



**“Keeping more than hope alive!”**

**CHOC Childhood Cancer Foundation  
South Africa**

**Pietermaritzburg Division**

**PARENT SUPPORT PACK**

<b>SUPPORT PACK</b>		
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## 1. TO THE PARENTS

### **An Open Letter to a Parent with a Child Newly Diagnosed with a Life Threatening Disease**

You have just started one of the periods in your life that you will always remember.

You never thought that something like this could ever happen to your child. You thought that it was your right that your child would grow up to be just like you, with the occasional illness or broken limb, but you never anticipated an illness that could take their life.

Now you know differently, and if you are like most of us who have been down this path ahead of you, then your outlook on life will probably be changed forever from this week onwards.

During the next few weeks you will go through many emotions.

- You will feel anger at the unfairness of it;
- You will grieve that all the dreams you had for your child could come to nothing;
- You will try to bargain with God to cure your child;
- You will blame yourself for causing the illness;
- You will regret not doing things with your child that you intended to do;
- You will feel lost and confused by lots of medical jargon and new words;
- You will agonise over what you should tell your children, your parents, your friends; and you will wonder how you will cope with it all.

In other words you will behave just like the rest of us parents who have been in your situation. You will have to develop your own methods for coping with things, depending on your own personal situation.

However, you may find a few guidelines useful as a starting point.

- Be honest and open about the illness, to your relations and friends, to the school, your employers, but, most of all to yourselves and your children. Your child knows that he or she is ill; don't make him or her hide his or her feelings to try and protect you.
- Your family and friends will not at first know what to say to you, and they will be very uncomfortable with you. The more openly you talk about things, the easier it will be for them to respond to you and give you the help that you will need so much in the coming months.
- Get used to saying the name of the illness out loud. Words like cancer, leukemia, aplastic anaemia, Fanconi anaemia are normally spoken in hushed voices, and never in the presence of someone who has them. It will be with you for a long time, so get used to saying it, and even talk about death. It makes it so much easier for your family and friends to talk openly if you do so.
- Don't be afraid to feel or show emotion; it just shows that you are human. If you didn't feel angry, sad, confused and many other emotions when you learned about the diagnosis, then you are very unusual. Don't forget your sick child, and

your other children, will have to cope with many new experiences and emotions. Let them see it is alright to feel afraid, to be unsure and to cry at times.

- Remember that you are in this as a family. Many families who have a good marriage to start with, find that they are all strengthened by the experience; but it is not unusual for a marriage to be very stressed by all the extra demands that an illness like this will put upon it.
- Call you the resources that you have. Use your family and friends; if they are true friends they will only be too glad to help you now that you really need them. Use your church; get people to pray for you and your child. You will be surprised how much and how readily people will open up and help you, if only they knew how; and that is why you need to make your needs known.
- Don't be afraid to ask the medical staff. You will probably not take in half of what is said to you in the early discussions, and there will be a whole new vocabulary in your life. Keep notes of the questions you want to ask. There is a lot of literature available, and you will want to get as much knowledge as possible, so ask the staff what they recommend.
- There are no guarantees. The medical staff will do their best; there may be a very good prognosis for your child; but it is still a life threatening illness, and you will live with this for a very long time

There will be times when all seems dark, and some very happy times. The best way to get through the coming weeks and months is to take it one day at a time.

May you find the strength in yourself, your family and your friends to grow through this trying time in your lives.

From: Other parents who have been there before you.

## WHEN TO CONTACT THE DOCTOR

Contact a doctor if:

- Your child has a temperature greater than 38°C even if it responds to Panado.
- You must use a thermometer. Avoid Aspirin, Disprin, Brufen, Voltaren, Indocid. Use Panado, Tylenol, Ponstan, and Lentogesic.
- Any persistent vomiting/nausea, bleeding, diarrhoea or any other symptom, (complaint) that you cannot explain.
- If your child comes into contact with any children with a childhood disease such as chicken pox, measles, mumps, jaundice or the creche/school has an immunisation complaint etc
- If your child is put on any medication by another doctor for whatever reason, or if to be seen by a dentist.
- If you are/plan to use any homeopathic/alternative medications for your child.
- If you are to start chemotherapy at home, do not start unless the doctor has said so. He may require a full blood count (FBC) done before starting the medication. If you are unsure, phone!
- If there is any discharge, redness or swelling.
- If you are unsure how to take the medication, when to come back or if the medication (type of medication or dose) has suddenly changed and the doctor has not discussed it with you.
- If you are unsure as to whether you should contact the doctor, then you should do so. If there is no answer at the offices, the doctor's cell phone or the doctor's home, contact the hospital.

## TIPS FOR TREATING CANCER SIDE-EFFECTS

The following tips for treating side effects may be helpful if your child experiences difficulty during therapy:

### **Nausea and vomiting:**

- Offer plain, bland foods, such as cereal, canned or fresh fruit, rice, pasta, toast, mashed or baked potatoes, soup, crackers, or plain meat. Avoid spicy, heavy or fatty foods.
- If food smells bother your child, use cold or room temperature foods. Use a cup with a lid. Encourage the child to avoid areas where food is cooking.
- Don't offer solid food and liquids at the same time, as this can induce nausea by making the child feel too full. Have your child eat solid foods for meals and snacks, and give liquids 30 to 60 minutes before or after eating.

### **Diarrhoea:**

- Offer plenty of liquids.
- Try the BRATT (bananas, rice, applesauce, toast and tea) diet. Other foods on this diet include pasta, crackers, and mashed potatoes. Use this diet for two to three days at most, since it is too low in certain nutrients.
- Serve several small meals throughout the day, and avoid serving heavy, fatty foods or anything with caffeine.
- Cut back on fibre in the diet. Use canned fruits, mild cooked vegetables (like carrots, green beans, squash and potatoes) and cereals and breads made with refined flour rather than whole-grain or bran-containing products.

### **Constipation:**

- Provide extra fluids.
- Offer beverages that have caffeine, like coffee, tea, and cola.
- Increase the fibre in the diet by serving plenty of fruits, vegetables and whole grains.
- Encourage your child to increase his activity level.

### **Poor Appetite:**

- Offer small amounts of food four or more times a day.
- Offer liquids between meals.
- Make every bit count by offering "power-packed" foods.
- Start with small portions and increase gradually.
- Try to obtain the foods and beverages that your child wants.

### **Sore mouth and throat:**

- Offer soft foods like pudding, jelly, macaroni cheese, applesauce, bananas and ice cream.
- Avoid acidic foods like oranges and tomatoes, spicy foods or foods that require a lot of chewing.
- Encourage good oral hygiene.

**Heartburn or reflux:**

- Don't give your child high-fat, spicy foods, caffeine, citrus juices, cinnamon, peppermint or pepper.
- Keep your child upright for at least a hour after eating.

**Difficulty chewing or swallowing:**

- Give your child soft, moist foods and have her drink liquids while eating.
- Avoid hard foods that require a lot of chewing.
- Cut your child's foods into small pieces. Encourage your child to eat slowly and chew well.
- Use extra butter, sauces and gravies.

**Belching, intestinal gas or cramps:**

- Avoid gas-forming foods such as cabbage, broccoli, cauliflower, cucumber, beans and carbonated drinks.
- Encourage your child to eat and drink slowly.
- Avoid letting your child chew gum.

**Dry mouth:**

- Offer moist foods, extra butter, gravy and sauces.
- Offer hard candy or gum.
- Have your child rinse his mouth often, and keep fluids available to sip on.

**Excessive weight gain:**

- Provide enough fruits and vegetables.
- Limit junk food to occasional small amounts.
- Cut back on fattening foods and offer low-fat or skim-milk dairy products. Take advantage of low-fat and fat-free products. Use lean meats. Avoid frying foods in any kind of grease. Instead, bake, grill, microwave or roast foods and use only minimal amounts of fat during cooking.
- Limits sweetened drinks to one serving each day, and substitute diet drinks or water for other servings.
- Limit portion sizes to those appropriate for the child's age. If the child wants a second helping, provide one extra serving of a low-fat fruit or vegetable. If the child is still hungry, offer foods like raw vegetables, sugar-free jelly or gum.
- Encourage an increased activity level.
- When eating out, allow just one high-calorie food.
- Support the child by changing the eating habits of the family. The child cannot be expected to eat low-fat foods if the rest of the family is eating cheese-burgers, fries and milk-shakes. Set a good example.

If at any point during the treatment you become concerned about your child's nutrition, please discuss this with your doctor.

## 2. CHOC COMMITTEE INFORMATION

### CONTACT INFO

**Address:** Postnet Suite 295, Private Bag X6, Cascades, 3202  
**Telephone/fax:** 033 386 3218  
**Mobile:** 082 402 3428  
**E-mail:** [chocpmb@saol.com](mailto:chocpmb@saol.com)  
**Website:** [www.chocpmb.org.za](http://www.chocpmb.org.za)  
**Banking Details:** First National Bank – Hayfields  
Branch Code – 221425  
Account number – 620 219 652 75

### COMMITTEE MEMBERS

**Chairperson:** Mark Duncan  
083 272 3130  
Daughter with Leukaemia

**Vice Chairperson:** Freek Botes  
083 232 4234  
Son with leukaemia

**Treasurer:** Roanne Duncan  
072 621 7005  
Daughter with leukaemia

**Secretary:** Lesley Duncan  
082 402 3428  
Granddaughter with leukaemia

**Member:** Mary Godlonton  
033 386 3859  
Granddaughter with leukaemia

**Member:** Judith Mbhele  
083 922 8230  
Daughter who passed away with leukaemia

**Member:** Charmaine Hardie  
082 952 3757

**Member:** Dr Nigel Walker  
342 8909 / 082 561 1157  
Paediatrician

### 3. HOSPITAL INFORMATION

#### **Useful articles to take for your stay in hospital:**

This is a list of articles that other parents and children found useful during their long stays in hospital. It helps to make your stay more comfortable and “homely”. Feel free to change the list to suit your own needs.

- Cell phone or Telkom phone card or enough change for the public telephone.
- Notebook with the phone numbers of all your friends and family.
- Notebook and pen to write down all the questions you want to ask the doctor.
- Own bedding, for example your child’s own duvet and pillows.
- Towels.
- Your child’s favourite games, books, videos and music.
- Radio/CD/cassette player (earphones are a good idea)
- Something to keep you busy; books, magazines or handwork.

## 4. INFORMATION ONLINE

**Note :** Caution and discretion is strongly advised when using the Internet to find information. In addition to good information, there is also a lot of very dangerous stuff out there. Information obtained from websites should always be discussed with the doctors at your treatment centres.

### Childhood Cancer

National Cancer Institute	<a href="http://www.cancernet.com">www.cancernet.com</a>
Children's Cancer Research Fund	<a href="http://www.childrenscancer.com">www.childrenscancer.com</a>
Children's Cancer Web	<a href="http://www.cancerindex.org">www.cancerindex.org</a>
The Paediatric Oncology Group	<a href="http://www.sianbradwell.com">www.sianbradwell.com</a>
Paediatric Oncology Resource Centre	<a href="http://www.acor.org/ped-onc">www.acor.org/ped-onc</a>
CHOC South Africa	<a href="http://www.choc.org.za">www.choc.org.za</a>
The Foundation for the Children's Oncology Group	<a href="http://www.ncf.org">www.ncf.org</a>
International Confederation of Childhood Cancer Parent Organisations (ICCCPO)	<a href="http://www.icccpo.org">www.icccpo.org</a>

### Blood Disorders

Aplastic Anaemia	<a href="http://medic.med.uth.tmc.edu">http://medic.med.uth.tmc.edu</a>
Aplastic Anaemia sites	<a href="http://www.geocities.com">www.geocities.com</a>
Aplastic Anaemia Foundation of America Inc.	<a href="http://www.aplastic.org">www.aplastic.org</a>
The Marrow Foundation	<a href="http://www.themarrowfoundation.org">www.themarrowfoundation.org</a>
Leukaemia Research Fund	<a href="http://www.leukemia.demon.co.uk">www.leukemia.demon.co.uk</a>
Fanconi Anaemia	<a href="http://www.fanconi.org">www.fanconi.org</a>
Darren Serebro Bone Marrow for Africa Foundation	<a href="http://www.bonemarrow.co.za">www.bonemarrow.co.za</a>
The Sunflower Fund	<a href="http://www.sunflowerfund.org.za">www.sunflowerfund.org.za</a>

## **5. SPIRITUAL GUIDANCE**

### **GOD'S PEACE**

**Don't anticipate disasters. Keep a quiet mind. Don't pull at the tangles when the threads you can't unwind. Have a little patience. Time may put it right for you - if you take the bright and optimistic point of view.**

**Do not let your thoughts go leaping forward spurred by fear - or listen to the gloomy goblins whispering in your ear... The sky will look much clearer when your worries have dispersed. So wait and see how things work out before you think the worst.**

**Patience Strong**

### **SIX WAYS TO ACHIEVE BALANCE IN YOUR LIFE**

- 1. Go on a deep journey within yourself**
- 2. Be creative**
- 3. Learn to say "No"**
- 4. Have the courage to develop parts of yourself that you are not comfortable with**
- 5. Live your life with warmth, wackiness, culture and kindness**
- 6. Spend time in and with nature.**

**Dear God**

**I'm in this difficult situation right now. You know all about it. I am honest, I cannot cope. I know You can help me. I need You Lord, not only to help me through this crisis, but to change me inside. I willingly open up my heart and my life to You Lord. I want You to come and take over. I have so much uncertainty, hurt and anger. I confess: I'm sorry, please forgive my sins – I want to be different now. Please help me. From now on I want to do what You want me to. Teach me to pray, to talk to You about everything. Help me to trust in You. Thank You that You hear me.**

**Amen**

## **CANCER IS SO LIMITED**

**It cannot cripple love.**

**It cannot shatter hope.**

**It cannot corrode faith.**

**It cannot destroy confidence.**

**It cannot kill friendship.**

**It cannot shut out memories.**

**It cannot silence courage.**

**It cannot invade the soul.**

**It cannot reduce eternal life.**

**It cannot quench the spirit.**

**It cannot lessen the power of the Resurrection**

**There are two ways to live your life.  
One is as though nothing is a miracle.  
The other is as though everything is a miracle.**

**Albert Einstein (1879 – 1955)**

## 6. GENERAL INFORMATION

### Supportive Organisations

**Cancer Community Care Givers**

Mrs Naseem Aboo, 44 Mountain Rise Drive 033 397 9439

**Compassionate Friends**

033 342 5472

**Hospice**

206 Swartkop Road, Prestbury 033 344 1560

Vulindlela Hall, Old Edendale Road, Edendale 033 398 8698

**Lifeline**, 24 Hour counselling

14 Princess Street 033 394 4444

**Reach for a Dream**

5 Committee Lane, Hilton 033 343 4911

**Sunflower Fund**

### Hospitals & Doctors

**Greys Hospital**

Town Bush Valley Road 033 897 3000

**St Anne's Hospital**

320 Loop Street 033 897 5000

**Medi-clinic**

90 Payne Street 033 845 3700

**South African National Blood Service**

294 Loop Street 033 342 5035

**Hopelands Cancer Centre**

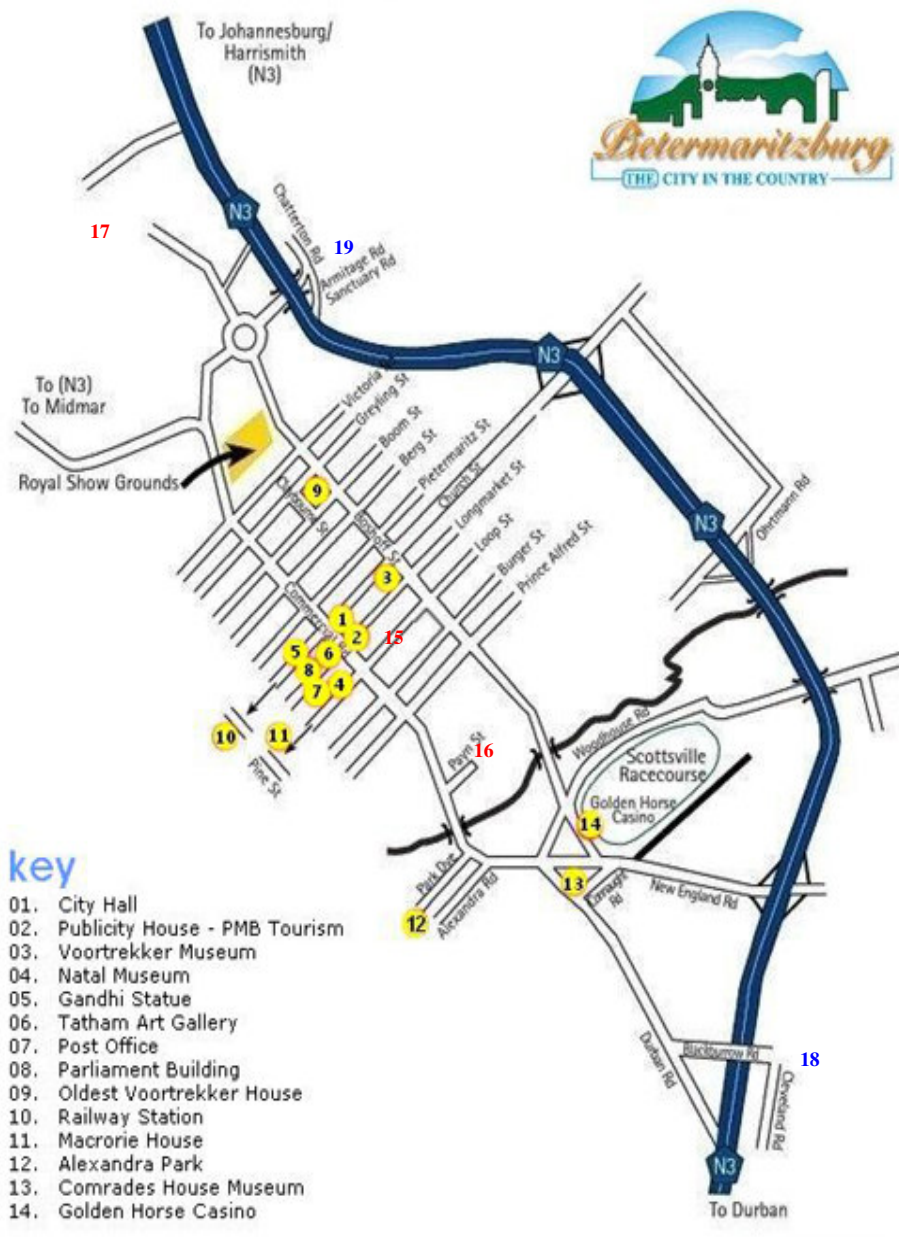
Dr Shane Cullis, Radio-oncologist 033 342 0380

Sr Di Webb, Oncology Nurse

**Paediatrician's Rooms**

Dr Nigel Walker, Paediatrician 033 342 8909

# MAP OF PIETERMARITZBURG



## key

- 01. City Hall
- 02. Publicity House - PMB Tourism
- 03. Voortrekker Museum
- 04. Natal Museum
- 05. Gandhi Statue
- 06. Tatham Art Gallery
- 07. Post Office
- 08. Parliament Building
- 09. Oldest Voortrekker House
- 10. Railway Station
- 11. Macrorie House
- 12. Alexandra Park
- 13. Comrades House Museum
- 14. Golden Horse Casino
- 15. St Anne's Hospital
- 16. Medi-Clinic
- 17. Grey's Hospital
- 18. Hayfields Mall
- 19. Midlands Mall

## WHERE TO STAY

### **PMB Bed and Breakfast Network**

A variety of establishments from bed and breakfasts to self-catering are offered, with standards ranging from comfortable to luxury. Our prices however offer value for money and are always competitive.

**Phone :** 033 347 3808

**Ascot Inn**, hotel 033 386 2226  
Woodhouse Road

**City Royal Hotel**, hotel 033 394 7072  
301 Burger Street

**Rehoboth Chalets**, self-catering/bed & breakfast 033 396 2312  
276 Murray Road

**The Gables**, self-catering/bed & breakfast 033 346 0792  
New England Road

**Imperial Protea Hotel**, hotel 033 342 6551  
Loop Street

## CHURCHES / TEMPLES / MOSQUES

Afrikaanse Protestante Kerk	033 982 1814
All Saints United Church, Montgomery Drive	033 347 3177
Apostoliese Geloofsending, Bisley	033 386 5586
Assembly of God Fellowship, Durban Road	033 386 1169
Baptist Church - Central, 165 Chapel Street	
Catholic Church - St Mary's, Loop Street	033 342 2807
Church of England in SA, Cross Road, Pelham	033 386 7916
Church of the Latter Day Saints, Alexandra Road	033 386 8613
Church of the Nazarene, 383 Burger Street	033 394 2817
Church of the Province of South Africa (Anglican) - Cathedral of the Holy Nativity	033 394 1567
Full Gospel Church of God - Open Door, Taylor Road, Scottsville	033 386 1952
Jehovah's Witness, Botanical Gardens	033 347 3204
Lutheran Church, Bester Road, Hayfields	033 396 5169
Maritzburg Christian Church	033 386 9270
Methodist Church of South Africa, Metropolitan	033 345 3245
Nederduitse Gereformeerde Kerk, 408 Prince Alfred Street	033 345 3400
St John's United Church, 344 Loop Street	033 345 3157
Hindu Temple - Shri Vishnu Temple 560 Longmarket Street	033 342 8527
Muslim Mosque	

As this cannot be a complete list, please consult with your nursing sister at the hospital for any other numbers

## SHOPPING CENTRES / ART GALLERIES / POLICE

### Shopping Centres:

Checkers Cascades	033 347 1991
Hayfields Mall	033 386 7030
Liberty Midlands Mall	033 342 0062
Nedbank Plaza	033 345 4917

### Museums & Art Galleries:

Natal Museum	033 345 1404
Voortrekker Museum	033 394 6834
Macrorie House	033 394 2161
Tatham Art Gallery	033 342 1804

### Police

Loop Street	033 342 2211
Alexandra Road	033 342 2907
Bishopstowe	033 390 3521
Hilton	033 343 3009
Mountain Rise	033 387 5791
Prestbury	033 344 3755
Plessislaer	033 398 5467
Town Hill	033 342 1433

### Library

260 Church Street	033 345 2383
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### Emergency Numbers

Flying Squad	10 111
Ambulance	10 177

## TAKE-AWAYS AND FAST FOOD OUTLETS

Bombay Curry Den, 64 Victoria Road	033 345 1602
Debonnairs Pizza	
• Nedbank Plaza, Durban Road	033 394 0586
• Commercial Road	033 345 5813
Kara Nicha's , 64 Durban Road, Scottsville	033 386 3880
Kentucky Fried Chicken	
• Nedbank Plaza, Durban Road	033 342 4923
• Liberty Midlands Mall	033 345 1053
• Commercial Road	033 342 8420
McDonalds, Commercial Road	033 345 6643
Mr Delivery	033 345 2616
Nandos Chicken, 64 Durban Road, Scottsville	033 386 9024
Pizza Chicken Perfect, Hayfields Mall	033 386 4383/4
Scooters Pizza, Mc Donalds Centre, Commercial Rd	033 3459170
Skippers, 48 Commercial Road	033 394 1180
Something Fishy	
• 64 Durban Rd, Scottsville	033 386 8467
• 33 Commercial Road	033 345 3688
Spur	
• Cascades	033 394 3311
• Nedbank Plaza, Durban Road	033 342 9104
Steers Fast Food	
• 31 Commercial Road	033 342 8299
• Blackburrow Road, Hayfields	033 386 3731
Westminster Pies,	
• Hayfields Mall	033 386 5178
• Liberty Midlands Mall	033 342 2799
Whistlestop, 10 Durban Road	033 345 4477

## 7. CALENDAR

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