Return to School

for Students with Cancer

A guide for parents/caregivers, whānau and teachers

Faith, diagnosed age 2

Contact list

Child's name: ______________________________

Parent/caregiver

Name: ______________________________

Phone: ______________________________

Email: ______________________________

Parent/caregiver

Name: ______________________________

Phone: ______________________________

Email: ______________________________

Health School Teacher

Name: ______________________________

Phone: ______________________________

Email: ______________________________

Other

Name: ______________________________

Phone: ______________________________

Contents

Introduction

For over 40 years, Child Cancer Foundation has ensured that every family going through childhood cancer in New Zealand has someone there to support them at a time when they need it most. We connect every newly diagnosed family with a dedicated Family Support Coordinator, who is there to provide them with the specific help they need, every step of the way.

This booklet for parents, caregivers, whānau and teachers of children or young people with cancer.

This guide provides an overview of childhood cancer and discusses the medical and psychological effects of cancer upon children and young people. It also includes recommended steps for teachers to support a smooth transition back into the classroom for children and young people with cancer and their classmates, siblings, teachers, parents/caregivers and whānau.

Any return to school/early childhood centres (ECC) following diagnosis is a critical step in the rehabilitation process. This allows the young person to stay connected to a normal life and contributes to their sense of wellbeing. For these reasons, young people on treatment for cancer are encouraged to attend school/ECC as soon as possible following diagnosis.

Children with cancer are treated in two major specialist childhood cancer service providers:

- Starship Children's Hospital at Auckland DHB
- Christchurch Hospital (CHOC) at Canterbury DHB

For an excellent electronic resource for teachers, parents/caregivers and whānau on returning to school, visit Kids Health: kidshealth.org.nz/tags/childhood-cancer-and-education.

Nicole, diagnosed age 7

Childhood Cancer – A Medical Overview

A lot of people ask "Why do children and young people get cancer?"

To date, no definite causes have been identified. However, research is ongoing into risk factors that can contribute to cancer developing in children and young people.

Childhood cancer is very rare. In New Zealand, approximately 160 children under the age of 15 are diagnosed each year. Childhood cancer is not contagious – it cannot be caught from other people. With advances in treatment, today more than 80-85% of children with leukaemia and more than 75% of all children with cancer will survive five years or longer, and many will be cured.

All cancers are made up of cells that behave differently from normal cells. Normal cells grow in a controlled way, while cancer cells grow and multiply in an uncontrolled manner, sometimes forming a lump (often referred to as a tumour). Cancer cells can hinder normal cells by preventing them from growing or working properly. This may cause pain as it adds pressure to the surrounding areas of the body. As well as growing continually, cancer cells have the ability to metastasise (spread around the body).

There are several different kinds of childhood cancer, for example leukaemia, brain tumours, kidney and bone tumours. They each have different treatments and cure rates. Childhood cancers generally respond well to treatment and cure rates have improved drastically.

Childhood cancer differs from adult cancers in many ways. Children's cancers are unlikely to be caused by specific environmental exposure (such as the sun or cigarette smoke), whereas many adult cancers may be linked to these factors. There is ongoing research into what might cause cancer. Childhood cancers generally grow quickly, while adult cancers are slower growing.

For a brief overview of specific childhood cancers, visit:
acco.org/types-of-childhood-cancer/

Medical Considerations

Treatment for childhood cancer impacts on each child or young person differently. Some tire easily or find it hard to concentrate. They may have physical difficulties, hearing or visual problems. Others may have medical aids like a central line/ portacath or nasogastric tube.

Children and young people recently treated for cancer or undergoing treatment are prone to infection. It is important for schools and ECCs to have a chicken pox and measles policy and a 'contact with chicken pox or measles strategy' in place. Actual or suspected exposure to these illnesses must immediately be reported to the child's parents/caregivers. See page 23 for a letter template that can be sent to parents.

Teachers should be vigilant with rough play and take good physical care of the child or young person, i.e. keep them warm and dry (don't leave younger children sitting in a wet swimsuit after swimming).

Following a general discussion or meeting with caregivers about the child or young person's individual needs, the school/ECC may need to distribute information to relevant school personnel on any physical or intellectual difficulties that may be present.

A list of **emergency phone numbers** must be made available to all who supervise the child or young person. These should include family and medical emergency numbers, including the primary healthcare team.

It is important to remember that children and young people with cancer may have concerns about their physical appearance and their ability to keep up and maintain friendships. Support and guidance can make a huge difference. Be aware that children and young people will sometimes over-extend themselves in order to appear 'normal'.

***Special note:** Staff members involved in toileting children or changing nappies would normally wear gloves. It is important to ensure gloves are worn if the child is still having treatment as chemotherapy is excreted in urine. Chemotherapy can damage normal cells as well as cancer cells and any form of exposure creates a minimal risk.

For more information, see the section: 'Preparation & checklist' on pages 18 and 19.

Psychosocial Considerations

Helping children or young people return to school/ECC

Careful planning will help make a child or young person's return to school/ECC easier. Individual and cultural considerations must be taken into account when developing and implementing a plan.

Strategies

- Identify a staff member who will act as the child or young person's advocate. Include the child or young person and their family in this decision. This person should be someone the child or young person can relate to and trust to handle their concerns with discretion. Once this person is identified, clearly explain their role as confidant and support to the child or young person.
- The child or young person should be consulted about how they want to proceed. While some may be happy for the class to hear about their illness, others might prefer to keep their situation private. Talk to them about different approaches and ideas for handling situations which may arise. Establish strategies with them and their family.

Communication

Good communication between the child or young person with cancer, the school/ECC, parents/caregivers and health professionals is essential.

After being treated for cancer, some children and young people develop strong coping skills and resilience. Some interact with adults in a manner beyond their years but may lack social skills with their peers as a result of having been in hospital for long periods.

Communication strategies

- Have a discussion with the family about how much information will be given to the child or young person's classmates regarding their illness and treatment. The child or young person's personal wishes should be taken into account. Also, discuss how widely this information will be shared. Discuss a simple story or scenario with the child or young person which can be repeated and used to answer questions, e.g. "I was in hospital for a long time and I was really sick and had to have lots of medicines, but I'm better now." Some children or young people may want to include something about their hair in their story or scenario, e.g. "The medicine made my hair fall out but it has grown back really fast."
- Discuss possible responses to questions that might be asked by different people or children. If asked "Why have you been away?" the child or young person could reply "I've been sick", or "I've been in hospital" or "I don't want to talk about it right now." Keep it simple.
- If the family and child or young person agree, provide classmates with information on the individual child or young person's treatment and change of appearance. It is important to emphasise that cancer does not define an individual; they are much more than 'someone with cancer'.
- Some students may welcome the opportunity to do a presentation on their illness for the benefit of other students and teachers while others will not, so make sure this is discussed. Younger children may want to take their Beads of Courage® to school/ECC and talk about their journey. A parent/caregiver and/or Regional Health School teacher may accompany them and facilitate a simple Q&A session. The potential impact on others should also be considered. While the child or young person may be relaxed talking about their illness and treatment, it may distress others, such as those with family members who also have cancer or are sick.
- A communication notebook is an excellent tool for teachers to write comments about the child or young person's day for parents/caregivers to read. Parents/caregivers can respond and add their own notes for the teacher to read. This way both parties are aware of the child or young person's present circumstances, successes and difficulties.

- Some children and young people in the class may need extra help to deal with their classmate's illness. Identify who they can talk to. This may be a voluntary support person or a counsellor.
- Medical play is an effective communication tool, particularly in early childhood. A quiet area containing a range of real and pretend medical equipment will offer children the opportunity to explore and express their experiences through play. Adult or teacher involvement in this play will mean the experiences and emotional needs of the child can be supported. Other children playing alongside are also able to be included or supported (these children may have had different healthcare experiences).

Consideration for parents and caregivers

Having a child or young person diagnosed with cancer requires significant adjustments for the whole family. Support is available for families through Child Cancer Foundation. Most families will already have had contact with a Family Support Coordinator from Child Cancer Foundation.

It is likely that parents/caregivers will be closely monitoring their child's health and wellbeing when they return to school/ECC. Initially, there may need to be a lot of communication from teachers to parents/caregivers about the child or young person's transition.

Parents/caregivers understand their child best and should be the first point of reference if there are any concerns.

Education Considerations:

Childhood cancer and its treatment may have implications for a child or young person's education. Here are some points for general discussion and awareness:

Topics for general discussion

- A child or young person with cancer tires easily or lose concentration. How will staff recognise this and support them to take breaks during the day? How will this be communicated?
- The child or young person may have good days and bad, particularly in cases where they are on steroid treatments, e.g. they may be irritable, aggressive, tearful or more easily frustrated than usual. This may also have an effect on other students. How will this be managed?
- The child or young person may need days off for treatment, recuperation or appointments. How will that be communicated between caregivers and the school?
- Some children or young people will have identified learning difficulties due to their illness or treatment. How will any identified learning difficulties be addressed?
- While it is important to set the same homework as other students, it may not always be completed to the same standard. How will the child or young person's individual circumstances be taken into account?
- Children and young people with cancer may have specific physical requirements. They may need a pillow for their seat or space for a wheelchair for example. How will their needs be met?
- It is important that all staff members are consistent and sensitive with information regarding the child or young person. How is the school going to ensure all staff are aware of the child or young person's situation?
- Some children and young people may experience bullying or teasing about their change of appearance and/or abilities. How will this be handled? What strategies will be put in place?
- There may be other issues that need to be discussed. How will these be handled?

Regional Health Schools:

Regional Health Schools provide a free New Zealand-wide individual learning support service for students whose health prevents them from attending school for significant periods. In most cases, the family's first contact with a Regional Health School teacher takes place when the child or young person is being treated in hospital.

Regional Health School teachers provide education and teaching programmes in association with each student's parents/caregivers and their regular school. These programmes are delivered to students either in hospital or in their home and are reviewed and adapted to meet each child or young person's changing needs. Learning support is provided for as long as it is needed.

As well as assisting young people to maintain their learning, Regional Health School teachers will liaise with the family, health professionals and the student's regular school. They will also assist with the development and implementation of return-to-school strategies.

For further information, contact the nearest Regional Health School:

- **Northern Health School**
  nhs.school.nz, 0800 153 002 or admin@nhs.school.nz
- **Central Regional Health School**
  crhs.school.nz, 0800 153 000 or admin@crhs.school.nz
- **Southern Regional Health School**
  srhs.school.nz, 0800 774 700 or secretary@southernhealth.school.nz

Early childhood

Most hospitals have a licensed, chartered early childhood centre as part of their hospital play specialist service. Play specialists help young children with their development and learning throughout their hospital stay. This is especially important for young children with cancer as many of them experience long stays or repeated short stays in hospital.

Hospital play specialists will liaise with teachers in the child's usual early childhood centre where appropriate in order to build on the child's strengths and interests and minimise the disruption to their learning.

Play specialist programmes also help children to gain an age-appropriate understanding of what is happening to them and to cope with hospitalisation and treatment. Siblings are also welcome to participate in hospital play specialist programmes.

From more information, parents/caregivers or teachers can contact the play specialist at the hospital where the child is receiving treatment or the Hospital Play Specialists Association website: hospitalplay.org.nz

Te Kura Pounamu is available for children under five years who are unable to attend or return to an early childhood centre. A medical certificate is required, along with a specific form which is available from hospital play specialists or the Te Kura Pounamu website: tekura.school.nz

Further help may be available from psychologists, Ministry of Education, Group Special Education (GSE) and Child Cancer Foundation's Personal Development Grant programme. Visit Kids Health for more information on support available: kidshealth.org.nz/specialist-support-available-schools-help-student-cancer

Long Term Follow-Up

In 2006, New Zealand established a Late Effects Assessment Programme (LEAP) for survivors of childhood cancer. It is now well recognised that, depending on their initial disease and treatment (chemotherapy, radiotherapy and surgery), survivors may be at risk of long-term consequences or 'late effects'. These may affect the survivor's physical health, emotional, behavioural or educational wellbeing.

Late effects may include:

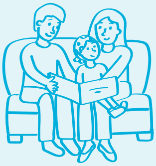
- Short stature (impact on physical and social functioning)
- Endocrine problems which may prevent them entering puberty naturally
- Difficulty with focus and attention
- Mental health and wellbeing concerns such as depression and anxiety
- Low energy levels – physical and cognitive
- Behavioural changes
- Heart or lung damage which may affect physical (exercise/tolerance/stress) activities
- Specific learning disorders

Some children, such as those with brain tumours or those who have had radiotherapy to the brain, may have late effects in one or more of these areas.

The LEAP programme incorporates a multi-disciplinary clinic in the three tertiary treatment centres: Auckland, Wellington, and Christchurch. There is a pediatric oncologist, a clinical psychologist or neuropsychologist and a nurse specialist in each team.

Many of these late effects may become more or less apparent over time after treatment has finished. Parents/caregivers will have been informed that their child could experience late effects and may be the first point of contact for information about these problems. The parent/caregiver can discuss concerns with the LEAP team, who will advise on any need for assessment or intervention and how to access these. If indicated, a LEAP clinical psychologist or neuropsychologist may assess a child or young person. This will involve consent from the parents/caregivers and contact with the school.

If teachers notice consistent problems with the child or young person's ability to learn, these should be discussed with the parents/caregivers as the problems may be related to their treatment. There are guidelines on how to deal with specific long-term effects.



For more information on how late effects of cancer treatment can affect your student's learning visit Kids Health: kidshealth.org.nz/how-late-effects-cancer-treatment-can-affect-your-students-learning

Siblings

The siblings of children and young people with cancer have a particularly difficult time. Siblings often experience long periods where their needs take a lower priority in the family. They may be separated from their parents/caregivers for extended lengths of time, and can experience much anxiety and fear.

While parents/caregivers usually do their best to share their attention with all children in the family, other adults tend to ask about the sick child or young person first. This may go on for many years, which can leave siblings feeling that they are not as important.

Siblings will often react with strong feelings such as jealousy (wishing they could get cancer and all the presents that go with it) and resentment (that the sick child or young person gets to eat whatever they want or use the computer whenever they want).

Information siblings receive about their brother or sister with cancer's illness may be misunderstood or inaccurate. They may worry that they somehow caused the illness. Even very young children will pick up on the stress and upset in a family. It can be difficult for young people to learn that their parents/caregivers are not able to control everything.

In the case of older siblings, they may have increased family and household responsibilities. They may become unable to concentrate at school because they are worried about what is happening at the hospital or home. School can often provide a sense of normality. Some older siblings may not want their peers to know what is happening, and school may be the one place they can forget about everything.

It is important for parents/caregivers and teachers to maintain communication so both are aware of how the siblings are doing. Parents/caregivers should be made aware of any behavioural or academic changes noticed by teaching staff. These children and young people will need more attention and support from their teachers than they did previously. Again, it is important they are asked how they are before asking about their sibling with cancer.

Research has shown some siblings of children with cancer are at risk of future psychological problems. Research also shows that some may become much more nurturing and caring than their peers.

For more information on common reactions that brothers and sisters may experience, visit: kidshealth.org.nz/brothers-sisters-student-who-has-cancer

Brianna, diagnosed age 6,
with her brothers Brock and Liam

Preparation & Checklist

Before the child or young person returns to school/ECC, a meeting should be held with the child or young person's parents/caregivers and Regional Health School teacher.

Information should be provided by the child or young person's parents/caregivers about their illness and treatment, including any side effects, behaviour changes and out-of-classroom activities such as medical appointments and/or further treatments.

Prior to the meeting, teachers who will be working directly with the child or young person may need to have their concerns addressed. Consideration should be given to their level of knowledge on the subject and possible emotional reactions to the material being presented.

Suggested topics for the meeting:

- Discuss how information will be communicated to staff and personnel who are not in attendance at the meeting.
- Discuss the child or young person's specific academic or social requirements at the present time.
- Discuss strategies for intervention in the event that the child or young person starts having difficulties in any area.
- Discuss the long-term needs of the child, the development of a plan and a review process

Checklist

○ **Handouts**

Handouts from the child or young person's health professional team and parents/caregivers regarding the child or young person's illness and treatment. These should include basic information on diagnosis and treatments along with possible physical and emotional side effects that may be anticipated.

○ **Medical aids**

Ask the family whether the child or young person has been fitted with a central line (see Glossary on page 22) or any other medical device.

○ **Emergency phone numbers**

This should include family and medical emergency numbers, including the primary healthcare team (GP).

○ **Medical issues**

- Medications to be given at school (these must be in original prescription bottles labelled with directions on how they should be administered)
- Information for physical education teachers
- Care of central lines
- Precautions regarding the danger of the sick child or young person being exposed to infectious diseases such as chicken pox and measles

○ **Practical information**

Many schools do not allow students to wear hats in the school building. If a child or young person returns to school and wants to wear a hat because of hair loss, all school personnel must be aware this is acceptable. There may be other adaptations that need to be made to the school's dress code due to the child or young person's circumstances.

○ **Education**

Access information about any education the child or young person may have received through the hospital system.

For additional information on children returning to school after a cancer diagnosis, visit: kidshealth.org.nz/tags/teachers

Palliation And Bereavement

This section introduces a very difficult topic. Despite successful improvements in cure rates and quality of life for children and teenagers with cancer, some will have a poor prognosis and some young people with cancer will die. Even in the final phase of illness, school can remain a rewarding experience for the young person and those around them.

Some simple measures to help students get the most from their remaining life:

- If a student becomes too fatigued to attend school for a full day, they will often benefit from half days or even an hour's attendance daily.
- If a student feels comfortable, giving them permission to take naps may be helpful. As energy ebbs, assigned work should be adjusted accordingly.
- If the student has lost a lot of weight, they may be uncomfortable sitting in a school desk chair. Encouraging them to bring along a pillow or cushion to sit on may help.
- The student's palliative care team may be able to help with support. It is always best to speak with the child's parents/caregivers in the first instance for permission before contacting any of the child's specialists.

If a child with cancer in your school community dies, each person's reaction and grieving process will be unique. Responses to grief depend on the individual's personality, how close they were to the person who has died, their own experiences with death and their access to support services. Bear in mind that it is normal for someone to feel out of control, overwhelmed or even disbelieving.

Feelings of loss for the young person with cancer should be acknowledged, with the understanding that young people deal with grief in their own way and at their own pace. It is okay to give students space and time to grieve for their classmate. They should be able to turn to school staff for support and guidance when they are ready.

Organisations such as the Grief Centre, Skylight and Kenzie's Gift provide resources and more information about death, grief and loss. See the 'Useful resources' section for links.

For more information on when your student's cancer can't be cured, visit Kids Health: kidshealth.org.nz/when-your-students-cancer-cannot-be-cured

Useful resources

Child Cancer Foundation
childcancer.org.nz

Back to School Research - CCF & NCCN
childcancer.org.nz/research/back-to-school-research

Kids Health - Childhood Cancer and Education:
For teachers - kidshealth.org.nz/tags/teachers
For parents/caregivers - kidshealth.org.nz/tags/parents

CanTeen New Zealand
canteen.org.nz

Leukaemia & Blood Cancer NZ
leukaemia.org.nz

Skylight
skylight.org.nz

Young Lives vs Cancer (UK)
younglivesvscancer.org.uk/life-with-cancer/my-student-has-cancer

American Childhood Cancer Organization
acco.org

Grief Centre
griefcentre.org.nz

Children's Cancer and Leukaemia Group (UK)
cclg.org.uk

Red Kite
redkite.org.au/real-stories

Kenzie's Gift
kenziesgift.com

Glossary

Biopsy
When a small sample of tumour is taken from the body and looked at under a microscope.

Blood transfusion
Extra blood may be given when the body's blood supply is low.

Bone marrow aspiration
A needle is put into the pelvic bone and bone marrow is drawn out. This is usually done in theatre under general anesthetic.

Bone marrow transplant
A procedure which allows a new set of blood-forming cells to develop into healthy new red and white cells and platelets. This involves a lengthy stay in hospital.

Cancer
The body is made up of millions of tiny cells that form things our bodies need – such as blood, muscle or bone. When cells divide and make new cells too quickly and do not do their job properly, a lot of damaged cells are made instead. They stop the good cells from working properly. This is called cancer.

Central Line/Portacath
A long plastic tube that is inserted, under anesthetic, into a large vein near the heart. Central lines are used to take blood samples and give blood and medicines.

Chemotherapy
A mixture of different medicines which work against the cancer cells. They may affect normal cells as well and have various side effects.

CT scan/MRI
Scanning machines that take pictures of the inside of the body.

Leukaemia
A form of cancer where the cells that make blood start reproducing damaged cells at a fast rate.

Lumbar puncture
A needle is used to take spinal fluid from the spine and sometimes medicines are put in. This is usually done in theatre under general anesthetic.

Metastasis
When the cancer has spread to a different part of the body from where it started.

Radiotherapy
Very powerful X-rays that work against cancer cells.

Side Effects
Side effects are the unintentional consequences of chemotherapy and radiotherapy. They may include hair loss, nausea, learning difficulties and weight changes.

Tumour
When damaged cells stick together to form a lump, that lump is called a tumour (cancer). Diseases that have tumours can include osteosarcoma, Ewing's sarcoma, Wilms tumours, brain tumours, neuroblastoma, retinoblastoma and rhabdomyosarcoma. These are different from leukaemia, which is a disease of the white blood cells.

Letter to parents template

Dear parent,

One of your child's classmates has recently [found out they have cancer/been treated for cancer].

The child [will soon be returning to school/has recently returned to school].
There are two reasons for this letter.

The first is to make you aware of their cancer diagnosis and reassure you that your child cannot catch cancer.

The second is to ask you to please contact me (or school nurse or class teacher) straight away if your child has chicken pox or measles.

Measles and chicken pox can have very serious consequences for someone having cancer treatment and we will need to tell their parents so that they can take the appropriate action.

We will also be working with your child's class to help them understand what their classmate is going through.

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

Thank you for your help.

Yours sincerely,
Principal

Contact us

National Support Office
76 Grafton Rd, Grafton,
Auckland 1010

Phone 0800 4 CHILD (0800 4 24453)

Email info@childcancer.org.nz

childcancer.org.nz

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