A champion’s journey
You get a very special gift with this book

By now you know that there are many children all over the world fighting cancer like you. And here is a boy who got better - meet Keemo and his mom Thandi...

Keemo is a young cancer survivor. He was born on a cold winter’s day in the year 2000 to his parents Thandi and Mfundisi. In 2004, Keemo was diagnosed with cancer but with the help of his parents, the doctors and CHOC, he survived.

Keemo is now 12 years old. He likes riding his bicycle, playing soccer and spending time with his friends. When he grows up, Keemo would like to be a doctor (his hero is Professor Horace Horzowsky; the paediatric oncologist who treated him).

Keemo will be with you every step of the way and he knows exactly what you are going through. He wants to help boys and girls just like you. It can seem scary, but Keemo knows he survived because he got the right treatment early.

His mom Thandi will also be with you all the time. She knows it can seem scary for your mom and dad, but she is there to help you and your parents when you feel scared or have questions.

You can take Keemo and Thandi with you every time you visit the hospital or your doctor. They are there for you and you can squeeze them tight when you need to. They can also sleep next to you in the bed if you have to sleep at the hospital or in your bed at home.
1. What is cancer?
Find out how cancer starts, and the answers to some of your questions. Write down all the questions you want to ask your doctor.

2. Treatment
Here you will find information about the different ways that cancer can be treated, how your doctor will decide which is best for you and ways to feel better after treatment. Write down your questions and answers at the end of the section, it’s hard to remember everything!

3. Healing food
Healthy food is extra important when you are sick. Find out what’s good for you and what’s not. There are also some ideas for fun, easy meals you can make yourself. Check out some fun food facts and make your own foodie bookmark at the end of this section.

4. Keeping healthy
Good food, activity and relaxation can help your body heal and make you feel better. Try some relaxation exercises and make a happiness collage at the end of the section.

5. How are you feeling?
Here are some ways to handle stressful feelings and details of who to call if you need some help with your feelings and thoughts. Record or draw your thoughts and feelings at the end of this section – it’s important to express yourself and sometimes writing’s easier than talking.

6. Never give up
Read some stories about brave cancer survivors.

7. Things to do
Here you’ll find a whole section of fun activity pages for those hours in hospital.

8. Useful stuff
You might hear a lot of new and complicated words on your cancer journey, here is a list of some of them and what they mean. There’s also a list of people on your treatment team and what they all do, as well as a list of what to pack for a hospital stay.

For moms and dads

9. Contact us
In this section you’ll find contact details to register on Discovery Health’s Oncology Programme. You’ll also find a handy glossary of medical aid and medical terms to refer to, to help you navigate the cancer landscape.

10. How to help
This section offers information and practical guidelines on how to best support your sick child and the rest of the family. From how to handle common side effects and strategies for the various stresses you might experience, to providing good nutrition and when to call the hospital.
There is also a list of useful websites and resources a the end of the this section.
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Stick your photo here
This is a book for you – about you

Not only will you will meet many other children who face similar challenges to you, you’ll also make many new friends along the way. These friendships will become very important, and you will remember them forever. You can share your experiences with other children at your hospital.

We hope that you will see this book as your friend through your cancer journey. Take it with you to appointments and to the treatment room. Make it your own: stick your picture in it, write down the names of your treatment team members, your next appointment and treatment dates, record thoughts, feelings and any questions you have.

We hope you will find that this book gives you information when you need to know and distraction when you want to forget – there are loads of fun activities to do. At the end of your journey, it will serve as an inspiring record of how far you have come and how much you have achieved.

We know these times are not easy – we will be with you every step of the way.
 Acknowledgements

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Most of the time, cancer affects older people, but children get cancer too. If you do, it can be treated. We don’t know why children get cancer, but medical scientists and doctors around the world are working very hard to find out and find ways to stop cancer. As they learn more about how cancer works, they are developing better medicines and ways to fight it.

Understanding what cancer is

Your body is made up of tiny building blocks called cells. The human body is made up of about 10 trillion cells! They are too small to see with your eyes, but you can see them under a high-powered microscope.

Normal cells are the ones we need to keep our bodies working well and keep us healthy. Normal cells grow and divide and stop when they should, but sometimes they don’t know to stop!

Cancer starts when one normal, healthy cell turns into a bad, unhealthy cell and this cell keeps on growing and dividing (multiplying) out of control.

Cancer cells don’t look like normal cells and they don’t work like normal cells

Cancer cells grow very fast and crowd out normal cells. Sometimes cancer cells stop normal cells from doing their jobs. You can say that a cancer cell’s job is to make you sick. A group of cancer cells is called a tumour.

Cancer cells can damage the part of the body where they are and they can spread to other parts of the body – and do damage there too.

There are lots of different types of cancer and the type is named after the place in the body where the first bad cells start.

You’re special

Children don’t get cancer very often. Children’s cancers are rare – and that makes you very special. In South Africa, only one in 600 children under the age of 15 gets cancer each year.

Children’s cancers are different to adult cancers

Children’s cancers affect different parts of the body to adult cancers. They look different under the microscope and respond differently to treatment. Cure rates for children’s cancers are higher than those for adults. Thanks to all the medical scientists and doctors who discover new medicines for cancer, more and more children are being cured. That’s good news!

The most common children’s cancers

The most common children’s cancers are in developing cells like bone marrow (leukaemia), lymph nodes (lymphoma), the brain (as a tumour, or lump of bad cells), kidneys and the nervous system.
Say thanks...

Research tells us that people who are grateful for what they have are happier and healthier. Although it can be hard during tough times, don’t forget to look around and count your blessings...

Onco-what?

Oncology is a word you’ll be hearing a lot. Oncology (say: on-co-lo-gee) is the medical study of cancer and tumours. Your oncologist is a medical doctor who specialises in cancer treatment for children.

Finding the best treatment for you

To help you get well again, you might need some tests to find out where the cancer cells are, how many there are and if they are spreading. Knowing this will help your doctors find the best way to get rid of the cancer cells.

There are three main ways to fight cancer cells, or three main types of treatment:

1. **Chemotherapy**: where medicines are used to kill the bad cells
2. **Radiation therapy**: when special x-rays target the sick areas of your body
3. **Surgery**: an operation to take out the bad cells or a lump of cells called a tumour

Some cancers need more than one type of treatment

Your treatment plan is special and your cancer doctor will design it for your cancer. You may meet other children who have different treatment plans to yours. This is because they have different cancers at different stages to yours.

Leukaemia (say: loo-kee-me-ah)

When you have leukaemia, your body makes lots of abnormal white blood cells inside the bone. Usually, white blood cells fight infections, but the white blood cells in someone with leukemia don’t work the way they should.

Cancer of the bone marrow

This is the most common cancer in South Africa and the whole world. Bone marrow is the inside part of some bones where blood cells are made.

Brain tumour

Brain tumours usually do not spread to other parts of the body.

“Living with cancer is not about feeling sorry for yourself but making little moments count...”

Dean Botha (17) Hodgkin’s lymphoma

You can keep a copy of your doctor’s treatment plan in this file.
I have a question...

Here are the answers to some common questions. If you have a question that is not answered here, write it down on the page at the end of this section and remember to ask your doctor.

Don’t be shy: Knowing all about what’s happening to your body will make you feel better about it. Keep asking until you get an answer you understand.

What causes cancer?
We don’t know why some people get cancer and others don’t. Nothing you did or didn’t do made you get cancer.

I have cancer, now what?
Having cancer means you will need to have tests and treatment and sometimes spend a lot of time at the hospital. It means sometimes you will feel very sick. But, most of the time children recover fully and go on to have a normal, happy life.

How does cancer start?
Cancer starts off as one normal, healthy cell that changes into a bad one. When this cell multiplies into lots of cells, they can form a tumour, or a lump of bad cells.

How does cancer spread?
Instead of dying off and being replaced like normal cells, cancer cells live a long time. As they multiply, they damage the normal cells and can move into different parts of the body. Some cancers affect only a specific area, while other types can spread to other places in the body — even far from the place where they started.

Can you catch cancer from someone else?
No, cancer is not contagious, you cannot catch it from someone else or give it to others like a cold or flu.

How do doctors find cancer cells?
Doctors can look inside your body with scans (like x-rays and ultrasound), surgery (when a small piece of a tumour is cut out) and blood tests.

Will I lose my hair?
Chemotherapy kills fast growing cells like cancer cells. Some healthy cells that normally grow quickly may be harmed, too. Hair is made of fast growing cells. That’s why hair falls out from certain kinds of chemotherapy. But don’t worry, your hair will grow back after your treatment ends.

Why does cancer sometimes come back?
Sometimes cancer can come back. This can happen when tiny cancer cells are left behind after treatment, or when the cells are not killed by the treatment. Over time these cancer cells can begin to divide again and form another tumour.

What does ‘in remission’ mean?
Remission is when the cancer goes away after treatment. There are no signs of it in your body and it doesn’t make you sick anymore.

“I have lots of baddies in my blood. I have to take Barney (Prednisone). His friends need to help him - like BJ (Mycostatin, which is yellow) and Baby Bop (Panado syrup, which is green). All of these go and fight the baddies. The red chemo is the Transformer and it kicks the baddies”. 

Ayaana Patel (3) acute lymphoblastic leukaemia

REMEMBER...
nothing you did or didn’t do made you get cancer.
Write down all the things you can think of that you want to ask your doctor. Use this space to make a note of the answers too – it’s hard to remember everything!

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Different types of cancers grow at different speeds and respond to different treatments. Not all cancers form lumps that you can feel. For example, with leukaemia, which is a blood cancer, the cancer cells replace the white blood cells.

Your treatment will be aimed at your particular kind of cancer. It will also depend on how much your cancer has spread.

There are three main types of treatment

1. **Chemotherapy:** Medicines given by mouth or in a drip or by injection
2. **Radiation therapy:** Special x-rays
3. **Surgery:** An operation.

Some cancers need more than one type of treatment. This depends on:

- What type of cancer you have
- If you have a tumour and how big it is
- How fast it is growing
- Whether it has spread to other parts of your body and if so, where and how far it has gone
- Your age, symptoms and general health

**Different treatments**

Your doctor will explain the best treatment for your cancer. Here is some information on the different treatments.

**Surgery**

Surgery is best for types of cancer that haven’t spread.

A whole tumour can be taken away if it’s in its early stages and is easy to reach. Surgery can cure you of cancer if there is no spread of the disease to other organs or places in the body.

Sometimes radiation or chemotherapy is used after an operation to make sure that all the cancer cells have been killed.

“I knew and trusted my team of doctors. I knew that to get better I had to take the chemo and meds they gave me.”

Radhiyyah Kika (19) acute lymphoblastic leukaemia

Finding the path that’s best for you

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Radiation

With radiation (also called radiotherapy or x-ray therapy), special x-rays send beams into the cancer cells, killing them. Radiation acts only in that specific area. Some of the healthy cells nearby are also killed by radiation.

Radiation can be used on its own, before surgery to make a lump smaller, or after surgery to make sure all the cancer cells are gone.

How radiotherapy is given

Radiation can be given in two ways: outside or inside your body – mostly it’s outside.

The beams come from a machine called a ‘linear accelerator’. The machine aims its high energy x-rays at the cancer, zapping the bad cells.

How long radiation treatment lasts

Each treatment takes five to 10 minutes and is painless; it feels a little like having an x-ray.

Radiation is usually given once a day, for between one and eight weeks. The number of days your treatment lasts for depends on the type of cancer and where it is. It’s very important to zap exactly the same area each time, so you will have to sit or lie very still.

What happens during radiation treatment

The radiotherapist will make some marks on your skin to make sure you’re in exactly the right position and then you must stay very still. Although you may be alone in the room during treatment, there is a camera system so the therapists and your parents can see you and talk to you all the time. If you feel sick or very uncomfortable, tell your therapist straight away. The machine can be stopped at any time and restarted again without any problem.

You might hear a sound while the machine is running, but don’t worry, this is normal. You won’t feel a thing.

After starting treatment, your doctor will see you at least once a week to check how you’re doing and your response to the treatment.

ZIP-ZAP, SIT TIGHT!

Don’t forget to stay very still during the treatment so that the radiation reaches only the area where it’s needed and the same area is zapped each time.

You don’t have to hold your breath – just breathe normally.

It’s best to wear loose-fitting clothes that are easy to take off and put on again.
Side effects of radiation

A side effect is something that you experience after a medicine or treatment. Not everyone has side effects and the after effects of radiation are minor for most people.

You might feel a bit sick, have a runny tummy, feel tired or get dry skin during or after radiation. But there is treatment available to limit or get rid of side effects, so you should mention them to your mom and dad or your doctor.

Take care of yourself

How you can help your treatment work, and take care of yourself during radiotherapy:

- **Rest**: Your body uses a lot of extra energy during treatment and you may feel very tired. Sleep as often as you need to.
- **Try to eat well**.
- **Wear loose clothes**: Anything tight can irritate the skin.
- **Try not to scratch** or rub sensitive areas.
- **Always protect your skin** from the sun by covering up.
- **Don’t** put any creams on the skin affected by radiotherapy.
- **Use** only creams your radiotherapist says you must use on your skin.
- **Don’t** play with or wash off any of the markings put on your skin by the radiotherapist.

Chemotherapy

**How chemotherapy works**

Chemotherapy (also called chemo) uses medicine that travels in the blood stream, destroying cancer cells.

Chemotherapy may also be given before and after surgery and radiotherapy.

**How chemotherapy is given**

There are different ways to take chemo medicines:

1. Swallowing tablets.
2. An injection in the muscles of the thigh or under the skin of the leg or forearm.
3. A drip into the veins (this is most often used for children).
4. A central line: Sometimes if the chemo is very strong or your veins are small, the doctors will give you an ‘artificial vein’ called a portocath or Hickman line.

A portocath comes in different sizes – from the size of a 50c coin to a R2 coin - and sits under your skin. You can wash normally and shower and swim. Treatment is given more easily and without the pain.

A Hickman line sits outside the skin, usually on your chest. You can’t shower or swim, and you must wash around the line.

5. An injection into the fluid of the spine (called lumbar puncture).

The way you get your chemotherapy will depend on the type of cancer and medicines your doctor wants to use.

**How often chemotherapy is given**

How often you have your chemo depends on the type of cancer you have and the medicines used.
Chemotherapy shouldn’t hurt, but can cause some discomfort

Some medicines can make your legs or arms feel itchy or make them burn a little. If you have any pain during the treatment, you should tell your nurse or doctor right away. Your doctor will put some ice on your legs beforehand, which helps. If chemo in the vein burns, it is easy to fix with some cream and a warm towel.

Chemotherapy side effects

Because chemotherapy attacks not only those bad cancer cells but also normal, healthy cells, you might have some side effects. The good news is that normal cells repair themselves and most side effects will go away once your treatment stops.

You might get some of these side effects:

**Anaemia (say: a-nee-me-a)**

Anaemia is when you have a low red blood cell count. The signs of anaemia include:

- Lack of energy
- Increased tiredness
- Headache
- Paleness
- Shortness of breath
- Racing heart
- Dizziness

Low white blood cell count

White blood cells fight infections – when there are too few of them, you can get an infection more easily.

- Visitors at home and in the hospital must wash their hands before coming to see you.
- Avoid large crowds of people (like at shopping centres, supermarkets, the movies, churches, shul and mosque).

“‘My treatment wasn’t as bad as I expected it to be. I thought I’d throw up all the time but I didn’t. I’ve had just chemo and will get radiation at the end.’”

Danielle Oosthuizen (15) acute myeloid leukaemia

“I wash my hands to keep free of germs, and tell adults to wash theirs too.”

Julian Hainebach (2) brain tumour

You can carry on with school, playing with friends and going out between treatments, but you must avoid contact with people who are sick.
Diarrhoea

Some chemotherapy medicines and antibiotics can cause diarrhoea. Follow these tips to help prevent this:

- Eat little snacks more often, rather than a big meal all at once.
- Drink water or rooibos tea and slowly try plain foods like mashed potatoes, plain rice or pasta, or dry biscuits.
- Avoid high fibre foods like fresh fruit and vegetables.
- Avoid fatty, fried or spicy foods.
- Eat high potassium foods like bananas, avocados and potatoes.

Constipation

Drinking less fluid, eating less fibre, a decrease in exercise and some chemotherapy medicines, can cause constipation.

- Avoid white bread – stick to high fibre cereals and brown bread.
- Drink more water and fruit juices.
- Eat more fresh fruit and veggies.
- Try to exercise a little every day.

Nausea and vomiting

Nausea or vomiting after treatment is often caused by irritation of the stomach lining. You might feel nauseous right after chemotherapy, or after several hours or days. There is very good medicine you can take to control nausea and vomiting. Your doctor will always give this to you by mouth or in a drip before you get your chemo or radiotherapy.

- Avoid fried foods, spicy and rich foods.
- Try dry foods like toast and biscuits instead.
- If you throw up, try to rinse your mouth out well, otherwise stomach acid can make your mouth even more sore and it is bad for your teeth.

Low platelet count

Platelets help the blood to clot. When there are too few platelets, you bleed more easily. The platelets can recover by themselves or sometimes you need more help.

Look out for:

- Increased bruising
- A persistent nose bleed that doesn’t stop with pressure
- Gums that bleed easily
- Bleeding from small cuts and scrapes that’s hard to stop
- Red freckles that suddenly appear on your skin
- Blood when you go to the toilet

Stay away from contact sports or rough play that could cause an injury.

Use a soft-bristle toothbrush for cleaning your teeth. Anything harder may cause bleeding.

Mouth ulcers

The cells on the inside of your mouth normally change quickly to repair any damage caused by the teeth and normal wear and tear. Cancer treatment causes redness and swelling and can stop this repair work for a little while and that’s why you can get mouth ulcers. When your mouth is sore from chemo, some infections can also cause mouth ulcers.
**Hair loss**

If you lose your hair after chemo, it will always grow back.

Hair loss usually begins two to three weeks after starting the treatment. (If you have radiotherapy to the head, hair loss can happen more quickly.) When your hair grows back it may be different from before you got sick (but it’s almost always more beautiful than before!)

Because a lot of heat is lost through the scalp and the skin is especially sensitive to the sun, you should cover your head outdoors. Try on fun hats, bandanas, scarves, caps or wigs.

**Skin changes**

Sometimes your skin changes colour in some areas after chemo. Don’t worry – your skin colour should return to normal after treatment has stopped. Once it’s safe, moisturisers can help your skin to repair. Always check with your doctor first.

**Following up**

When your treatment is finished, you will need to check in with your doctor regularly to make sure you stay well and there are no complications.

**Where to have treatment**

Childhood cancers need specialist treatment by a paediatric oncologist. It’s one area where it’s generally accepted that private medicine isn’t the preferred route. To develop the expertise needed, the medical team needs to see a large number of patients and the rate of childhood cancer is a lot less than that of adult cancer.

This has led to most of all childhood cancers worldwide being treated in public sector hospitals. Contact your local CHOC Division (www.choc.org.za/divisions.html) for referrals to recommended doctors. And remember, you have the right to a second opinion.

Source: Vanessa Vermaak, Western Cape Divisional Manager of CHOC
Questions to Ask My Doctor

Use this space to write down things you want to ask your doctor or the nurses about your treatment. We know you’ve got a lot to remember, so write down the answers. This will help to remind you later on.

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Eating well helps fight disease. Healthy food is extra important when you are sick because you need nutrients to fight your illness, nourish your body and help it to heal.

Here are some ideas to help heal your body with food.

**Food is fun!**

A healthy diet includes all the protein, carbohydrates, fats, vitamins, minerals, fibre and water that your body needs to work properly.

Each of these nutrients has an important job to do. If you have too little of any one of them, your body may not be able to protect, repair, refresh and cleanse itself. Because of this, you feel tired and sick.

**That’s why balance and variety are so important**

A balanced diet means eating different types of foods from the different food groups, rather than having the same foods every day.

Eating different types of foods also helps to make sure that you get all the vitamins and minerals your body needs to feel as strong as possible – and keeps meal times interesting!

**Protein: Your body’s building blocks**

Try to eat two servings of protein a day.

Proteins are the building blocks of the body. Without them the body can’t build and repair cells and tissue properly.

We get protein from fish, dry beans, peas, lentils, eggs, soya, lean chicken and beef.

**Carbohydrates: Energy on tap**

Carbohydrates (carbs) give the body lots of energy. The best types release energy slowly: vegetables, fresh fruit and wholegrains like brown rice, oats, barley, mealies or corn and other high fibre options like rye or health bread, high-fibre crackers, sweet potatoes and high-fibre cereals.

Not so good are fast-release types: sugar, honey, sweets, bread and mealie meal. If mealie meal is a major part of your diet, try to eat it in small portions, with some protein to help slow down digestion.

“I must eat fresh food and drink 100% pure juice. I like water and milk.”

**Tirsten Timm (5) acute lymphoblastic leukaemia**
When I was diagnosed I was 16 and I wasn’t really interested in eating… anything that went down my throat was a celebration! I do remember jelly being so soothing.”

Radhiyyah Kika (19) acute lymphoblastic leukaemia

We should all have at least five pieces of fruit or vegetables a day. It’s best to eat them fresh and raw because they are full of good nutrients that keep cells healthy and help protect against cancer. Try to get different types and different colours of fruit and vegetables: The more colours you are getting in, the more likely you are to be taking in all of the micronutrients that your body needs to keep it healthy. Each week try a new type of vegetable or fruit or choose one that you have not had in a while to mix things up.

Because carbs are broken down to sugar (for energy), your doctor will sometimes ask you to cut down on the amount of carbs you eat to help keep your blood sugar low. This is because some cancer drugs can make your blood sugar very high.

Fibre: Your waste removal expert

Fibre is good for digestion as it cleans out your system and takes away waste.

Vitamins and minerals: Your secret weapon

Vitamins and minerals help the body to work well.
They protect cells, keep the nervous system healthy and boost the immune system. They also convert food into energy, keep bones and teeth strong, and help with healing. Good sources of vitamins are nuts, fruits, vegetables, seeds, dry beans and wholegrains.

Some vitamins may interfere with cancer treatment and your doctor will tell you which ones to avoid during certain phases of treatment.

Fats: Choose the right ones

The right fats help us stay healthy. Good sources are: unsalted nuts, avocados, sunflower seeds, sesame seeds, pumpkin seeds, and olive and canola oils.

Water: Essential to life

Drinking lots of water helps your body work at its best.

Try to have six glasses of water every day and choose water instead of sugary and sweetened cold drinks and juice mixes – much better for your precious body!

Fun food facts

Did you know...

- China makes over 10 million tons of garlic. That’s more than 75% of the whole world’s output! Garlic has loads of health benefits and can be used to flavour your food.
- India is the world’s biggest producer of bananas, with nearly 22 million tons! Bananas are high in good-for-you fibre and potassium and make a great snack.
- Cabbage is 91% water and an apple is made of 25% air, and that’s why it floats! (So they say!)
- Cherries are a member of the rose family.
- Mealie plants always have an even number of ears of corn.
- The actual corn part makes up about 8% of the weight in a box of breakfast flakes.
- Eggplants (or brinjals) are actually fruit, but are classified botanically as berries.
- Lemons contain more sugar than strawberries.
- There isn’t a single word that rhymes with oranges.
- Peanuts are one of the ingredients in dynamite!
- Tomatoes are full of the natural cancer fighter: lycopene.

It’s good for you to eat 5 servings of fruit or vegetables a day. Yum!
Some food for thought

Things to think about at the different stages of your cancer journey

**During treatment**

Sometimes cancer treatment makes it hard to eat well and enjoy healthy foods. Your sense of taste or smell may change, your mouth might be sore, or you may simply not feel like eating.

It’s important that you try to eat something to keep up your energy and help your body deal with treatment. Here are some ideas to make it easier:

- Eat when you’re hungry, even if it’s not time for a meal
- Eat lots of little meals in the day rather than three big ones – ask for the things you feel like
- Eat when you feel your best and let you parents know that you want to eat
- Keep some healthy snacks close by for nibbling on
- Drink milkshakes

**After treatment**

When your treatment is over, help your body get strong again. Try to eat well by choosing healthy options and enough variety to make sure you’re getting all the nutrients, vitamins and minerals you need.

Carry on eating balanced meals, with a little of everything, especially colourful fruit and vegetables, which contain loads of important nutrients.

Splish, splash, splosh!

Always wash your hands well before and after eating

**Some solutions to help you eat well**

It’s not always easy to eat well. Here are some solutions to common problems:

- Try soft foods like yoghurt and oats, soups and smoothies. Don’t eat things when they are too hot – allow your food to cool first. Try drinking through a straw and avoid rough or dry foods like rusks, toast, and biscuits. Also avoid foods like pineapples, oranges and tomatoes – they are acidic and can hurt your mouth.

- It’s important to keep your mouth clean. Ask your doctor to tell you which mouthwash is best for you, or look for one with ‘chlorhexidine’ in it (isn’t that a mouthful?!). It has a local anaesthetic in it, which will help when your mouth is sore. You can also get a gel to put on.
Nausea and vomiting

- Keep the windows open while you eat, this can help if smells bother you
- If you feel sick when you wake up in the morning, try and eat something dry before you get up
- Eat and drink slowly to give your stomach time to adjust
- Smelling lemons or eating ginger may help to lessen nausea
- Cold foods or those at room temperature and drinks are better for you when you are feeling nauseous than hot or warm foods
- Sip iced water or suck an ice cube
- Don’t lie down straight after you eat, but rest often
- Listening to music or watching TV while you eat can help distract you.

A mixture to help your tummy work

For a natural constipation remedy, ask one of your parents to mix a quarter cup of warm water with a tablespoon of prune juice. Add a few drops of fresh lemon juice. Add three to four teaspoons of canola or olive oil and drink this mixture first thing in the morning and last thing at night.

Ginger: A nausea-fighting ninja!

Ginger is great for combating nausea and it can be used before or after chemotherapy.
Ask one of your parents to grate a little ginger into water and keep it in the fridge to sip on during the day. Also try ginger tea and ginger ale.

Eat well, feel good!

Some healthy recipes you can make yourself at home

Very Berry Smoothie

What you need
- ¾ cup freshly sliced strawberries, blueberries or any berry of your choice
- ¾ cup mixed frozen berries
- 100ml cranberry juice
- 100ml apple juice
- 1 small banana
- 175ml low-fat plain yoghurt
- Crushed ice (as much as you like)
- 2 teaspoons flaked almonds
- Some mint leaves

How to do it
1. Blend together all of the ingredients (except the almonds).
2. Add the crushed ice – add as much as you like depending on how runny you like it.
3. Pour into serving glasses, sprinkle with the flaked almonds and the mint leaves.
4. Serve cold and enjoy.
Vital vegetable dipping lunch with hummus and wholewheat pita bread

What you need

- Baby carrots
- Snap peas (also called mange tout)
- Cherry tomatoes
- Cucumber, cut into chunks
- Red, yellow and green pepper slices
- Hummus
- Avocado pear
- Whole wheat or rye pita mini breads
- Lemon juice, balsamic vinegar and black pepper to taste

How to do it

1. Mash the avocado with a dash of lemon juice, balsamic vinegar and black pepper into a dip and set aside.
2. Toast the pita bread and cut into quarters.
3. Arrange the raw vegetables strips on a platter and put the hummus and avocado dip in the middle of the platter.
4. To enjoy, dip the vegetables and pita bread in the hummus and avocado dip. So yummy and good for you!

Try making your own hummus. It’s fun and easy

What you need

- I tin chickpeas, rinsed and drained
- 1 small dried red chilli (but only if you want it)
- ½ teaspoon ground cumin
- 1 clove garlic, peeled
- 2 tablespoons tahini (sesame seed paste)
- 2 tablespoons lemon juice to taste
- Salt and freshly ground black pepper to taste

How to do it

1. In a food processor, finely chop the garlic and chilli (use these ingredients if you want, but not if your mouth is sore).
2. Add the chickpeas, cumin and tahini and blend until smooth. You can add some water if you prefer the hummus thinner – sometime it thickens when chilled.
3. Add the salt, pepper and lemon juice to taste.

Chicken, pineapple and vegetable stir fry

What you need

- 1 tablespoon olive oil
- 4 medium chicken breasts, cut into strips
- 8 slices of pineapple, cubed
- 10 – 20 snap peas (or mange tout)
- 3 – 4 carrots, cut into strips
- ½ punnet of button mushrooms, washed and sliced
- ½ packet baby spinach leaves
- ½ head of fresh broccoli
- ½ red pepper, sliced into strips
- ½ yellow pepper, sliced into strips
- ½ teaspoon crushed garlic
- ½ teaspoon ground ginger
- 1 tablespoon soy sauce (choose MSG free or low-sodium if possible)
- 2 tablespoons fresh lemon juice
- ½ cup chicken stock

How to do it

1. Heat the olive oil in a pan. Place on high heat on stove plate.
2. Add the chicken strips and stir fry quickly to brown just a little.
3. Add the vegetables, pineapple, spices, soy sauce, lemon juice and chicken stock, stir quickly to avoid chicken sticking to the bottom of the pan.
4. Place a lid on the pan to allow the vegetables to sweat. Leave the lid on the pan for about 2 – 3 minutes.
5. Then remove the lid and stir-fry the vegetables and chicken in their own juice using a wooden spoon until vegetables are just tender. If the pan becomes a little dry add some water.
6. Serve on a tasty wholegrain carbohydrate such as brown rice, barley, quinoa or corn.
Cut out and keep your own fun fruity bookmark

To make your bookmark you’ll need magazines to cut out from, scissors, a glue stick and coloured pens if you want to add some detail.

What to do

1. Cut out the bookmark shape from this page.
2. Cut out pictures of your favourite colourful fruit and vegetables from magazines.
3. Stick them down on the bookmark to make a yummy collage.
4. Add any details you want with the coloured pens, like your name.
5. Tuck your bookmark into your book to keep your place. Don’t forget to have your 5-a-day!
Be sun smart

Treatment for cancer can make your skin sensitive to the sun. Here are some sun smart tips:

- Stay out of direct sunlight between 10:00 and 15:00 when the sun’s rays are most dangerous.
- Always wear a hat – the wide-brimmed ones are the best.
- Cover your arms with a long-sleeved top.
- Make sure you have sunblock on any exposed skin, especially on your face. SPFs 30 to 50 are best.
- Don’t forget to put more sunblock on after two hours, after swimming, activity or drying yourself with a towel.
- Use a lip balm.

Activity and relaxation are some of the most important things you can do to help your body and feel better.

Play!

Even though cancer treatment might make you feel tired all the time, a little bit of activity is great for having fun, keeping you strong, helping you feel happy, helping your body work well and helping you eat and sleep better.

Do things you love to do, like swimming, throwing a ball or frisbee, hide and seek, playing games like Wii Fit, walking the dog or jumping – as long as your parents and doctors say it’s okay.

- You will feel stronger and more in control of your body when you exercise regularly.
- Exercise also triggers happy hormones, which will make you feel better.
- Even if you feel tired to begin with, after you exercise you have more energy.
- You may also find you sleep better at night when you’ve exercised.
- There are lots of ways you can play in the day. Try to do a physical activity for at least half an hour on most days of the week.

Did YOU know?

Because harmful ultra violet (UV) rays from the sun reflect off cement, water, sand, glass and grass, you can get sunburned even in the shade! Make sure you’re always covered, even on cloudy days.

Top 8 reasons to move your body

1. Boosts brainpower
2. Melts stress
3. Gives you energy
4. It’s fun!
5. Builds friendships
6. Fights disease
7. Strengthens your heart
8. Keeps your body strong and fit
Did you know?
Research says relaxing helps to lower tension, anxiety and depression in people having chemotherapy and radiation. It can also relieve unpleasant side effects like nausea, pain and vomiting.

Keeping clean
Cancer treatment can make you more vulnerable to infections, especially when you have a low white blood cell count. This means you can catch things like colds and flu more easily. Germs are passed on from person to person when we touch each other. That’s why it’s more important than ever to wash your hands often and avoid people you know are sick.

“I’m much more hygienic now. I wash my hands all the time and I’m more aware of people who are sick – like coughing and running noses. I appreciate life more too – the small things.”
Danielle Oosthuizen (15) acute myeloid leukaemia

Stress
You might not have experienced stress until you were told you have cancer. It’s a natural reaction to a very challenging situation. Stress can make you feel frightened, worried and out of control. A lot of stress all the time can affect your health in a bad way – lowering the immune system’s ability to fight illness. But positive, happy thoughts can help you fight illness and feel better.

Relaxing helps you feel less stressed and worried and can help you cope with pain. When you relax, you feel warm, comfortable and peaceful.

“‘I like to use my hands, doing art and cutting out. Just being quiet and doing something creative helps me relax.’
Lwando Mpongoshe (11) lymphoma

Here are some ways to relax
- Make sure you rest as often and as long as you need to. Your body is busy fighting and recovering and this can be tiring!
- Build up your strength with good food and activity when you can.
- Try to name your emotions and tell your mom and dad how you are feeling. It’s natural to feel lots of different feelings at this time. Sad, angry, afraid, confused and tired are just some of them.
- Collect pictures of things that make you feel happy.
- Laughter really is medicine: Read funny books, be with people and watch movies that make you laugh.
- Make yourself a comfort zone: If you’re staying in hospital or at home, make a cozy place that you love to go to. Find a super-soft duvet, pretty pillowcases, add your favourite toys, pictures and books.
- Keep busy: Watch television or movies, listen to the radio, read books or magazines, do puzzles, play games, make crafts or paint.
- See your friends whenever you can.

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Try some visualisation and breathing techniques:

Our minds and bodies are connected (you know how you get butterflies in your tummy before a test when you’re nervous? That’s your mind sending a signal to your body, and your body reacting). Sometimes, if we help our minds feel calm and relaxed, our bodies can feel better too.

Visualisation and deep breathing are ways of relaxing that use our imagination. Picturing yourself feeling well, happy and relaxed can help your body to actually feel well and relaxed.

Here are some fun exercises for you to try...

Ask your mom or dad to do these exercises with you in the beginning, if you like.

**Take your mind on holiday**

Sit comfortably in a quiet place and close your eyes.

Imagine in your mind a peaceful, calming place – this could be a real place that you know and love (like a family holiday spot, your garden at home, a best friend’s trampoline, or wherever you feel truly happy), or a made-up place.

As you make the picture in your mind, imagine it with all your senses: What does it look like, smell like, sound like, feel like and taste like?

If you are imagining relaxing by the sea, for example, think about how the salt water tastes or your favourite ice cream, the smells of the sea and sun lotion, the sound of crashing waves and laughing and the warmth of the sun on your skin.

After a 15-minute ‘journey’, you should feel happier and more relaxed.

**The candle and the flower**

Make relaxed fists with both hands and pretend that your left hand is a flower and your right hand is a candle. Take a deep, slow breath in to smell the flower, and then blow out as if you’re blowing out the candle. Picture the flower and the candle – what do they look like? Use your imagination to picture them.

Repeat smelling the flower and blowing out the candle a few times with slow, deep breaths and you should feel calmer.

**Blowing bubbles**

This is lots of fun and helps you learn to breathe deeply, which helps you to relax. Think of any worries or fears you have and imagine that you are blowing them into the bubbles. When the bubbles float away, the worries float away along with them, never to return.

**Floppy muscles**

You might feel your muscles tighten when you start to feel worried. Imagine you’re a big rubber band, all floppy and wobbly. Move around like a rubber band, wiggling your arms, legs, tummy and head. Pretend someone is gently pulling on you and stretch your muscles in that direction. When the person lets go, you become floppy again. Doesn’t that feel funny? But it’s a good way to relax!

**Paint yourself calmer**

Choose a colour that makes you feel relaxed and comfortable. Close your eyes. Practise breathing in that colour and sending it to the sore places in your body. Then imagine the colour going down through all the different parts of your body, like from your elbow through your arm to your hands and fingers. Breathe out as the colour moves down your body. Imagine this colour flowing down all the way until your body is full of the colour and fully relaxed.

“Before I was diagnosed, I was a tomboy, doing all the boy things like cricket and soccer. Cancer stopped that for a while; but having my family was so wonderful... especially when my sisters could stay over with me and we had fun playing a silly game called “pulling hair”. I knew I would always win because I got to pull their hair... and guess what? I had none for them to pull!”

Radhiyyah Kika (19) acute lymphoblastic leukaemia
Collect pictures of people and things that make you feel happy and stick them onto, or draw on these pages...
How are you feeling?

You can learn to handle stressful feelings in many ways, like:

- Exercising
- Listening to music
- Reading books, poems, or magazines
- Expressing yourself through art, music or movement
- Keeping busy with things you love to do, like drawing, arts or crafts
- Talking about your feelings with family and close friends
- Doing relaxation and deep breathing exercises: Try some of the exercises in section 4.

Cancer treatment is very good at getting rid of children’s cancers, but it doesn’t take away the feelings of stress that come with having cancer. Having cancer can make you feel as though nothing is under your control.

But, there are some things that you can control. There are things that you can do to cope with the stress of having cancer.

Your feelings (emotional health) are just as important as your body (physical health).

Think about how you are feeling

At times, you may:
- Not really believe that you have cancer
- Be sad, afraid, or lonely
- Be angry, resentful, or worried
- Feel out of control
- Have a sense of acceptance and hope for the future

All of these feelings are perfectly normal, and you may change quickly from one to another. That’s okay too.

“Think positive thoughts.”
Chara Adams (11) acute lymphoblastic leukaemia

“I stay positive and motivated because I have two dogs at home. I’ve been away from home a long time and they need me.”
Dean Botha (17) Hodgkin’s lymphoma

“Don’t worry about it. At the end of it you look back and you see the whole experience and you inspire people not to worry. Try not to worry about the small, small pains you have.”
Rwe Kiiza (8) acute lymphoblastic leukaemia
**And don’t forget...**

- Nothing you did, thought, or said, caused you to get cancer.
- You can't catch cancer from another person. Just because you have cancer does not mean that others in your family or school will get it too.
- You are not alone. Lots of other children in this country and in the world have cancer too.
- It is okay to be upset, angry or scared about your illness.
- You can’t do anything to change the fact that you have cancer. But you can do lots of things to help your body fight the disease (like eating well, resting, exercising when you can, and doing what your doctors tell you).
- Family members may act differently because they are worried about you.
- You may have a diagnosis of cancer, but cancer does not define you. You are still the same, loveable person.
- When you are having treatment, sometimes your body’s fighter cells may not be strong enough for you to see your friends. But, you can keep in touch with one another by sending letters, emails, SMSs or BBMs.
- Know that those important to you are thinking about you as much as you are thinking about them.
- Talk about and share your feelings as much as possible. When you are feeling strong, you may feel up and happy. On days when you feel tired or weak, you may feel sad. This is all normal.
- Ask as many questions as you want to. Speak to your parents and to your doctors. Knowledge is power. And having knowledge can help calm your fears.

Sometimes your feelings may seem so big or you might be afraid to upset your mom or dad. It is okay to want your own person to share all your thoughts and feelings with. Ask to speak to a counsellor.

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**Who to call**

If you have a question, or feel sad or lonely, or if you want to talk to someone who understands how you feel, or want to find out about meeting with other families who have children with cancer in your area, talk to your parents. Here are some numbers to call together:

**CHOC Childhood Cancer Foundation SA**

- Call: 086 111 3500
- Email: headoffice@choc.org.za
- Visit: www.choc.org.za

**The South African Anxiety and Depression Group (SADAG)**

- Call: 0800 21 22 23 (free)
- SMS: 31393 and someone will call you back
- Visit: www.sadag.co.za

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“Sometimes I would not even want to speak to anyone but I did enjoy speaking to other children who had been through the same experience as me. I never thought I would not make it – I just knew I would pull through.”

Radhiyyah Kika (19) acute lymphoblastic leukaemia

“Don’t be sad”

Julian Hainebach (2) brain tumour
Here is a place for you to record your thoughts and feelings. Sometimes writing them down is easier than talking about them. Expressing yourself is very important, writing down how you feel can help you figure out your feelings too. You could also draw a picture of how you are feeling.
Vincent’s story

My name is Vincent Segone. I’m a happy, healthy 23-year-old young man. I was not so healthy 18 years ago when I was first diagnosed with leukemia (a blood cancer) at the age of 5.

Being diagnosed with leukemia at a very young age was very hard for me and my family. From age 5 to 8 I went for treatment for this illness, but at such a young age it was scary and confusing to both me and my parents.

It was difficult going for treatment at first, but I had the help of doctors and nurses who understood and loved to be around children. There were also other children and families dealing with the same illness and this made getting better easier. With the help of these great people and God we beat leukemia.

Today I am very healthy and looking after myself. I am also helping others deal with cancer and letting them know they can beat it.

My message to you is you can get through your disease. Just pray and believe in your great doctors, nurses and the support you get from other families dealing with the same illness. Remember that leukemia is best cured at early detection and that your diagnosis is not the end, but the beginning of a long healthy life.

By Vincent Segone

Prudence’s story

My name is Prudence Serapedi and I live in Soweto. When I was 8 years old I was diagnosed with liver cancer. That was in 1996 and I had to go to Chris Hani Baragwanath Hospital for treatment.

I soon learned that having cancer does not mean you are going to die or infect other people. I went for an operation, which went very well.

Then I had to go for chemotherapy. You know, from the first day to the last I lived with pain, crying every day and missing school. It’s okay to cry if you feel pain or miss school. There is nothing wrong with that.

But even with the treatment, I was still very sick. So I had to go back to hospital for another operation. I did not lose hope and the nurses, doctors and my parents never once stopped praying. Finally, after the doctors believed they had done all they could, they let me go home.

I went for check ups twice a week and then only once a week and now only every six months. We had such a wonderful time during my cancer, playing and going out and having fun that today I don’t even feel like it was difficult.

By Boipezo Prudence Serapedi

Never give up

Life is not always easy. Sometimes it feels unfair. You might be asking yourself: “Why is this happening to me?” But sometimes, things happen for no reason that we can see, that’s just how life is.

We all have good times, bad times, fun times and difficult times. And all times pass. The difficult times are soon forgotten when you move on to something better, but they will serve to remind you how much you have grown – and how you beat challenges.

You are stronger than you think. You can overcome more challenges than you think. Here are some stories of children who had difficult times, just like you are having, and some inspiring messages about how they beat their challenges. This is their champion’s journey...

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I have done a lot of harmful things in my life, including: driving peas and straws up my nose and choking on stones.

My name is Mamorene Kgotlelelo Seleke, I am 14 years old and attend Princess High School, currently doing grade 10. I have been diagnosed with severe aplastic anemia (SAA) with an unknown cause. Never have I let this come between me and living life to my fullest. Although there are certain things I can’t do, I honour my doctors and praise God for the ability to see the dawn of new beginnings.

My story began 3 days before I turned 6. I’ve always been a curious and energetic person and while arranging the birthday invitations with my mom, I needed the toilet, which was outside the house. I headed for it at about 30 km/h and reached the building, but with my forehead. But before I could do anything, I passed out like a light. On my birthday, having forgotten about the ordeal, I went through 3 days earlier, my friends brought it up by questioning me about the black eyes. It was a question I couldn’t answer because about five hours of my life was lost. When it got worse, I was taken to hospital.

I hate hospitals. After confessing my fear, I was told to face it and all would be well, plus it would be fun. I faced the fear but it wasn’t that fun. What happened from the evening when a drip was put on me for the first time to the time I woke up in a ward in the morning remains a mystery. All I know is that I was getting rather uncomfortable about the instruments around me.

I remember the day my mother came back from work and told me I had cancer. I had no clue that it could affect children, so what was happening? I was a good girl all my life so why was God punishing me? This is a question I learned to answer myself, that having cancer was in no way a punishment but in one way or another, a gift. What kind, I’m still learning.

From being the “miss-know-it-all”, I was now in the midst of darkness. I would feel the anger-meter rise within me when my teacher and class mates came to visit and tell me ‘not to worry, all will be well’. I would break down every time my mom would go home. My soul deteriorated and would clash with every wall of that room when waiting for the fairies and angels my cousins promised me would come. All I wanted was to go home.

My condition worsened and soon I found myself in ICU. All those lovely nights with a lonely song sung to the melody of beeping machines. I missed the sound of laughter, the power I had once possessed of knowing all that was happening to and around me.

“So it was true, the only thing to fear was fear itself.”

Returning to school was a dream come true. Yet, with all the weight I had gained, deepened voice and eight months gone by, I was the joke of the school. It was torment, I couldn’t bear it and it lasted four months. It was easy on me, I must admit, because my aunt was one of the meanest teachers there. But I still wanted to make a fresh start, new school, faces and all. So I did, I ran away from it all but for once I ran away from something and it didn’t come tumbling back. I learned quite late to accept myself because of unawareness and ignorance.

There are a lot of things I wanted people to learn, one being that an individual with cancer is still a human. There were also things I learnt, one is to be accepting of all that I am created as and rejoice with it, no matter how painful or wonderful it is.

By Mamorene Kgotlelelo Seleke
**Things to do**

You may spend many hours waiting at the hospital or having treatment. In this section you’ll find loads of fun activities and colouring-in pages to do.

Other things to bring from home are:

- Reading books
- Homework
- Magazines
- Puzzles
- Games
- Toys
- Movies
- iPod and headphones

“I like to play with my toys in hospital to pass the time.”

*Malvin Chinyanya (4) Burkitt’s lymphoma*
Flynn’s spotted some shields, so guards must be near! Can you complete the sequences, by colouring the white shields the correct colours?
A clean path

Mi-a has to clean! Can you help him clean a path across the grid by colouring the squares with the numbers 1, 2 or 3 in?
Bolt is in New York, where there are so many skyscrapers! Can you put these in height order, starting with the tallest?

New York, New York
tallest

Mittens
shortest
c b e a d

Colour this box the same colour as the tallest building!

Answers: c, b, e, a, d. Blue.
Mickey loves to go for a ride in the countryside on his scooter. **Colour** Mickey and his scooter using the dots as colour guide.
Mater’s maze

Mater needs your help to make it through this maze! Can you find the right route for him, tipping all the tractors on the way? Tuck the box each time you tip one!

How many tractors have already been tipped?
Maximus, the horse, needs your help. How many horseshoes can you count?
You might hear a lot of strange new words on your cancer journey, here is a list of some of them and what they mean.

What does that word mean?

| Audiology | Hearing tests. Some medicines can affect your hearing. If you’re on one of these, you will have regular tests during and after your treatment. |
| ALL | The acronym for acute lymphoblastic leukaemia – it’s the most common form of childhood leukaemia. |
| Anaemia | A low number of red blood cells. |
| Antibiotic | A medicine used to fight infections (bacterial). |
| Artery | A blood vessel that carries blood from the heart to the tissues and organs. |
| Biopsy | When some cells are taken from your body while you are asleep so they can be examined under a microscope. |
| Blood tests | Blood tests are done at the time of diagnosis, during treatment and sometimes afterwards. The blood cells are counted – that’s one way to check how your treatment is working. |
| Blood culture | Blood is taken and kept for 24 – 72 hours. If there is an infection in the blood, germs will grow in the sample and the doctor can work out which medicines will work best. |
| Blood type | The 4 main types are A, B, AB and O. These types are important when cross-matching blood that has been taken from one person to give to another. |
| Bone marrow | Bone marrow is like a factory where all the blood cells in the body are made. This happens in the spongy tissue inside the long bones of your ribs, pelvis and hips. |
| Bone marrow biopsy or aspirate | A sample of bone marrow is taken from the bone (usually the hip) while you are asleep and is examined under the microscope. |

Benign tumour | A non-cancerous lump of cells, it does not invade nearby tissue or spread to other parts of the body. It can grow and cause problems by pushing on body parts that are close by.
When a picture is taken of a bone to see if there is any cancer. Usually an injection is given first and this material collects where there are cancer cells.

A test used to check heart function.

Minerals that your body needs to keep cells healthy.

This records the rate, rhythm and electrical activity of the heart.

A small needle, with butterfly-shaped plastic wings, used for taking blood or giving intravenous (into the vein) drugs.

A drip gives you fluids and medicines through a vein.

A scan that takes lots of pictures of the tissue inside the body. A computer puts all the pictures together to show any tumours. (CT or CAT stands for Computerised Axial Tomography).

A sac filled with fluid.

When the body temperature rises above 37.5°C.

When scar-like tissue forms anywhere in the body.

When your finger is pricked with a tiny needle to get a blood sample.

Checks the blood and counts the number of red blood cells, white blood cells and platelets circulating in your blood.

The body’s defence system against infection and germs.

When your immune system is not working normally and you are more at risk of getting infections.

When small organisms get into the body and cause trouble (infection) either at the site of entry or somewhere else.

Fluids or drugs that are given through your veins over a period of time.

A cancer of blood cells usually starting in the bone marrow. There are several types of leukaemia.

A few drops of the spinal fluid are removed with a fine needle between two vertebral bones in the spine. You will be given medicine for pain to help you feel relaxed and sleepy before — and a special cream is put on your back so you won’t feel the needle going in.
A network of glands and vessels that carry lymph – a fluid that makes and stores infection-fighting cells.

The study of cancer.

A type of white blood cell that helps protect the body against foreign substances by making antibodies and keeping up the immune system.

A cancer of the bone.

A cancerous growth, which tends to invade and destroy surrounding tissue spread to other parts of the body.

When cancer spreads to other parts of the body (you would say it has metastasised).

A test that uses a radioactive substance called a tracer to look for disease in the body. The scan can tell the difference between normal and abnormal cells. (PET stands for Positron Emission Tomography.)

A white blood cell that helps stop bleeding.

A little tube inserted under the skin, usually in the chest. It provides quick and easy access to your veins and can be left in place for a long time, which means you don’t have to have injections all the time.

X-rays, ultrasound scanning, MRIs and other scans used to investigate, diagnose and treat cancer.

A type of treatment using X-rays to destroy abnormal cells.

Blood cells that pick up oxygen from the lungs and transport it to tissues throughout the body.

The return of a disease after a period of remission

When your cancer disappears.

Cancer of the bone.

An abnormal lump or mass of tissue. Tumours can be benign (not cancerous) or malignant (cancerous).
Ultrasound waves are sound waves that the human ear can’t hear. A special machine directs the waves at a certain part of the body. An image from the waves shows where there is a tumour.

Blood vessels that carry blood from the tissues and organs back to the heart.

Blood cells that protect the body against foreign substances. They are divided into groups with different jobs.

A type of cancer of the kidney. After brain tumours, this is the most common type of tumour in children.

Radiation that goes through body tissues and is used to get a picture of what’s inside.

The head of your medical team. He or she will make the diagnosis and decide which treatment is best.

A doctor who looks at test samples in a laboratory.

A physiotherapist uses special exercises to help you recover after an operation or injury.

A healthcare professional who can help you find ways to deal with stress or anything you are unhappy with.

A healthcare professional who takes x-rays.

A doctor who takes x-rays and other scans and then figures out what they mean.

A doctor who specialises in radiotherapy, who will plan your radiation treatment.

A professional counsellor who you can talk to about any worries you have. You can ask your social worker any questions you have or talk about any difficulties you experience.

Staff nurses will look after you and help you to feel comfortable in hospital.

A doctor who does operations and biopsies.

Your head nurse. He or she will make sure the nursing team look after you, give you your medicines and make sure your doctor’s orders are carried out.

What does that person do?

Cytologist

A specialist who looks at cells under a microscope in a laboratory.

Haematologist

A doctor who specialises in blood. Sometimes you’ll see them in the ward, but sometimes they work in a lab.

Occupational therapist (OT)

Someone who works with you to help you stay healthy while in hospital and at home.
A list of things to pack for a hospital stay

- Day clothes
- Pyjamas
- A favourite toy and other things that make you feel happy, like a blanket
- Toiletries – soap, toothbrush, toothpaste, facecloths
- Music and headphones, games, movies, books and other things to do
- Any medicine you’re on.
Hearing your child has cancer is life changing. Along with the initial shock of the diagnosis, there is often an overwhelming amount of new information to take in, medical facts to make sense of and an urgency to make decisions and start treatment right away. We want to help you to focus on what’s most important for you and that’s your child. At the end of this section, you’ll find a handy glossary, with explanations of some of the more commonly used medical (and medical aid) terms used in your Plan.

Register on the DiscoveryCare Oncology Programme

The first thing you need to do is register with DiscoveryCare’s Oncology Programme.

You can do this by calling us on 0860 99 88 77.

This gives you access to Discovery Health’s Oncology Benefit. We’ll need a copy of the test results that confirm your child’s diagnosis. Ask your treating doctor for these results or to send these to Discovery Health.

Contact information

DiscoveryCare Oncology Programme

Telephone 0860 99 88 77
Email DCO_Oncology@discovery.co.za
Fax 011 539 5417
Hospital preauthorisations department
Email preauthorisations@discovery.co.za
Website www.discovery.co.za

Please contact the oncology team if you need information on the Oncology Benefit.
Explaining some of the terms we use

A host of new medical – and medical aid – jargon can be overwhelming. To help you understand these, here’s a guide to some of the most common terms you’ll find on your plan’s list of benefits.

<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>Above Threshold Benefit</td>
<td>The Above Threshold Benefit is included in the Executive, Comprehensive and Priority Plans. This is when Discovery Health starts paying for non-hospital expenses once you’ve reached a certain accumulated amount.</td>
</tr>
<tr>
<td>Centres</td>
<td>These are medical facilities that Discovery Health has chosen to partner with. Discovery will refer you to your nearest centre for treatment. You can choose not to go to these centres, but then your cover will be limited.</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>Treatment with medicine to destroy cancer cells. Often used together with surgery or radiation if cancer has spread or come back or when there is a chance that it could come back.</td>
</tr>
<tr>
<td>Co-payment</td>
<td>The portion that you have to pay yourself, like when the amount Discovery Health pays is less than what your doctor charges.</td>
</tr>
<tr>
<td>Day-to-day benefits</td>
<td>These are the funds available in the Medical Savings Account or Above Threshold Benefit.</td>
</tr>
<tr>
<td>Deductible</td>
<td>This is the amount that you must pay upfront to the hospital or day clinic. You must pay this amount from your pocket.</td>
</tr>
<tr>
<td>Discovery Health Rate</td>
<td>This is the rate that Discovery Health sets for paying claims from healthcare professionals.</td>
</tr>
<tr>
<td>External medical item</td>
<td>Items like wigs, which are not part of prescribed medicine or treatment.</td>
</tr>
<tr>
<td>ICD-10 code</td>
<td>A clinical code that describes diseases and signs, symptoms, abnormal findings, complaints, social circumstances and external causes of injury or diseases, as classified by the World Health Organization (WHO).</td>
</tr>
<tr>
<td>Medical Savings Account (MSA)</td>
<td>Your MSA is an account that you contribute to each month when you pay your medical aid contribution. Some of the costs of your treatment (like external medical items) will come out of your Medical Savings Account.</td>
</tr>
<tr>
<td>Neutropaenia</td>
<td>A low white blood cell count, which means your child is more susceptible to infections.</td>
</tr>
<tr>
<td>Payment arrangements</td>
<td>Discovery Health has created a network of people with whom they have made payment arrangements to pay in full at a higher rate. When you use these providers, you won’t have to pay a co-payment.</td>
</tr>
<tr>
<td><strong>PET scan</strong></td>
<td>An imaging test that uses a radioactive substance called a tracer to look for disease in the body. The scan can tell the difference between normal and abnormal cells. (PET stands for Positron Emission Tomography).</td>
</tr>
<tr>
<td><strong>Portocath</strong></td>
<td>A Portocath is a type of central line that sits under your child’s skin and is inserted and removed under general anaesthetic. It’s a small plastic tube attached to a disc ranging in size from a 50c coin to a R2 coin. It’s helpful when your child’s veins are very small or when the chemo medicine is very strong. A local anaesthetic cream is put on the skin overlying the port about 40 minutes before it is accessed. Your child can swim, shower and wash normally with a portocath.</td>
</tr>
<tr>
<td><strong>Prescribed Minimum Benefits</strong></td>
<td>A set of conditions, including cancer, which all medical schemes must provide a basic level of cover for. This basic level of cover includes the diagnosis, treatment and costs of the ongoing care of these conditions.</td>
</tr>
<tr>
<td><strong>Radiology</strong></td>
<td>X-rays, ultrasound scanning, MRI and other non-invasive techniques used to investigate, diagnose and treat cancer.</td>
</tr>
<tr>
<td><strong>Radiotherapy/radiation therapy</strong></td>
<td>The use of high-energy rays to eliminate or shrink cancer cells before or after surgery, or sometimes as the main treatment. Radiation destroys or slows down the growth of abnormal cells. Normal cells should suffer little or no damage in the long term, but short-term damage is a side effect.</td>
</tr>
<tr>
<td><strong>Tumour</strong></td>
<td>An abnormal lump or mass of tissue. Tumours can be benign (not cancerous) or malignant (cancerous).</td>
</tr>
<tr>
<td><strong>Ultrasound</strong></td>
<td>A technique using sound waves to evaluate cysts.</td>
</tr>
<tr>
<td><strong>12-month cycle limit</strong></td>
<td>In the past, cancer benefits ran from 1 January to 31 December for each year. The timeframe is now individualised depending on when your child is diagnosed with cancer through a rolling limit. For example, if your child is diagnosed in early March and you register on the Oncology Programme in March, your 12-month cycle limit will begin in March and will refresh 12 months later – at the end of February the following year.</td>
</tr>
</tbody>
</table>
It's natural to experience many different emotions as your family deals with a diagnosis of cancer. Many parents go through stages of shock, denial, anger, sadness, anxiety, fear, guilt, doubt, insecurity and depression.

You may be feeling some of those emotions and may even feel overwhelmed with these emotions.

As a parent, you may be worrying about whether your child will survive, how your family will cope and what you can do to get through this difficult time. You are not alone.

Here is some information we hope will help you on this journey.

It's important to be there

You, as the parent of a child with cancer, are the most important part of his or her treatment team.

Not only are you primary caregivers, you will become advocates for your child's health. Your attitude and the way you tackle this challenge will have a great impact on how your child copes. Your child will look to you for clues and for guidance on how to behave. Doctors say: A calm parent is a calm child.

If you can manage to cope positively and be in control, your child will take up this attitude and it will help them to cope. Research shows that the better a family can adjust to the diagnosis, the more likely the child will find ways to cope.

The key to coping is open and honest communication. Be straightforward with your child and don't make up elaborate stories. Rather give as much information as they ask for and that is age-appropriate. The same applies to any sibling.

Younger children find it hard to think about the future or see beyond the present. They therefore interpret things quite literally. So it's important to be truthful and take the time to explain to them what's going to happen.

Older children may be more emotionally vulnerable and need more reassurance about the future.

Many little deeds by many little people in many little places can change the face of the world.

Chinese proverb

Happy parents mean a happy child

Spending lots of time at appointments and treatments with your child can be emotionally draining. It's important to take care of your own health and emotional wellbeing so you can continue to be strong to care for your family. While you take a break, the nursing staff will make sure your child is well cared for.
**In the hospital**

As a parent, your role in caring for your child during the time in hospital is very important. Your presence helps comfort your child and lets them feel safer and more secure.

**You are an essential member of the team**

You are an essential member of the team in providing practical and emotional support. This includes:

- Continuing your normal parenting role
- Engaging your child in play and distraction activities
- Telling the staff what food and drink your child has had and how many toilet visits and/or nappy changes
- Talking with staff about any concerns you have about your child or your child’s care
- Letting your child be as active as he or she wants to be (when appropriate).

**Helping your child cope with being in hospital**

Different children cope differently with being in hospital, with medical procedures and treatment. Here are some suggestions to help your child cope with being in hospital. Please talk to people on your child’s treatment team for more help.

**The younger child**

Babies and toddlers will feel most secure with their main caregivers. They may fear strangers and separation from their parents. Toddlers will find ways to try and assert their independence. Some ideas to help your younger child cope are:

- Bring favourite items from home – toys, security blanket, dummies, stuffed animals, books, music
- Soothe or relax your child with music, singing, rocking, cuddling, reading favourite stories
- Offer your child real choices where possible, for example “Do you want to walk to the treatment room or let me carry you?”
- Encourage your child to express their feelings and help them to work through experiences by letting them play with real or pretend medical equipment, dolls and puppets and art supplies
- Read books to your child that relate to his or her concerns or experiences
- Reassure your child that he or she has not done anything wrong and is not being punished
- Encourage your child to participate in his or her care as much as possible – for example, letting them count out their tablets
- Enhance your child’s sense of security by setting limits and boundaries
- Ask members of the medical team to talk to your child before touching him or her.
School-age children have an increasing ability to solve problems and prefer to be in control of situations. They tend to worry and may fear bodily harm or loss of function and being left out of social groups. Some may still fear separation. Adolescents are able to think about the future. They value independence, privacy and interactions with their friends and peers.

Some ideas to help your older child cope are:
- Allow your child to make choices and participate in their care whenever possible
- Allow your child to direct familiar procedures when appropriate – for example, announcing the next step in a dressing change
- Use humour as a distraction technique
- Read books with your child about their feelings and experiences
- Keep your child informed about what’s going on at home with brothers, sisters, friends and pets
- Bring familiar items from home such as books, games, pictures of people and pets
- Respect your child’s need for privacy by allowing them time to be alone
- Encourage your child to express feelings in whatever way feels comfortable – speaking, music, art, and writing
- Encourage your child to participate in group activities with other children of the same age.

Going home: It’s a team effort
Living with a child with cancer requires teamwork from your family, relatives and friends. Here we suggest ways to help during tests and medical procedures, during treatment and at home.

Helping your child cope with tests and medical procedures
Your child will have some tests and medical procedures before, during and after treatment. It can help your child if you can be there at these times. If you can’t be there, think about asking another person your child is comfortable with to go with him or her.

Before the procedure

<table>
<thead>
<tr>
<th>Talk with the nursing and medical staff to get a good understanding of what the procedure involves and why it is being done.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prepare your child by giving simple, accurate information in a calm, non-emotional way. Use language your child can understand. Answer any of your child’s questions.</td>
</tr>
<tr>
<td>Listen to your child’s concerns about the procedure – your child’s worries may be different from your own.</td>
</tr>
<tr>
<td>How much information you give depends on your child’s age and how your child will cope. For a young child or for an anxious child, talk about the procedure only a day or two beforehand – rather than risk overwhelming your child.</td>
</tr>
<tr>
<td>Talk to your child about coping techniques, for example distraction and breathing techniques to help manage any worry or discomfort about the procedure. Practise these techniques together. Talk to your child about when and how to use them. (You’ll find some ideas for deep breathing and visualisation in section 4 called Keeping healthy).</td>
</tr>
<tr>
<td>Give your child a choice where possible. For example, your child can choose which finger for a finger-prick, or choose a position such as lying down or sitting in your lap (but first check with the nurse or doctor if this is possible). Remember though that it is not helpful (or possible) to have your child choose when to start a procedure.</td>
</tr>
</tbody>
</table>
During the procedure

Avoid giving your child long explanations about the procedure while it is happening. Take your cues from the doctors and nurses who have experience and will guide you and your child through the procedure. Stay calm during the procedure – this will let you support your child as best as you can. Useful techniques include:

**Touch:** Patting, rubbing and stroking can be very soothing.

**Distraction:** Encourage your child to focus on other things rather than on the procedure. Try blowing bubbles, looking at a pop-up book, playing I Spy, or watching a video.

**Imagery:** Imagery involves imagining happy places and events using all your senses as if the events were actually happening. (For how to do this, see the section called: Keeping healthy, under the heading: Take your mind on holiday.)

**Breathing and relaxation:** For younger children, suggest they pretend to be a rubber band (floppy muscles). Older children can be taught to breathe in comfortable feelings and breathe out tension and to notice changes in their muscles and whole body.

**Coping statements:** It may help for your child to use some coping statements before, during and after the procedure. These statements can help your child to use their coping techniques and to praise themselves – ‘I need to relax now. Soon it will be finished. It is helping me get better’.

After the procedure

Praise your child and highlight any attempt at using a coping technique. Rewards can be very helpful but avoid bargaining with your child during a procedure.

If your child cries or is distressed because of pain, let your child know that it is okay to feel upset.

Continue with coping techniques even if they do not seem to be effective at first. Talk with your child and build on the parts that he or she found helpful. These techniques require practice.

Give your child opportunities to explore his or her feelings about their illness and treatment. Talking about things can help them identify and work through feelings, this is very important.

If you are worried about your child’s level of distress or anxiety, ask your child’s doctor, nurse or social worker for a referral to a psychosocial expert.
Side effects of treatment and ways to cope with them

Fatigue and sleepiness

Fatigue (or tiredness) is a common side effect of treatment. While your child may not appear to be doing much, the treatment is creating a great deal of work inside the body, fighting the cancer.

Tiredness may be acute (short lasting) or chronic (lasting some time). In the short term, it may be tiredness relieved by rest. In the long term, it may be a feeling of exhaustion accompanied by other symptoms such as lack of energy, dizziness, weakness or trouble concentrating. Fatigue may continue for some time after treatment is finished.

Sleepiness can be a side effect of radiotherapy to the brain. It’s called somnolence syndrome and can last for many weeks. If your child is having radiotherapy as part of his or her treatment, the radiotherapy healthcare team will discuss this with you.

Tips for managing fatigue

- Plan appropriate rest periods during energy lows
- On return to school, plan for half days at first, then full days
- Avoid having too many visitors at once
- Make sure your child is active to maintain fitness and wellbeing
- Continue normal activities as much as possible
- Plan outings when your child has more energy
- Make sure to maintain your child’s food and fluid intake.

Inactivity and lack of exercise

Your child might be less active while having treatment – usually for good reason. Your child may not be able to exercise at a particular time, for example with a high fever or low blood count.

But, prolonged inactivity can lead to tiring more easily, decreased muscle strength, and a decrease in daily activities.

When appropriate, encourage your child to walk every day and participate as much as possible in family activities. Include your child in activities as part of the normal routine. Outdoor activities such as walking or bike-riding can have positive effects during treatment, but they should be kept fun (and not seen as workouts). The amount of an activity can be altered depending on how your child is feeling. Even small amounts of exercise will help.

You might need to consult a physiotherapist if your child has particular mobility issues, but for most children, keeping active is all that is needed.

Infection

Sometimes your child is well enough to go home but his or her white blood cell count may be low. This means your child has a greater chance of getting an infection. Take care when in crowded public places and avoid pools and spas while the count is low.

Remember, most infections in children with low blood counts come from germs within the patient’s own body and are not caught from others. If you aren’t sure what to do, speak to your doctor. If you notice any of the following symptoms, contact the hospital immediately:

- Temperature: If your child has a temperature of 38°C, bring him or her to hospital straight away. If the temperature is 37°C, do not give your child anything and check it again in 20 minutes. If it has increased to 37.5°C or above, go straight to hospital. If it’s below 37.5°C and your child is well, you can wait to see your child’s doctor.
- Flushed appearance, complains of being hot and/or cold, sweating, shivering
- Coughing, sneezing, runny nose, shortness of breath, tightness over the chest
- Redness, swelling and/or pain in the throat, eyes, ears, skin, joints, abdomen
- Blurring vision, headaches and difficulties with sight
- Smelly, discoloured urine, needing to wee often and urgently, stinging
- Redness, swelling or discomfort, or both, at the site of a central line or catheter
- Diarrhoea
- Any skin rash or red spots
Chickenpox, measles and mumps

Your child can catch these common childhood diseases because chemotherapy medicines reduce their immunity and ability to fight off infection. A child’s immune function may take up to six months to recover after chemo has stopped.

Unfortunately, even if your child has been vaccinated or has had these diseases, they won’t be protected. The best protection is not being exposed to them in the first place. This means asking the school, crèche, and the parents of children who play with your child to tell you if their children have any signs of chickenpox or measles.

Signs of chickenpox
- Slight fever, headache, decreased appetite
- Very itchy pink spots of different sizes that look like blisters
- Spots first appear on the body, then on the face
- Blisters burst and form scabs.

Chickenpox is spread by direct contact with someone who has it, through tiny droplets in the air – coughing, kissing, sharing cups or touching the fluid in the blisters. It is contagious from one day before the spots appear until six days after the last blisters become scabs. If your child has contact with chickenpox, or you think your child might have chickenpox, phone your doctor immediately.

Signs of measles
- Sneezing, watery red eyes, similar to signs of a head cold
- Hoarse voice or harsh irritating cough
- Hot skin
- Red blotchy rash appears four days after flu-like symptoms.

Signs of mumps
Mumps is less infectious than chickenpox or measles.
- Painful swelling of the saliva glands near the jaw (parotid glands)
- Fever
- Headache
- Loss of appetite.

The mumps virus is usually spread by contact with tiny, airborne droplets of saliva when people laugh, sneeze or kiss, or on shared drinking glasses and tissues. It is contagious from two or three days before the first signs until six days after they disappear. There is an incubation period (the time while the disease develops) of 12 to 25 days after contact. Phone your doctor if you think your child has been exposed to mumps.

Poor nutrition and not eating well

Your child may eat a little less than usual during treatment. There are many reasons for this. Your child may be very tired or feel quite sick. It is very common for taste to change during active chemotherapy treatment.

Try these tips to encourage your child to eat

Offer small servings more often (five times a day) to avoid your child’s stomach getting too full or too empty
- Offer cold foods that don’t smell strongly
- Don’t force your child to eat but encourage and praise when they eat
- Eat meals in a well-ventilated room to clear the smell of foods away
- Sit and eat with your child
- Offer fluids often, try fun ways to encourage sipping throughout the day
- Offer a variety of foods and keep nutritious snacks handy
- Keep portions of favourite foods in the freezer for quick access
- Limit snack foods and soft drinks – there will be less room for more nutritious foods.

Adding extra nutrition to foods

Use full-fat milk in milkshakes, on cereals, in puddings, to make up soups and to mash into potato
- Add white or cheese sauce to pasta and vegetables
- Offer yoghurt for snacks and add it to desserts
- Grate cheese into soups, mashed vegetables, sauces and omelettes and over vegetables
- Serve meat, chicken and fish with sauce or gravy
- Add oils, margarine, butter, cream and mayonnaise to foods.

Consider supplements: Check which ones are suitable with your child’s oncologist.
Try these tips to help your child eat well with a sore mouth

Some children have a sore mouth or mouth ulcers as a side effect of treatment. This makes eating uncomfortable or even painful.

- Use lip balm or Vaseline on the lips
- Try soft foods like minced beef or chicken and gravy with mashed vegetables, scrambled eggs, soups, ice cream, jelly, custards, mousse, breakfast cereals with milk (keep sauces and gravies plain)
- Make nutritious milkshakes to help wash foods down
- Cut food into small pieces or puree food in a blender
- Avoid foods with sharp or rough edges, such as chips or toast
- Avoid foods with high acid content, such as tomatoes, orange juice and pickles
- Provide cool drinks rather than hot ones
- Keep up fluids to keep the mouth moist.

Good food hygiene at home

During treatment, your child’s ability to fight infections is lowered. Sometimes, bacteria can grow in food and cause gastroenteritis, which then causes nausea, vomiting and diarrhoea.

Here are some things you can do to stop bacteria growing in your child’s food. These guidelines are particularly important when your child’s blood count is low.

Good food hygiene tips to follow at all times

- Wash your hands before preparing any food
- Fruits and vegetables should always be washed before eating
- Store raw and cooked foods in different sections of the fridge
- Defrost and cook foods thoroughly, particularly meats
- Never use unpasteurised dairy products
- Do not keep hot foods at room temperature. Keep hot foods hot in the oven and cold foods cold in the fridge
- Check ‘use by’ and ‘sell by’ dates of foods.

Oral medicines

Many children don’t like taking any sort of medicine, particularly tablets. If you help to give your child his or her medicines in hospital, it may make medicine-taking easier at home. Here are some ideas to help the process of taking medicine easier:

- Rewards are more helpful than threats (try a star chart)
- It might be easier to give medicines with a syringe instead of a spoon. Your nurse will show you how to do this. You might need to hold your child firmly. Your nurse will help you with this
- If the medicine is missed out, you need to tell your child’s team
- Some medicine must be taken at specific times. Make sure you know when your child’s medicine should be taken and always check the expiry dates
- Crush tablets and add to a teaspoon of jam, ice-cream or juice, but take care not to put your child off something he or she likes. NOTE: Some tablets shouldn’t be crushed. Check with the pharmacy first
- Break large tablets into halves or quarters
- Tablets that taste horrible can be put inside a gelatine capsule that you can get from the pharmacy
- When taking capsules, take a mouthful of water first to wet the mouth
- Before giving any medicine that has not been ordered by your child’s doctor, check it with your child’s care team.

“I’d heard and learnt about cancer, but never thought it would happen to me. Even after I’d had all the tests and been told my diagnosis I was still full of hope that it wasn’t true. It was much better when people told me the truth about what was happening.”

Radhiyyah Kika (19) acute lymphoblastic leukaemia
Going back to school

School is a big part of every child's life. It is important for your child to maintain links with the school community, particularly if treatment is long and there are many absences.

- Clear and constant communication with your child’s school can make a difference for your child, siblings and yourself. This is especially important when your child returns to school.
- Your child’s re-entry to school should be gradual and well supported. Please discuss the appropriate time for school return with your child’s doctor and then plan the return with the school. You can decide how much information about your child is given to the school community.
- A school visit just before a return to school can also be valuable.

Pets and your child

You don’t have to get rid of your pets – they are an important part of your child’s family. There are however some basic rules to follow to ensure your child stays healthy:

- Wash hands after handling or patting the pet
- Wash hands before meals
- Your child should not clean out pets’ cages or beds during intense phases of chemotherapy
- Check with your child’s treatment team if you’re thinking about getting a new family pet
- Make sure the pet is appropriate for your child’s age and watch out for playful puppies (and other pets) that can scratch and bite
- Keep your pet’s immunisation and de-worming schedule up to date
- Keep your pets free of ticks and fleas
- Allocate a sleeping place for the pet – keep the pet off your child’s bed
- Keep away from horses and farm animals, particularly grooming and mucking out stables.

Fun in the sun

Protection from the sun is essential for children having chemotherapy or radiotherapy. Some treatments make the skin more sensitive to the sun and make the skin burn more easily.

When outside, all children having treatment must dress in light-coloured, long-sleeved clothing, and wear a wide-brimmed hat. When applying factor 30+ sun screen, pay special attention to the backs of the hands, tops of the feet, back of the neck, ears, and scalp.

If your child is having radiotherapy, do not put sun screen on the skin where the radiotherapy is done. The sun screen may cause the skin to burn when it gets radiation.

Important to remember:

- Healthy, intact skin protects your child against infection.
- Hair normally protects the back of the neck, ears and shoulders. There is less protection when there is hair loss.
- Bald heads burn very easily.

Wigs

Wigs can be uncomfortable. But if your child wants to wear a wig, let him or her do so – it may help boost confidence and help your child feel less self-conscious.

Going on holiday and treatment

When your child is on treatment, please speak to your child’s doctor before booking a holiday away from home. This is important to avoid conflict with the treatment schedule and the need to cancel holiday arrangements or make unscheduled adjustments to the treatment regimen.
Helping your child cope with illness

Coping with cancer and treatment can be difficult at times for children and their parents. Children may show they are not coping through changes in their behaviour and emotional state. Here are some tips on how to recognise these signs and some strategies that may help.

**Signs that your child may not be coping**

- Your child’s behaviour is different to what it was like before his or her illness.
- Your child may be more ‘clingy’ and show some separation anxiety from you or others.
- Your child may act more like a younger child. For very young children this may be regression in behaviours such as toileting, sleeping and eating.
- Older children may swing between being dependent and independent. You may find it hard at times to know what your child needs or wants.
- Your child may become withdrawn from friends and family members and seem less confident.
- Your child may be more tearful than before or show other signs of sadness such as thinking in a more negative way or having trouble sleeping.
- Your child may worry more about things than before.

**Ways you can help your child**

Most children who have cancer will make good psychological adjustment in the long term. Remember this when you are feeling worried about your child and how he or she is coping.

It helps if you can respond to your child’s emotional or behavioural changes in a calm and reassuring way. One of the most important things is to make sure you are well supported and can find ways to care for yourself, as this will help you to help your child.

Try to keep your child’s environment as consistent as possible, despite the hospital visits. Maintaining routines — baths, bedtime, sleeping and eating — is very important especially for younger children. For older children, keep consistent limits and expectations. Treat your child as normal.

Stick to your family rules and expectations about behaviour. Children feel more secure knowing what they can and can’t do.

If your child is experiencing separation anxiety, make sure your child has familiar toys or special things to help feel more secure.

If your child is finding it hard when you need to leave, even for brief times, try giving something belonging to you – keys, your cardigan. This helps your child to feel confident you are coming back.

Think of creative ways your child can release strong feelings – banging pots, punching a pillow or punching bag, making lots of noise, or digging a big hole in the garden at home.

If your child is showing negative behaviour, a reward system can help encourage more positive behaviours. Be clear with your child about the behaviour you would like to see and then give rewards when this has been achieved. With a younger child, a chart showing progress is a good idea. Remember, everyone loves to get praise.

Children do not always have the words to express how they feel. Sometimes you may need to guess at what your child may be thinking and feeling. It is important to raise these issues at a time when you can give your full attention to your child and when you are both relaxed. Before a medical procedure is probably not the best time.

If you see that your child is more sad than usual, you may start a conversation by saying that if you were in the situation you would feel sad sometimes. Then ask your child if he or she has felt sad.

As much as possible, encourage your child’s contact with his or her friends. This is very important for all children and especially adolescents. The social contact can not only help your child feel better, but will also help with his/her return to school and other normal activities.

Relaxation exercises are a great way for getting rid of stress and tension. Make sure that your child has an opportunity each day to do something that he or she finds relaxing. Often it is great to do these things together with your child. Try resting comfortably with your child while thinking about a happy past experience, making up a story or imagining you are in a special place together.

If you are concerned by your child’s level of behavioural or emotional distress, talk to your doctor, social worker or ask for a referral to a psychologist.
Dealing with stress

Stress and your family

There are lots of sources of stress for your family at the time of diagnosis. Knowing what to expect may empower you to cope with some of them:

Informational stress

You may find yourself overwhelmed with information. Not only are you trying to make sense of the diagnosis and come to terms with it, but you now also have to familiarise yourself with the treatment centre, the staff and how everything functions.

It would be helpful to keep a record of your questions and concerns and clarify them with your treatment team at an appropriate time.

Practical stress

You've already dealt with many of these – starting with having to take time off from work to get your child to the doctor. It can be very demanding working out how to manage your jobs, treatment for your sick child as well as your other children.

Interpersonal stresses

Managing your relationships during this time can be very challenging. Not only do you need to get to know and work with the treatment team, but you may also be inundated with questions and the anxiety of family and friends. What is important is to focus on and nurture those relationships that are significant and supportive to you and to set boundaries on those that bring stress.

Emotional stresses

You may be feeling a range of emotions or simply numbness. Find a way of coping that works for you – keeping a journal, talking to a trusted friend, reading, or prayer.

Existential stresses

Amidst everything, you are trying to make sense of the situation. Questions may be following you wherever you go. This is your journey, and your faith and philosophy on life will play a significant role in finding meaning for you.

Taking care of your relationships

Your marriage

A healthy marital relationship anchors the whole family. It empowers you to work together as a team to get through this and helps in creating a sense of security for your entire family. The roles in your family may change as there are more demands on your time and energy as a couple. Some couples find they grow closer in times of crisis.

Both of you will be emotionally stressed. It’s normal to have different ways of coping with stress, but these differences may bring problems. You might disagree more over important issues or feel more tension in your relationship. This is a common experience for parents of a sick child, but it is painful and can be distressing. It is important that you find time to talk about and express to each other, openly and honestly, your thoughts, feelings and experiences. If the tension between you and your partner becomes a problem, consider counselling.

Marital problems that existed before a child’s diagnosis are almost always amplified during the child’s treatment experience. If you need help, don’t be afraid to ask and get help early on.

“My faith keeps me strong and positive. When I see my mom and aunties pray, I do too.”

Dimitri Prins (7) acute lymphoblastic leukaemia
Your child, the patient

After your child is diagnosed with cancer, you will all experience a range of intense and complex emotions. This can sometimes lead to differences in behaviour and differences in the way that you see one another. Often the relationship can become closer as you face difficult times together. Sometimes your child will feel upset, sad or fearful and become withdrawn or angry.

Your child might focus anger on you because he she feels secure in this relationship and needs a safe target to express his or her feelings. Your child may alternate between being angry with you and being very clingy and dependent. Sometimes, it may feel like you are parenting a different child every day and a different child from the one before cancer. Your child may also want to protect you and may not want to tell you how he or she is feeling or thinking. It can be a challenge to create times with your child that are not focused on being sick or being in hospital.

Encourage open communication and discussion about feelings, thoughts and experiences as this will give your child the message that it’s okay and normal to have a range of emotions. This will also allow your child to ask for support when needed. Professional assistance can be helpful.

Guilt, fear and anxiety are but a few of the feelings your child may experience. You will not be able to access these feelings and allay their fears if you do not speak with them regularly throughout. They need to know they are not to blame.

Your child does not have control over most aspects of their treatment. One of the ways in which to empower your child to cope with the situation is to give them choices whenever possible in other aspects of their lives. Things that might seem insignificant, such as choosing what to wear or what to take with them when going to hospital may go a long way in giving your child a sense of control.

One of the most difficult aspects of raising a child with a life-threatening illness or blood disorder is that of discipline and maintaining boundaries. It is easy to fall into the trap of their manipulation because you will do anything to get them to co-operate. It is understandable that discipline and boundaries may not at all times be your priority, however it is not in the best interest of your child to let it go.

The purpose of discipline and boundaries is to give them a sense of security and inner control – and you want them to grow up to be well adjusted adults.

Your other children

It’s common for parents to feel guilty about their other children while they are caring for a sick child. The demands of treatment and trying to maintain normality for your other children can be exhausting. Sometimes, you can feel out of touch with your other children and may be confused by their responses or reactions. With these emotions being expressed in behaviour, it is important to encourage open communication and expression of emotion, as well as offer constant reassurance.

Brothers and sisters of a child who have cancer will also find they’re having a difficult time. It can feel like their world has turned upside down and they may feel frustrated that they can’t help and that they’re not getting the same focused attention as before. Some siblings can cope with the extra challenges that the illness brings to the family and learn something positive from the experience, but others find it very difficult. They may feel angry, scared, jealous or sad, which may result in acting-out behaviour, withdrawal, anxiety about their own health and difficulty at school both academically and socially. They may even feel guilty that their sibling is sick.

Stress and your family: What you can do

- Have a loved and trusted relative or friend come over specially to see the other children.
- Remind family and friends to ask about and visit the other children and bring small gifts for them if they are bringing something for the sick child.
- Make sure that the school is aware of their brother or sister’s sickness.
- Request a buddy system to support the well child. For example, a class teacher might check on the child each day. The teachers may make sure that the child knows who to talk to at school if he or she is feeling upset.
- Make sure that the well children have contact with a trusted adult friend outside the immediate family who they can talk to about their worries. Often children do not want to add to your stress by admitting that they are worried or upset as well.
- Make sure that the siblings are included in the treatment plan where possible and appropriate. Often the unknown is scarier than the known. It may be possible for siblings to spend some time with their brother or sister in hospital and they may be able to come up with ideas for entertainment. Just consult with the treatment team before you arrange for your other children or friends to visit.
- Make sure that the siblings can access age-appropriate child-friendly information about your child’s cancer.
• Try to make individual special time with each sibling where they can discuss anything that might be on their mind. It doesn’t have to be long, but must be focused on them. Make it clear that you are there for them and understand that it can be difficult to be a brother or sister of a child with cancer.
• Where possible make sure that the siblings have time for normal activities. Reassure them that it is okay to play and feel happy.
• Some siblings benefit from cancer support groups.

Family and friends

Family and friends are often not sure how they can help you. Sometimes their efforts may be misplaced but almost always their intentions are good. Sometimes you can feel overwhelmed by phone calls, visitors and advice. It may feel like you are supporting others when you and your child need the support. It is not uncommon to feel disappointed by people you thought would be more supportive and surprised by others who you did not think would be so helpful.

It is important to remember that your family and friends will experience a variety of different emotions and will respond in different ways. Those who maintain little contact usually do this because they don’t know what to do or say. It does not mean that they do not care or are not thinking of you or your child.

It can be helpful to have a list of things for when your family and friends ask if there’s something they can do – don’t be shy to hand over practical tasks: errands, making meals, shopping, taking the dog to the vet, or just say ‘Knowing you are there is helpful’. At times of great stress it can help to have a couple of people to give updates to the rest of your friendship and family groups. This can minimise the number of people you need to talk to when you are feeling overwhelmed.

Some parents set up a group email for people who want to know how things are going.

Grandparents

Social workers often see the invaluable role grannies and grandpas play in helping their children and grandchildren cope with this life-changing experience. However, in the process of trying to help, they may unknowingly be controlling and therefore take control from you.

It’s important that you communicate to them what is helpful and what is not. It is okay to set your boundaries.

Especially for brothers and sisters

It’s not easy having a brother or sister who has cancer.

You might feel lots of different things. You might feel jealous because your brother or sister is getting lots of attention and you aren’t. You may feel that your friends’ lives are not as complicated as yours or you may feel empty or lost.

Because you didn’t expect your brother or sister to get cancer, you may feel that you aren’t in control and don’t know what’s going to happen. It gets even more confusing because you may even feel happy that you aren’t sick and then feel bad because you felt happy. Your feelings may go up and down – and you might be surprised by them.

What you’re feeling isn’t wrong, but your feelings can affect other people.

Most other people won’t know how you are feeling. They think they understand, but they don’t. It’s not happening to them. Don’t expect your friends to be able to read your mind. Tell them how you feel and how you want them to act. They may be too scared to ask questions. Don’t let people play down your feelings. What you are going through is difficult and sometimes it’s good to hear someone else say this.

You might be hard on your friends because their problems aren’t as big as yours – but that’s not how they might see it.

It is important for you to be able to talk to someone who understands you, and who can help you when things are hard. People who might support you include friends, parents, other relatives, teachers, school counselors and hospital social workers.

You can help your brother or sister. He or she will need your company, love and support.

Some things you can do are:
• Schedule and arrange visits with your brother or sister in hospital through the oncologist
• Make phone calls
• Send letters and cards
• Do things together – games, puzzles, listening to music, reading aloud, writing and drawing
Communication with your child’s treatment team

Your child’s team will partner with you in the care of your child. Forming partnerships between the family and the team is a joint responsibility. It is important that you and your child have a trusting and open relationship with the team. Sometimes, tension and misunderstanding can crop up. Sometimes you might be angry towards staff who you believe are not being helpful. The people on your child’s team need to know if you are having difficulty interacting with them. Take a calm and non-confrontational approach. Telling the team in this way will not have a bad effect on the care your child receives.

What you can do to improve communication and build trust
• Ask questions at appropriate times and keep asking until you understand the answer.
• Be aware that there may not always be definite answers and you may not always get the answer that you want (no matter how many times or how many people you ask).
• If appropriate, write down questions down in advance so that you won’t forget. This helps you stay focused and you can feel more confident.
• It’s okay to interrupt to ask technical things that you don’t understand.
• Don’t expect the team to always anticipate your needs.
• Be sure to tell your medical team who you want to have your child’s medical information shared with (or not) to avoid added stress.
• Let the team know what you need, how much information you and your child want, what fears or worries you may have. The team will try to help once they are aware of your needs.

When to call the hospital
• Anytime your child does not feel well or look right
• Anytime you are worried about your child
• If their temperature is above 38°C with a normal blood cell count. If your child has a low white blood cell count (neutropaenic) with a temperature above 38°C, go straight to hospital.
• If you think there is infection
• If your child has had contact with chicken pox, measles, or mumps. Phone ahead rather than arriving unannounced as chicken pox and measles are very contagious.
• If there’s bleeding – such as a nose bleed for more than five minutes, bleeding gums, bruising or petechiae (tiny red or purple flat spots on the skin)

Handling difficult questions
As adults, we often find it hard to handle difficult questions with children. Try these guidelines:
• Open and honest communication is the key, even if it may bring up painful emotions. Engaging with your child fosters their trust in you, which is important. Without this they are left with a sense of fear and isolation, which can be far more painful than the actual situation.
• It is very helpful to first explore your child’s understanding of their own questions. They often have an innate wisdom that guides them but they seek your confirmation.
• Always try to answer your child’s questions on a level he/she will understand and steer away from using euphemisms and platitudes.

Be honest if you do not have an answer and undertake to find out more together. This is very empowering for both of you.

Beware the Internet!
Avoid undirected web surfing, there is a lot of inaccurate information out there, posted by unqualified sources. This can be both frightening and misleading.

Rather ask your child’s oncologist for good, peer-reviewed children’s cancer websites for reading and research. He or she will appreciate you bringing information to him or her for discussion and review, and can help you make sure what you are reading is evidence-based and thus accurate and helpful.
Useful sources and contacts

South African Children’s Cancer Study Group
Website  www.saccsg.co.za

Cancer Index
Website  www.cancerindex.org

BC Cancer Agency
Website  www.bccancer.bc.ca

National Cancer Institute
Website  www.cancer.gov/cancertopics/types/childhoodcancers

CHOC Childhood Cancer Foundation SA
CHOC provides direct practical help to children with cancer, from diagnosis onwards. This includes accommodation in CHOC Houses, support groups for parents and support to the state-funded academic treatment centres in the form of furnishings and equipment. It also includes support to the health professionals working in the field of paediatric oncology, advocacy and support into research studies and investigating the causes and treatment of childhood cancer.

Telephone  086 111 3500
Email  headoffice@choc.org.za
Website  www.choc.org.za

The South African Anxiety and Depression Group (SADAG)
SADAG offers counselling and a referral network of recommended therapists. Call anytime from 8:00 to 20:00, 365 days a year, for any kind of mental health or emotional support.

Telephone  011 262 6396
Website  www.sadag.co.za