign conditions and often do not raise alarms for doctors and parents alike.

Research into providing rapid and accurate tests for children at risk and the general public could reduce the length of time a cancer goes untreated. With treatment advances being made all the time, work on testing and diagnosis may provide a valuable path of research.

5.4 Finding Treatments

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This includes development of new anticancer drugs and research into other possible methods of curing childhood cancer.

The report, “Making Better Drugs for Children with Cancer”¹, analyses childhood cancer treatments in the light of historic advances.

“Over the past 40 years researchers and clinicians have achieved long term survival for most children and adolescence with cancer,” paediatric oncologist Peter C. Adamson, M.D. “however, our therapies are not curative for 30 percent of children and for children who are cured, the short term and long term side effects of current treatments are often too high.”²⁸

An important consideration in the issue of childhood cancers is the relatively small number of children with cancer when compared to the adult statistics. Due to this, pharmaceutical companies would not consider it as profitable to invest in research and development for paediatric drugs. Currently, many existing adult cancer drugs are utilised to treat children, but many of these drugs have toxic side effects²⁸. With this in mind, drugs being developed for adult cancers may still prove useful for children with less common cancers.

“The major childhood cancers are often distinct from adult cancers at the level of molecular abnormalities, and more focused research and development might allow us to better target those abnormalities,” Dr Adamson is quoted in the same report. “More targeted drugs might not only allow us to better attack the most difficult childhood cancers, but also cause fewer toxic side effects, by sparing healthy cells”²⁸.

The report suggests that many ‘*components of a paediatric drug pipeline already exist in academic medical centres, industry, universities, and in federal centres*’²⁸. This includes synthetic and natural products, laboratories to screen compounds for anticancer activity, drug discovery databases, and programs to support drug assays and clinical trials. A network to put all these pieces together into a paediatric drug pipeline would provide a perfect opportunity to further the research already going on into children’s cancer⁴¹.

5.5 Following up Childhood Cancer Survivors

One tool to further the advances in childhood cancer treatment could be to monitor the progress of people treated for cancer in their youth. Long term information like this can help in balanced decision making regarding the pros and cons of treatment methods and the effectiveness of each. It can also allow future treatments for sufferers to be tailored to avoid unwanted reactions and late presenting side effects without compromising a cure.⁸

¹ Published by the Institute of Medicine

At present there is a project being run in Australia as a collaboration between the Centre for Children's Cancer and Blood Disorders at Sydney Children's Hospital and the Children's Cancer Institute Australia for Medical Research (CCIA). The three major aims of the work are

- Monitoring survivors to gain new knowledge about the side-effects of cancer treatment.
- Education of survivors and their carers about the late-effects of treatment and early interventions to minimise side effects.
- Use of newly gained knowledge about the long-term effects of cancer therapy to influence the design of current cancer treatment protocols.

More information is available from the projects website found at <http://www.ccia.org.au/>

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6 The Need for Support

Over the last 30 years, survival into adulthood has increased from 30 to 80 percent⁹. A success of this magnitude can be due to better drugs and the use of child models in clinical trials. Previous sufferers of cancer as children can now enjoy an improved quality of life and fewer long term health issues than ever before⁹.

Despite these increases, children are still diagnosed with cancer, both curable and terminal forcing parents to make some very hard decisions. On top of the distress an ill child can cause, decisions must be made about the type and location of care and treatment as well as whether or not to utilise drugs and machines above and beyond the treatment of the cancer, to prolong their child's life.⁹

When a child is diagnosed with cancer this clearly places increased stress on the child and the child's parents and siblings. Macquarie University's Psychology department is examining the effects of childhood cancer on families. Childhood cancer affects a growing number of people worldwide. Although the type and severity of childhood cancers differ, they all affect a child's quality of life and family interactions.

*“Due to the diverse nature of childhood cancer and the vast number of families that are affected, it is important to look at how the condition impacts on other children in the family”
Kathryn Wakely, Researcher, Macquarie University.¹⁰*

Finding out that a son or daughter has cancer is a terrifying nightmare that thousands of parents from all over the world face each year. Although the type and severity of childhood cancers differ, they all affect a child's quality of life and interactions within a family.

A study titled *‘The psychological adjustment of children with chronic conditions’* was supervised by the University of Adelaide and Flinders University in 2000. In this report, recommendations regarding the support required by families with chronically ill children and the children themselves were detailed. These guidelines were ... *developed by a process of reviewing the literature and consulting with care providers and consumers.*¹¹

In summary, the guidelines are as follows:

- Practical support: clear communication between all of the healthcare professionals involved and the families is a must; practical assistance with finances, transport, respite care and recreation and well as choice of supports ¹². Staff and peers at school may also require support. A tangible benefit from involvement in self help groups was reported by some parents ¹².
- Multidisciplinary teams: Assessments by well qualified teams can improve communication between professionals, children and families as well as identify areas of immediate and future needs for both the child and their family and support group ^{12, 11}.
- Self determination: Children with chronic conditions should be allowed to take an active role in deciding which professionals participate in their care, what form of treatment they want, and how much of a part they wish to play in their own treatment ^{12, 11}.

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7 Australian Support & Research Resources

This list is by no means exhaustive and is simply meant as an indication of the wide range of support services available.

Kids Cancer Research Trust- The charity supplies Patient Accommodation to patients and their families who need to travel to metropolitan hospitals for appropriate treatment. The charity also conducts research projects, provides financial assistance to patients and their families and is active in community education programs about prevention.

3 Boys Legacy Inc. - The foundation is based in Western Australia and was established in 1998 to promote research into childhood brain cancer. The website includes details of events, sponsorship and research projects.

Camp Quality Australia - *Camp Quality is a non profit organisation that is committed to bringing hope and happiness to every child living with cancer, their families and communities through ongoing quality recreational, educational and financial support programs.* (as quoted from Camp Quality Australia's website www.campquality.org.au)

CanTeen (Australia) - A national group founded in 1985 by teenagers. It provides support for teenagers and young adults (ages 12-24 years) living with cancer and their teenage brothers and sisters.

Children's Leukaemia and Cancer Research Foundation (Inc) - The foundation was formed by parents of children with cancer, concerned supporters and with the support of the children's hospital to establish a childhood leukaemia and cancer research facility in Western Australia.

Children's Oncology Group (COG) - COG was formed by the merger of 4 major research organisations (CCG, POG, NWTG and IRSG). Member institutions treat nearly 90% of children with cancer in the USA and Canada, there are also centres in Australia and Switzerland.

Children's Cancer Institute Australia - (Randwick, New South Wales) Formed in 1976, the Institute is involved in research in conjunction with children's hospitals throughout Australia.

New Children's Hospital - New South Wales (Australia) A dedicated paediatric hospital, located at Westmead, near Sydney. The oncology unit treats between 120-150 children with cancer each year. There is an associated Oncology Research Unit undertaking laboratory investigations

Redkite - formerly the Malcolm Sargent Cancer Fund for Children in Australia, it provides funding counselling, tutoring grants, music therapy, bereavement support and family activity days to its clients. Based in NSW, Qld and WA it provides national coverage.

8 Improving Quality of Life

8.1 Living with Cancer

A child diagnosed with cancer faces an uncertain future. While advancements in the treatments for cancer have come a long way in a short time; treatment is still long and often painful. The treatment may involve long stays in hospital which is disruptive to the family and child. Important aspects of a child's life can be halted to make time for treatment including school, sporting events and friendships.

These children may experience long-term physical side effects from treatment: ¹⁹

- *Cardiac problems (heart muscle damage)*
- *Fatigue, malaise, loss of energy*
- *Hearing loss*
- *Muscular weakness, gait changes, poor balance.*
- *Compromised organ functioning*
- *Sleep problems*
- *Discomfort pain*
- *Limb amputation/reconstruction*
- *Mouth sores*
- *Loss of hair on head, eyebrows, eyelashes*
- *Damage to tooth enamel*
- *Surgical Scars*
- *Irritability, mental confusion, behavioural changes*
- *Dizziness*
- *Nausea/vomiting*
- *Loss of sensation, partial or full paralysis*
- *Diarrhoea or constipation*
- *Weight gain/loss*
- *Headache/pressure within the skull*
- *Anaemia, easy bruising*
- *Visual impairment*

(as taken from 'Teaching Exceptional Children' ¹⁹)

One of the most overlooked effects of a cancer diagnosis for a child is psychological damage which can be done. The feeling of invincibility associated with youth is fragile and to be faced with the fact that everyone can be in mortal danger is a massive shift of focus for a child. The chance of suffering depression, insecurity, and anxiety is understandably high. Sufferers may fear relapse, constant treatment and side effects. Emotional energy usually spent mastering basic development skills is now used to cope with this disease. ¹⁹

Cancer will also have an effect on the social life of sufferers. Time usually spent on normal childhood activities becomes filled with treatments and appointments. Even if the time was still available in its prior abundance, the sufferer may be forced to sit out activities because of strength reductions, mobility, tiredness and risk of infection ¹⁹.

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Cognitive development can also suffer as a result of treatment for cancer and can range from mild to severe. The decline in performance often resembles nonverbal learning disabilities or attention deficit disorder ^{22, 19}. The most serious effects result from high-dose radiation to the brain used to treat specific forms of brain tumours. Lower dose radiation and chemotherapy however, often produce less severe, subtler, and often later occurring learning disorders. ^{23, 19}

Some neurological effects of radiation and chemotherapy treatment may only become apparent years later when academic demands change ¹⁹. These effects, which include the list below, may not be acknowledged as part of the cancer treatment because of the time delay involved:

- *Neurological Damage*
- *Short/long term memory impairment*
- *Information processing problems and deficits*
- *Poor retention of new learning*
- *Delayed speed of mental processing*
- *Spatial orientation problems*
- *Poor sequencing*
- *Motor Planning dysfunction*
- *Decline in performance between 2 and 5 years*
- *Sustained attention and vigilance problems*
- *Resembles nonverbal learning disabilities*
- *Visual-spatial-motor coordination impairment*
- *Body image disorientation.*

(as taken from 'Teaching Exceptional Children' ¹⁹)

8.2 Returning to School

Being diagnosed with cancer is a life altering experience. It can be very important to retain some normality in a child's life. One way this can be achieved is through resuming the child's schooling routine.²⁰ Research has shown that if children do not re-enter school early in their illness, if even for a short period, they find it much more difficult to return at a later time.²⁶

Many children return to school in compromised physical states, often while still undergoing treatment. This means that children may have limited physical ability and may require nursing interventions during a school day. Treatments such as chemotherapy affect a child's immune system, making even a common cold or influenza a serious health threat. The issues that must be considered as a child returns to school are often further reaching than medical concerns alone. Many treatments can have serious effects on children's psychological, cognitive, academic and psychosocial development.

²¹
There may also be other obstacles to overcome like frequent absences, overprotection or overindulgence by parents, and social isolation.

In order to cope with the many stresses associated with a return to school children require strong family and teacher support.

The needs of other children in a class must also be taken into account. Class-mates can have a range of emotional reactions to the child's return. Many children's experience with cancer will be limited, they will not understand that it cannot be passed from one person to another.²⁷ They may also have experience with a grandparent that has died from cancer and assume that death is inevitable. Classmates may also be upset by the different appearance of their friend, they may be unsure how to play or talk with the child. A lack of understanding can also result in comments which may be hurtful or embarrassing to the sensitive returning child.

Before a child returns to school, teachers should prepare the class for the arrival of their peer. It may be useful to have someone visit the class to explain the disease and treatments used to deal with cancer. Children in the class could each be supplied with an information pack to take home, this is likely to initiate discussion with parents and allow for concerns to be easily expressed. Confidentiality and the child's wishes should not be breached, however, ensuring the class is made aware of the situation can reduce the feelings of isolation felt by the returning child.

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9 Long-Term Health of Children Treated for Cancer

For all childhood cancer combined, 5 year relative survival rates have improved markedly over the past 30 years, from less than 50% before the 1970s to more than 70% in the late 1990s, largely due to new and improved treatments ⁶. The exact survival rates vary considerably depending on the specific type of cancer. For the period spanning from 1995 until 2000, the 5 year survival rates for all cancers combined is 79% ⁶. The cancer type specific breakdown is shown in figure 2.

Cancer	5 Year Survival Rate
Neuroblastoma	66%
Brain and Other Nervous System	73%
Bone and Joint	73%
Leukaemia	79%
Kidney	92%
Hodgkin's Lymphoma	96%

Figure 2: 5 Year Survival Rates (6)

With the survival and recovery of childhood cancer sufferers increasing, the appearance of treatment related side effects several months or years after the cancer is not uncommon. Late treatment effects can include organ malfunction and secondary cancer ⁶.

Consequently, as more children survive cancer and reach adulthood, it is becoming vital to track the health and illness of these people ¹⁴. As previously discussed in section 5.5 of this report the collation of this information is the first step to finding where the priority areas lie. In addition to the Australian study mentioned there are several American studies underway which will help to shape the direction of cancer treatment in the future ¹⁴.

It has been shown that women who received radiation for Hodgkin's disease when they were children are at an increase risk of developing breast cancer later in life ¹⁴. Research is required into trying to prevent the development of this secondary cancer. Understandably the first priority of research has been to finding a cure for the primary cancer, as medical advances see more and more suffers reach adulthood it is important that resources are allocated into looking at this secondary cancer risk.

The use of anthracyclines (a class of chemotherapy drugs) in the treatment of sarcomas is linked to cardiac damage, although there is very little understanding as to the nature of the link. In 2003, a study was approved in the US to examine the effect on cardiac function of these drugs ¹⁴.

Childhood suffers need to know what challenges they can expect later life because of their illness. An understanding of the long terms effects of cancer and its treatments, which can be provided by research, will allow for informed decision making; while also allowing the use of preventative measures.

10 The Economic Cost of Childhood Cancer

Between 1993-1994² the total cost of childhood cancer (children aged 0 to 14 years) was 53.9 million of which 79% was categorised as hospital expenses (see figure 3). During this period there were 533 new cases and 147 deaths reported.

Australian Health System Cost of Childhood Cancer in 1993-94
(in millions of dollars) source: AIHW Cat No HWE 8

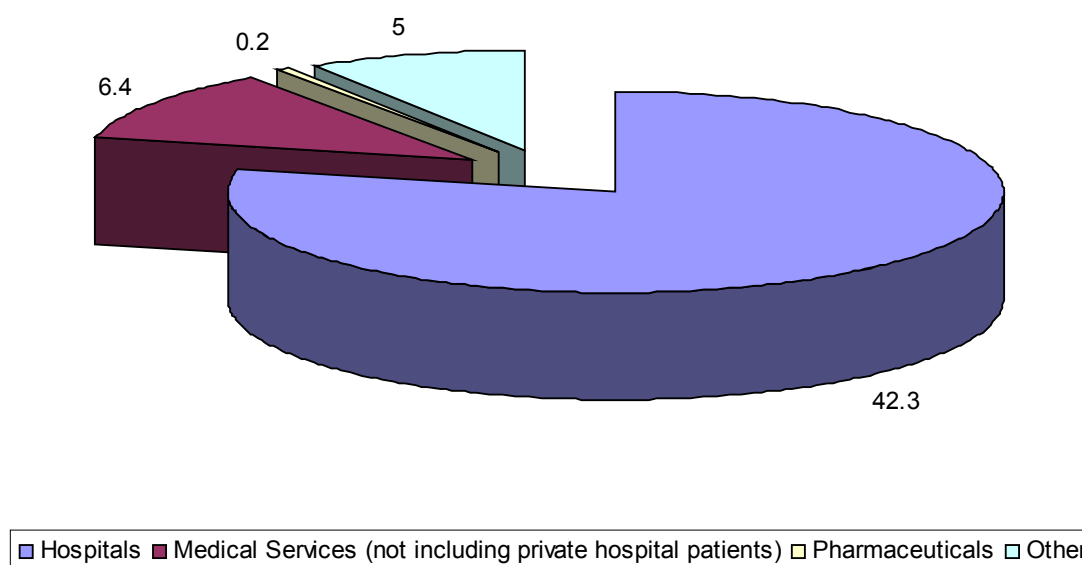


Figure 3: Economic Cost of Childhood Cancer

The treatment cost for cancer varies enormously depending on the type of cancer. The lifetime treatment cost of 1 case of leukaemia is around 58,000¹⁵. The average treatment cost per new case of cancer (all age groups) is estimated to be around \$16,000.

Lymphoma - \$18,500 per case
Brain & CNS - \$25,300 per case
Kidney - \$15,800 per case

These figures indicate only the direct treatment costs, as calculated by the Australian government. There is an increased financial burden placed on parents who are caring for a child diagnosed with cancer as concluded by a study conducted in New Zealand and published in the Journal of Paediatrics and Child Health, 2003.

A cross sectional survey of parents of 237 children throughout New Zealand was completed during the period 1990-1993. Of these 237 families, 192 of

² Although the figures quoted are dated 1993-94, the AIHW document in which they were reported was published in 1998. At the time of writing the latest version of this document was unobtainable.

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the children were still alive and 45 had passed away at the time the study was commenced. The dollar amounts were adjusted to the equivalent of December 2000 and on average, the extra amount spent, because of the child's illness, by the family of a living child was NZ\$220. On average this was 13% of the family's income after tax. After reported entitlements to various sources was allowed for families were left with a mean deficit of NZ\$157 for the 30 days. Of these 237 families, twelve had shortfalls of more than NZ\$500, including 3 families that had a shortfall of more than NZ\$1000. Expenditure was found to be greater for those whose children spent more time in hospital. For 24 families, the after-tax income in the month prior to participation in the study was at least NZ\$500 lower than it had been the month prior to the child's diagnosis. Most importantly, thirty-seven per cent of families reported that they had to borrow money because of the financial effects of their child's illness. ¹⁸.

The final part of the financial picture is the fact that a parent may be required to leave work to provide adequate care for the child. Additionally, new treatments, particularly those still in the trial phase, can require families to output significant amounts of money to participate when they are not covered by government subsidy schemes.

11 Adolescent and Young Adults with Cancer

Although progress in the treatment of childhood cancer over the past three decades is one of the most dramatic advances in medical history, adults and young adults with cancer have had strikingly less improvement in treatment outcomes than either younger or older patients. ¹⁶

According to W.A. Bleyer these gaps are attributed to the unique types and biologies of cancer and the different medical and psychosocial requirements of these patients. They are often disproportionately under-represented in clinical trials with as few as 5% of sufferers aged 15-25 represented compared with almost 65% of younger cancer patients. ¹⁶

Adolescents rarely receive care in settings designed to address their unique needs. They are neither adult nor child yet usually receive care in either adult or paediatric settings. They often miss the benefit of program assessments to determine whether the settings and resources meet their requirements. Variability exists in staff philosophy of care and skill required in engaging in activities appropriate to adolescent and consequently can hinder the effectiveness of a treatment regimen ¹⁷.

Research has indicated that adolescents will construct their own view of illness and treatment and it is this view that influences their commitment to treatment ¹⁷. This has been shown to be dependent on their perception of treatment decisions and decision making processes which supports the guidelines acknowledged in section 6 of this report. Further research is required if advances are to be made in this area of improving adolescent cancer care.

It was concluded in 'The Adolescent/Young Adult Experience' paper which was presented at the NIH³ and NINR⁴ sponsored workshop 'Moving the research agenda forward for children with cancer' in 2003, that;

The poorer outcomes for adolescents compared to younger ... patients should be thoughtfully and systematically addressed. In addition to the highest priority of developing and enrolling (adolescents) in appropriate treatment protocols, there is also a requirement to look into setting in which (adolescents) receive treatment. ... Research into illness-related distress and a focus on positive health concepts has been recommended to identify interventions that work well from the (adolescents) perspective ¹⁷.

With this conclusion in mind, it suggests that it is indeed the adolescent cancer sufferers which require the most assistance by research as the other age groups are already covered by current work.

³ National Institute of Health

⁴ National Institute of Nursing Research

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12 Priority Areas for Spending

Obvious priority areas for spending include: prevention, treatment and cure. The major areas of spending include funding initiatives for treatment facilities and research centres. Funding should be given only with a specific target in mind as considered on an individual needs basis.

Research: Priority should be given to research where initial findings have provided substantial evidence that further work is likely to reduce death rates or the pain and suffering endured during treatment.

The importance of understanding the unique nature of childhood cancer should also be considered important, provided that the research has the potential to lead to new treatment outcomes.

Funding organisations should always request to know exactly how money will be spent. It is advisable to request a full research proposal, including details of the proposed study, timeframes and credential of the researchers to be involved in the study. In this way funding organisations can be selective on how and where they wish to channel their resources.

Hospital and other treatment facilities: Funding requests for equipment must be considered on a needs basis. Priority should be given to equipment which is likely to result in a higher quality of care for childhood cancer patients. It is important for the funding organisation to request a full description of the equipment, its function, lifespan and what benefits it will offer to children's cancer treatment at the facility.

12.1 Priority Areas for Spending Determined Through this Investigation

Family Support

Particular attention should be given to the area of family support. While at some level we can all understand the suffering endured by a parent whose child has been diagnosed with cancer most of us cannot begin to comprehend the daily battle facing these people. Individual families will have different support requirements. In order to identify initiatives that would be of assistance surveys could be conducted among current families living with a child who has been diagnosed with cancer. A survey of this nature will provide detailed information on where current facilities are insufficient.

Support of the Child

Children suffering cancer require needs that cannot be met by current facilities. There appears to be a definite requirement for support as children return to the school environment. With the help of a support program the transition back to school could be made much easier. The main aim of this program would be to educate teachers and peers. Children would then return to a caring and understanding environment; the feelings of isolation that returning children currently feel would be dramatically reduced.

Research into the long-term impact of Childhood Cancer

Advancements in treatments of many childhood cancers have seen tremendous improvements in the number of children reaching adulthood. As the percentage of survivors increases it is becoming clear that the long term effects of cancer treatment can be devastating. Research in this area is an absolute priority so that the long term impact of cancer can be reduced.

Research into Adolescent Cancers

Adolescents have not fared as well as younger and older patients, perhaps this should be considered when looking at where to prioritize research spending. Adolescents have different requirements to both Adults and Children with cancer. Care needs to be tailored particularly to the needs of the adolescent.

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