

When Your Brother or Sister Gets Cancer



WAYS TO HELP DEAL WITH DIFFICULT EXPERIENCES



www.childcancer.org.nz

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This special booklet is for people like you who have a brother or sister with cancer!

We hope that reading this will help you find some ideas for getting through the difficult things you experience. We also hope it helps you discover some of the good stuff that can happen even when you have a brother or sister with cancer.

We know that some of the information you are given about your brother or sister's illness may be hard to understand, so that's why we have made this book especially for you.

We hope it will help answer some of the questions you may have.

Sibling is a word you will see used a lot throughout this book. It means 'a brother or sister'.

What's this Booklet About?

This book tells you about child cancer and some of the feelings you may experience while your brother or sister is sick. You will find some comments from other siblings about what it was like for them, and some suggestions to help you find more information about other kids like you.

When a child has cancer, it can be difficult for everyone in your family. Some of what happens, may be hard to deal with. For example:

- You may be separated from one or both of your parents while your brother or sister is in hospital.
- For a while it might seem that everything is focused on your brother or sister with cancer. While most families do their best to share attention with all the children in a family, it may feel like adults are only interested in your sibling who is in hospital or having cancer treatment.
- You may find you have to do more things around the home to help your family. This might feel a little unfair or that you have had to grow up faster than you'd like.
- There may be times when you can't concentrate at school because you are worried about your family. Sometimes you might miss out on schoolwork or spending time with friends. It might also be hard to tell people how you're feeling and some friends might not understand what you are going through and may say or ask things that are hurtful.
- It might not feel like it all the time, but sometimes there are some good things that can happen also. You might have the chance to make new friends and meet new people that are going through similar things to you. Many siblings of a child with cancer say their family has become much closer because of what they have gone through and that they have learnt and done a lot of new things!



What is Cancer?

There is a lot of information about cancer and the type of cancer your brother or sister has. Your parents might have some books which they've been given by the hospital or the Child Cancer Foundation.

Some of the books will have a lot of medical language in them which can be confusing. If you would like more books that explain cancer in a way that's easier for you to understand, you can talk to your Family Support Coordinator from the Child Cancer Foundation. If you have a computer with internet available to you, you may also like to check out the websites listed at the back of this booklet.

HERE ARE A FEW THINGS ABOUT CANCER:

Our bodies are made up of trillions of cells. Cells make up our skin, muscles, bones, teeth, nails and even our hair but they are so small that we can't see them unless we look under a microscope. Cancer is when some of the cells in the body start growing differently to other cells in the body. These cells can grow and divide very quickly and can sometimes clump together and form a lump which is called a tumour. Because cancer cells grow so fast they can stop the healthy cells from being able to grow and do their job.

You may find it helpful to think of a garden that's overgrown with weeds. Weeds grow really fast and don't leave much room for the other plants and flowers to grow.

Cancer cells are a bit like weeds and they make it hard for your sister or brother's body to work the way it should. The most common childhood cancers are leukaemia (cancer of the blood), brain tumours, kidney and bone tumours.

You may have heard people say things like "cigarette smoke causes cancer" and you might have learnt 'sun-smart' messages at school to prevent skin cancer. These are important things to know about adult cancers but childhood cancers are different and are not caused by things like smoking or sunburn.

More Facts about Cancer:

Most children with cancer are able to be cured.

Childhood cancer is very rare.
This means not many children get cancer.

Cancer cannot be caught from other people.

No one knows why some children get cancer. What we do know is that it's not because of anything they did or didn't do.



WHAT IS THE CHILD CANCER FOUNDATION

The Child Cancer Foundation is a not for profit charity organisation that gives support to children with cancer and their families as well as the health professionals who care for them.

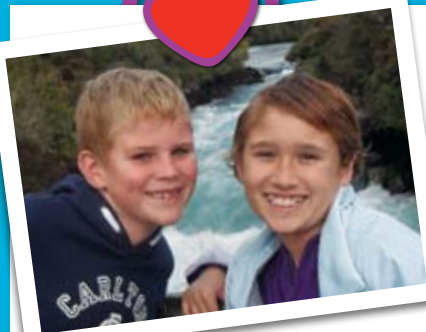
The Child Cancer Foundation doesn't get any money from the Government, and relies on donations and help from generous people and organisations in the community.

As a sibling, you are entitled to support from the Child Cancer Foundation and the Child Cancer Foundation's Family Support Coordinators.

WHAT IS A FAMILY SUPPORT COORDINATOR?

A Family Support Coordinator is a person who offers support to your whole family. They are trained, skilled people who can offer information, activities, and other support and help. They are available for you to talk to and will help answer any of your questions. Contact them by phone or by email – their details are in the back of this book.

Siblings are not Alone



Having a brother or sister with cancer can be a very lonely experience. You may feel different from your friends and they may not understand what it is like for you.

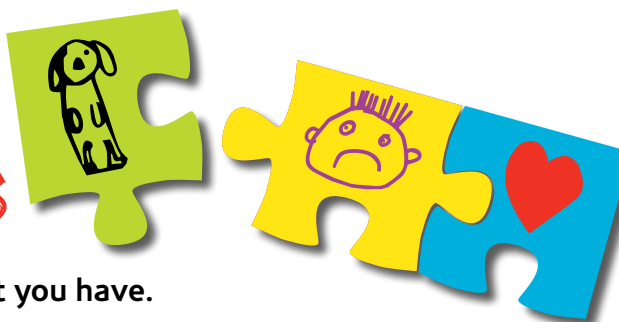
It is important to know that you are not alone. There are other siblings throughout New Zealand who are going through similar experiences. It is also important to know that there is a lot of support available to you so that you do not feel alone during this time. More information about this support can be found on page 14 of this booklet.

Below are some things that other siblings like you have said about how to get through the experience of having a brother or sister with cancer:

- "Don't try and hide your feelings, try and let it out because it helps more, 'cause if you try and keep it in, it can be harder."
- "I'd suggest talking to people a lot."
- "Don't cry too much about it, because after a while, it just doesn't really help."
- "Be patient and try not to get too frustrated that you have to wait and can't go on all the fun things sometimes that they get to do."
- "Just know it's not your fault."
- "Don't get jealous."
- "I would suggest that, even though you really want to go to the hospital to find out what is going on with your brother or sister, it's better for you to go to school and stay there and learn more."
- "Sometimes when your brother or sister needs attention, you just have to let him or her have it, so that your mum and dad can help him or her."
- "Be brave and be strong."
- "Remember that you are not left out and that it will be better soon."

These quotes and the comments on the following page come from Rebecca (Rosie) Dobson's research study, *Childhood Cancer: An investigation in to the experience for siblings*, 2007.

Emotions



Emotions are the feelings that you have.

For example fear, anger, joy, love. As a sibling of someone with cancer, you might feel some of these emotions:

Lonely – you might feel lonely because you are no longer able to play with your brother or sister with cancer like you used to. You might miss your family because they are at the hospital a lot.

Worried – you might feel worried about your sick brother or sister or worried about how your other family members are feeling. You might worry about the future and what will happen for everyone in your family.

Sad – you may feel sad about seeing your brother or sister so sick, or you might feel sad about changes that have happened now that your brother or sister has cancer.
"It makes me feel really sad sometimes."

Angry – some brothers and sisters with a sibling with cancer may feel angry about what is happening and the effect it is having on their lives.
"It makes me annoyed because it troubles mum and dad."

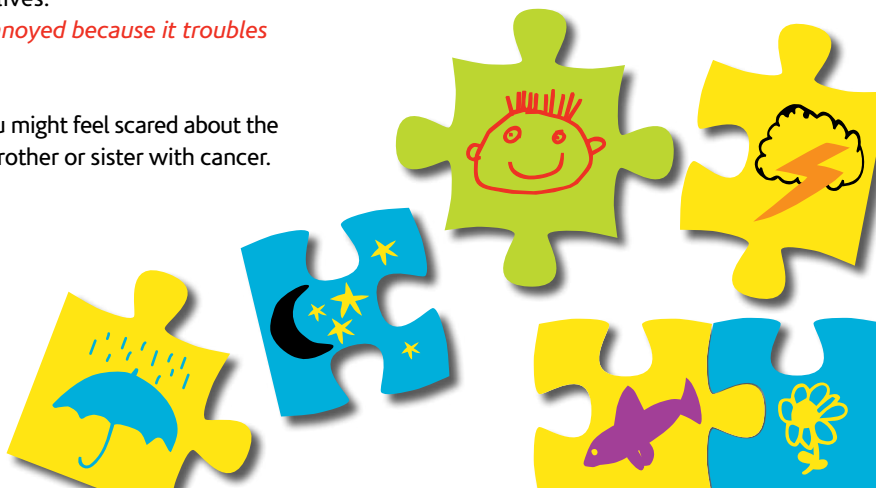
Scared – you might feel scared about the future for your brother or sister with cancer.

Frightened – it can be frightening to see your brother or sister so sick. The hospital can also seem frightening.

Concerned – you might feel concerned about your sister or brother who is sick, your parents or your other brothers and sisters and family members.

Upset – you might feel upset about having a brother or sister with cancer.
"Sometimes I get a bit upset."

Jealous – sometimes, but not always, siblings may feel jealous or left out because their brother or sister gets more attention because they have cancer.
"Sometimes I just think my brother gets too much attention... and I just feel kinda left out sometimes, normally I don't."





Questions

You may find you have a lot of questions.

It is important to know that it is always okay to ask questions.

Your parents or caregiver will be the best people to ask for most questions, but if you don't feel like you can talk to them, remember that you can always speak to your Family Support Coordinator. Their phone number is on the card on page 15.



**And always remember...
no question is a silly question!**

SOME QUESTIONS SIBLINGS HAVE ASKED:

Is the Child Cancer Foundation just for my brother or sister with cancer?

No – the Child Cancer Foundation provides support for your whole family, including you.

What do I tell my teacher?

That's up to you. You can tell your teacher as much as you like. It can be useful to talk to your teacher so they understand what is happening for you and your family. Your parents may be able to talk to your teacher with you. Your Family Support Coordinator also has a teacher resource book produced by the Child Cancer Foundation. They can give a copy to your teacher if you think that would be helpful.

Should I tell my friends?

You can tell your friends as much, or as little as you want. It might be easier for you if they know, so they can listen and support you. Some siblings prefer not to talk to their friends about it and that's okay too.

I'm worried about my mum and dad, they seem really stressed. What can I do?

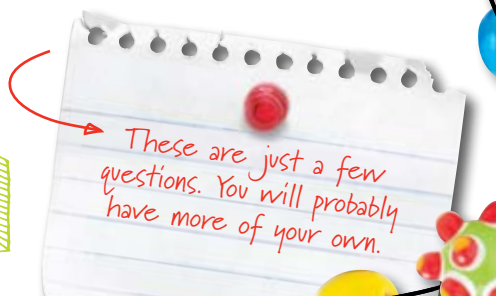
Talk to your parents about your worries and ask them if you can do anything to help.

Can I still play with my brother or sister with cancer?

Yes, most of the time you can still play with your brother or sister but it's good to check with your mum and dad first. You may not be able to do everything together that you used to and it's important to talk about this as a family so you all know how you are feeling.


Can I join CanTeen?

If you are 13 years or older you may be interested in joining CanTeen. See their website for details:
www.canteen.org.nz



Positive Things

Although having a brother or sister with cancer can be sad, some siblings say that there have been some good things that have happened because of it. **Some of the good things that siblings say about the experience include:**



It has taught them that life is special and to make the most of it

It has brought their family closer together

It has taught them to be more patient

It has made them more mature and sensitive to others

They get to experience things they wouldn't have been able to if they didn't have a brother or sister with cancer

It has made them want to help other people who have a brother or sister with cancer

What can you do to help?

Many siblings (and parents too) feel helpless when they have a child in the family with cancer, but there are some things that you can do to help your brother or sister feel better!

Here are some ideas to help your brother or sister.

It is important to remember that these are only suggestions.

All you really need to do is keep being you!

- ♥ Draw a picture for your brother or sister to take to hospital. Hospital rooms can be very dull and pictures on the wall can remind them of home as well as cheer the room up.
- ♥ See if your brother or sister would like a massage. Not everyone likes a foot rub, some may enjoy a shoulder massage or a gentle tummy rub. Make sure you ask first. Your sister or brother will be able to tell you if it's something they'd like. Massages aren't for everyone so it's good to check first.
- ♥ When your brother or sister is well enough they might enjoy doing activities with you, like – craft activities, jewellery-making, doing a jigsaw, painting or anything else you both enjoy.
- ♥ Take silly photos together and create a scrapbook. Take photos of home, friends, pets and family.
- ♥ Read a book to your brother or sister.
- ♥ Write letters or cards to your sister or brother and your parents when they are in hospital.
- ♥ Try growing flowers or plants in a special part of the garden and watch them grow. When your brother or sister is in hospital you could send them photos of how the flowers are doing.
- ♥ If your sister or brother went to school before they got cancer, you could suggest to the class teacher that the pupils write letters to send to the hospital. You can pass them on.
- ♥ Ask your school if they can do a fundraiser. Many schools are willing to do a mufti day or sausage sizzle to raise funds for the Child Cancer Foundation.

*When you can,
keep smiling!*





Beads of Courage®: Sibling Beads

The Beads of Courage® Sibling Beads offers special siblings like you the opportunity to earn beads by being a great brother or sister.

You can help by offering to do jobs around the house, or by drawing a picture or joining in a fun activity with your sibling while they are in hospital. There are several unique beads to collect, each bead recognises how special and brave you are and the special ways you show support for your brother or sister.

Beads of Courage® is a United States federally registered trademark of Beads of Courage®, Inc., and is used under license.

notes:

Stick a photo of you and your brother or sister here!



Common Cancer Terms and Their Meanings

These are some of the different medical words that you might see or hear while your brother or sister is having cancer treatment.

BIOPSY – when a small sample of a tumour (cancerous lump) is taken from the body and looked at under a microscope.

BLOOD TEST – a needle is used to take a small sample of blood from a vein in the body. The blood is then examined to see how many red cells, white cells and platelets there are.

BLOOD TRANSFUSION – extra blood may be given when the body's blood supply is low. This is normally given through a line into the vein. (please see port-a-cath).

BONE MARROW ASPIRATION – a needle is put into the pelvic bone and bone marrow is drawn out. This is usually done in an operating theatre under general anaesthetic so no-one can feel it.

BONE MARROW TRANSPLANT – a procedure which allows a new set of blood-forming cells to develop into healthy new red cells, white cells, and platelets. This involves a long stay in hospital.

CANCER – the body is made up of trillions of tiny cells. These cells make up our blood, muscle, bone, skin, teeth and even our hair. In fact our whole bodies are a collection of cells. Sometimes, our bodies can make damaged cells instead of healthy ones. These damaged cells divide too quickly and don't behave the way healthy cells do and can stop our healthy cells from working properly. These damaged

cells are called cancer cells. When someone has cancer cells in their body, this is called cancer.

CENTRAL LINE / PORT-A-CATH – a long plastic tube that is inserted under anaesthetic, 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 to destroy cancer cells and stop them from growing. Chemotherapy can affect normal cells as well and cause various side effects (please see 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 (cancer) cells at a fast rate.

LUMBAR PUNCTURE – a needle is used to take spinal fluid from the spinal canal and sometimes chemotherapy medicines are put in. This procedure is usually done in theatre under general anaesthetic.

NEUTROPAENIC – this is when there are a low number of white blood cells and the person is at risk of getting infections.

PLATELETS – found in our blood. Platelets help our blood clot.

RADIOTHERAPY – a powerful X-Ray that work to reduce cancer cells.

RED BLOOD CELLS – carry oxygen around the body.

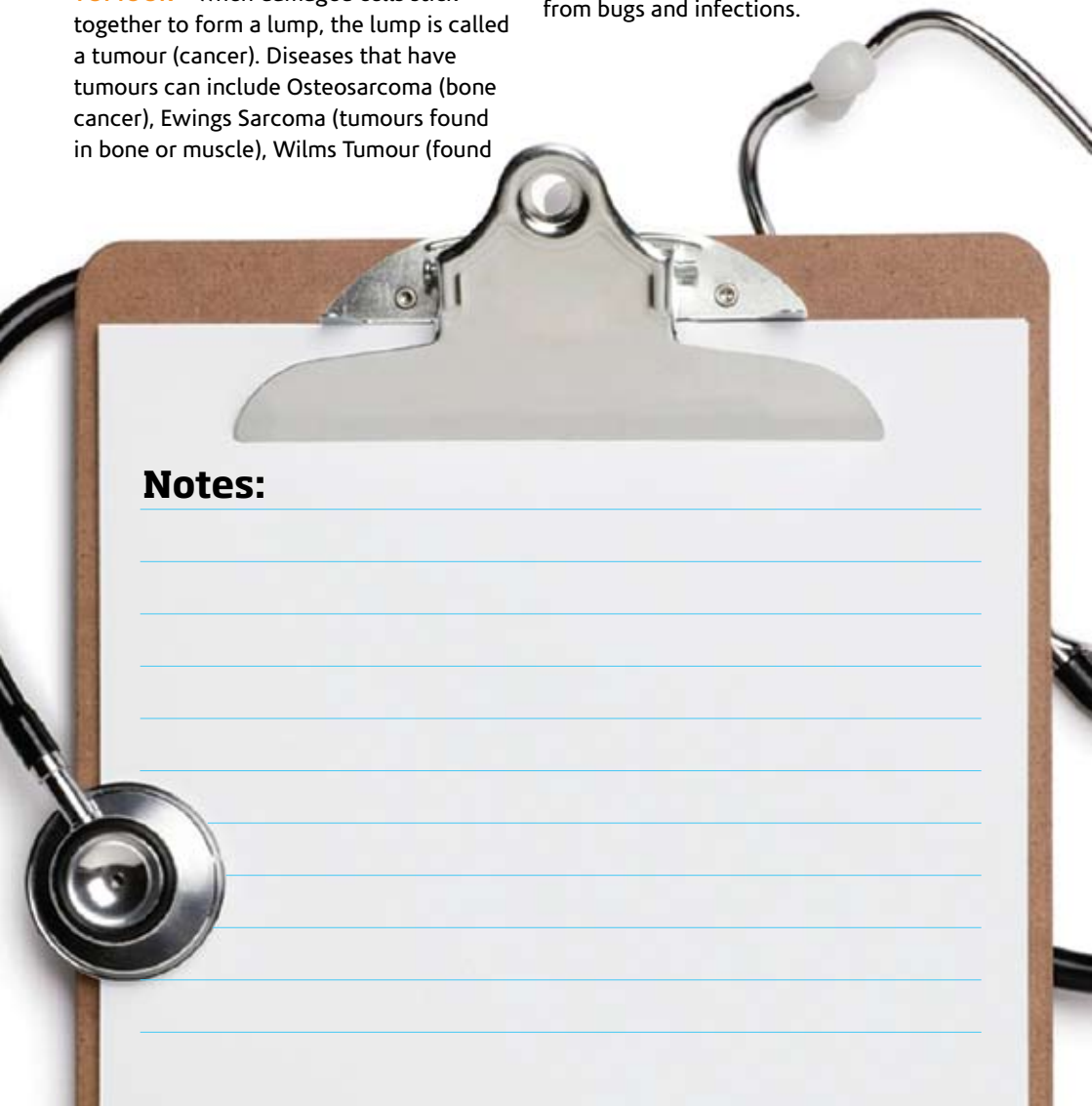
SIDE EFFECTS – side effects are what you can get as a result of chemotherapy, radiotherapy or other medical treatment. These may include hair loss, feeling sick or vomiting, memory loss, mobility issues or weight problems such as weight loss or gain.

TUMOUR – when damaged cells stick together to form a lump, the lump is called a tumour (cancer). Diseases that have tumours can include Osteosarcoma (bone cancer), Ewings Sarcoma (tumours found in bone or muscle), Wilms Tumour (found

in kidneys), Neuroblastoma (tumours of sympathetic nerve tissue), CNS tumours (tumours of brain or spinal cord), Retinoblastoma (tumour of the eye) and Rhabdomyosarcoma (tumours found in soft tissue). These are different from Leukaemia which is a disease of the blood cells.

WHITE BLOOD CELLS – part of our immune system. They protect the body from bugs and infections.

Notes:



Support Options

www.childcancer.org.nz

The Child Cancer Foundation supports families who have or have had a child with cancer. Some areas have sibling camps and activity days which are a lot of fun. There are also family days that you can attend with your whole family.

www.kidslines.org.nz

This site is set up to support kids with any issues they may be facing. They have a 24 hour free number you can call. The number is **0800 543 754**.

www.canteen.org.nz

CanTeen supports young people aged 13 to 24 years who have or have had cancer as well as brothers and sisters.

THE FOLLOWING ARE OVERSEAS
BASED WEBSITES BUT YOU
MIGHT FIND SOME OF USEFUL
INFORMATION ON THEM:

www.supersibs.org

This site supports, honours and recognises brothers and sisters of children with cancer. There is an interactive section that enables you to place messages and ask questions.

www.youthline.co.nz

Youthline supports teenagers and young adults to achieve their potential. There is also a help line **0800 376 633** and an email help line: **talk@youthline.co.nz**

www.skylight.org.nz

Skylight supports children and young people who have been affected by loss, change and grief. They have many resources to cover all types of loss issues. The Child Cancer Foundation has many of these resources available. Just ask your Family Support Coordinator.



www.candlelighters.org

This site offers information and support to siblings.

www.childhoodcancer.asn.au

This site supports siblings and states that it is a site for SIBS (Super Important Brothers and Sisters Programme) to study.

Acknowledgments

The Child Cancer Foundation would like to acknowledge the following people for their contribution to this resource:

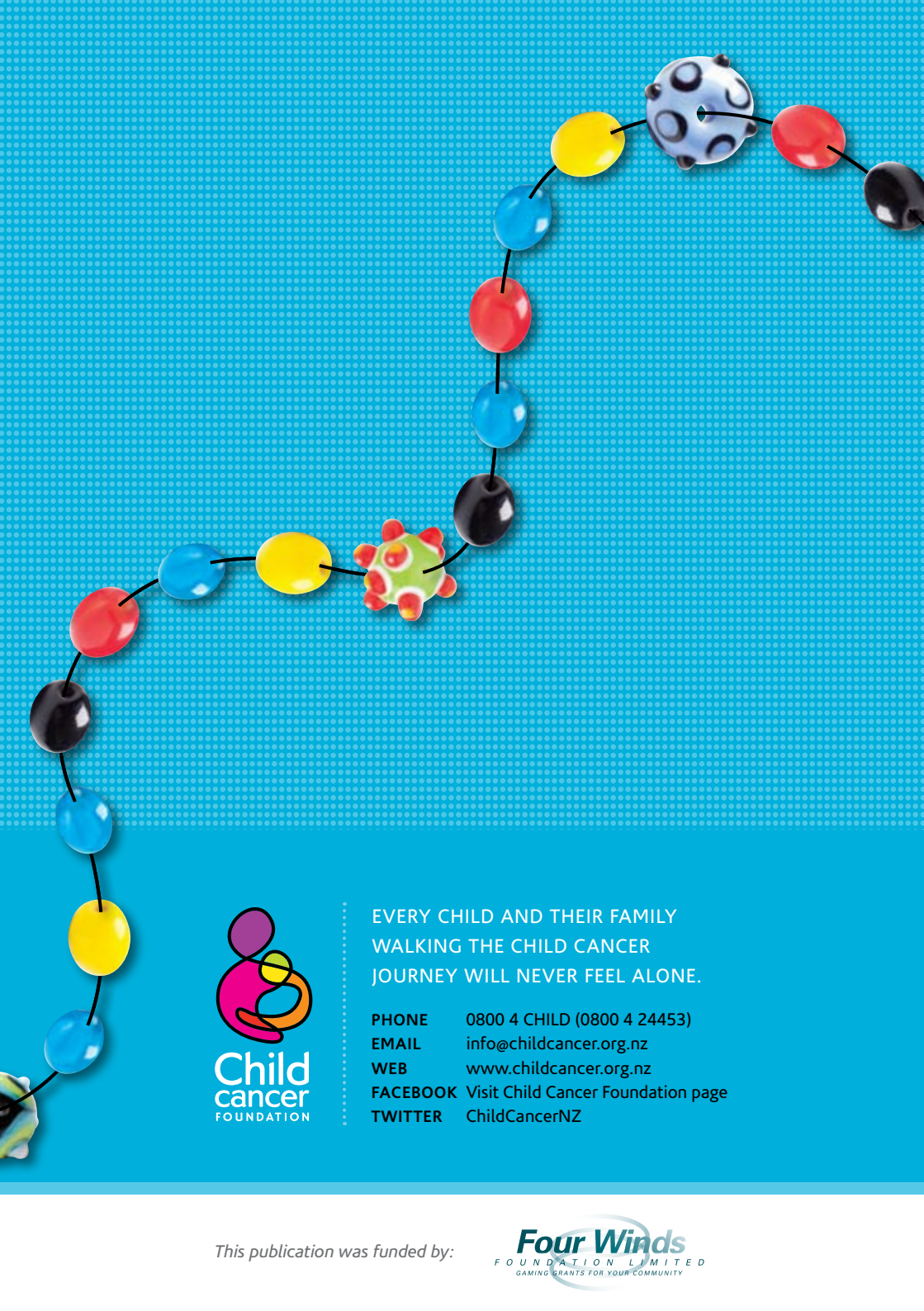
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Rosie Dobson Researcher University of Auckland and Barbara Mackay Play Specialist, Paediatric Haematology/Oncology Starship Children's Health.

Phone 0800 4 CHILD (0800 4 24453)
to contact your Family Support Coordinator

FROM THE TEAM AT THE
CHILD CANCER FOUNDATION





EVERY CHILD AND THEIR FAMILY
WALKING THE CHILD CANCER
JOURNEY WILL NEVER FEEL ALONE.

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