



Contact

Spring
2000

A quarterly publication from Candlelighters Canada

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The publication and distribution of this newsletter is one of the free services of the Childhood Cancer Foundation-Candlelighters Canada.

Candlelighters is a national volunteer charitable organization dedicated to improving the quality of life for families experiencing the effects of childhood cancer, through the provision of resources, parent support and the promotion of research.

55 Eglinton Ave. East, Suite 401
 Toronto, ON M4P 1G8
 (416) 489-6440
 Toll free: 1-800-363-1062
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Childhood Cancer Foundation Canada
Candlelighters

Project Smile spreads even more

Congratulations To Maureen and Mark Tresnak

Maureen Tresnak has been awarded the Governor General's award for her extraordinary volunteer work with children with cancer. In February, she received the Lieutenant Governor's Award for her outstanding contribution.

In March 1995, Maureen founded **Project Smile**, a group that makes quilts to provide warmth comfort, a feeling of security and a smile for children living with cancer.

The Tresnaks, Mark, Maureen and their five children, know first hand what childhood cancer means to a family. Their son Mathew, who is now 9, was diagnosed with leukaemia when he was 2 1/2. Mathew was in treatment for another 2 1/2 years.

Maureen says it is difficult to know exactly how **Project Smile** started, but she does know that Mathew had something special to offer to the project. He had a blood test every week and he always liked to have the yellow smile face put on his bandage.

Maureen was in the midst of making a quilt when Mathew was diagnosed, and his admission pushed her to finish it as quickly as possible. It had all his favourite animals on it.

On New Years Eve 1994, when Maureen was confident Mathew was doing well, and she wanted to do something more. She thought about the quilt she had made and sent a letter to 60 other parents and people she had met while her son was in treatment. Maureen told them she "wanted to make quilts and needed help".

Following that, Maureen received lots of help. Over 541 quilts have now been made. Volunteers in many cities and towns have made 311 quilts for children with cancer. Maureen has made the rest. Beautiful quilts can be found in several children's treatment centres and their homes across Canada.

On behalf of Candlelighters Canada, a warm and special thank you to Maureen, Mark and all their volunteers for such a wonderful programme.

Editor's Note: We encourage you to visit the Tresnak's booth at the 2000 Candlelighters Canada conference see these beautiful quilts and find out how to help the Tresnaks provide every child diagnosed with a new quilt.



Maureen Tresnak receives her award from the Honourable Hilary Weston, Lt. Governor of Ontario.

Photo by John Smee

LOOK
 for the
Conference 2000
Preliminary
Program inside



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Congratulations to the 1999 Bursary Winners

Once again, Candlelighters Canada is proud to award bursaries to the following students to assist with their studies during the 1999-2000 academic year.

We would like to wish each of them every success with their chosen programme. We hope these students will let us know how they get on with their studies and careers. (A note of apology: the announcement of the winners missed the publication of the last issue of *Contact*. These students are now well into their studies in their chosen programmes.)

- ☞ Manpreet Mann of Kitchikmat, BC will be studying in the faculty of health Sciences at York University in Toronto, ON
- ☞ Serge Bigras of Calgary, AB will enter the Bachelor of Engineering programme at Mount Royal College in Calgary, AB
- ☞ Mark Thomas of Landis, SK is pursuing studies in the Parts Management Technician programme at the Northwest Regional College in North Battleford, SK
- ☞ Zach Henschel of Minitonas, MN will begin a four year Bachelor of Arts programme with an Aviation Major in Providence College in Otterburne, MN
- ☞ Angela Braaksma of Aylmer, ON will study Early Childhood Education at Lambton College in Sarnia, ON
- ☞ Sheri-Anne Harrison of Sudbury, ON will enter Laurentian University to study in a Recreational Leadership programme in Sudbury, ON
- ☞ Bradley McGregor of Ottawa, ON will study Film and Video in the faculty of Fine Arts, at York University in Toronto, ON
- ☞ Matt Parker of Hamilton, ON will study in the Engineering Science programme at the University of Toronto in Toronto, ON
- ☞ Melissa Sant of Westmount, PQ will study Creative Arts at Marianopolis College in Montreal, PQ
- ☞ Jason Cooper of Chapel Arm, NF will study Petroleum Technology at the College of the North Atlantic in St. John's, NF
- ☞ Marie McNeil of Flin Flon, MB received the Goddard Nardelli Bursary for a student studying in the creative arts. Marie will be studying computer animation at the Red River Community College in Winnipeg, MB

NEEDED

Information Liaison Parent Volunteers

Parent volunteers are needed in each province to act as an information liaison for areas that do not have an active Parent Support Group. You would receive information to be distributed to families in your area. You would also send information to Candlelighters at the request of these families. We are not asking you to start a support group.





Dr Sheila Weitzman is a paediatric oncologist at The Hospital for Sick Children in Toronto. This article is reprinted from The Hospital for Sick Children Journal, Vol. 1, No. 3.1999 with permission given by Dr. Weitzman and the Department of Public Affairs at the Hospital for Sick Children.

by Dr. Sheila Weitzman

The case of Tyrell Dueck brought the debate surrounding the use of alternative therapies in the treatment of cancer, particularly childhood cancer, to the forefront of Canadian Society this year. And when Tyrell died on June 30, the conclusion to the debate seemed obvious to many.

Tyrell Dueck did not necessarily have to die. We will never know whether he would have survived the osteosarcoma he was fighting had he received the prescribed, conventional cancer therapies. But, we do know that he was not given the 65%-70% chance at life that these therapies offer children with this type of cancer when it is confined to the bone.

We, as a society, have a legal and moral responsibility to ensure that children have a chance for a cure, and a chance at life. Proponents of alternative therapies argue that chemotherapy is poisoning children, but chemotherapy, along with surgery and radiation is the only proven treatment for childhood cancer.

The strongest argument in favour of chemotherapy is the results it produces. Overall, we can now cure approximately 70% of childhood cancers and some types have even better cure rates. A few examples of these are: the common childhood leukaemia with a cure rate of 75%, rising to 90% for low risk patients; Wilms' tumour, 90%; Hodgkin's lymphoma, 80%-95%; and germ cell tumours, 85%-90%.

Undergoing chemotherapy may be an unpleasant experience, with acute side effects that include nausea, vomiting, hair loss and a drop in blood counts leading to admission to hospital for intravenous antibiotics and sometimes mouth sores. However, once the chemotherapy is finished, so are these side effects. This relatively short period of discomfort can buy the rest of a child's life. Talking of chemotherapy as "poisons" as if they adversely affect a child forever is ridiculous. You just have to meet and talk to the survivors to appreciate

Alternative Therapies **VS.** Chemotherapy in the treatment of childhood cancer

how wrong it is to take away a chance for cure.

A major problem arises when parents refuse the proven conventional therapies in favour of using an alternative. The result, in my experience, is usually a tragedy. There are many reports of patients dying because they abandoned the proven, effective, conventional treatment.

I can understand the desire to find a less toxic treatment, as well as one that will cure everybody. In the face of an incurable disease, families feel

that at least alternative therapies offer them hope, but for the most part it is a false hope. It is difficult for us to offer the same hope, and stick to the guidelines of truth and informed consent that our ethics review boards demand of us, and that parents and patients should demand of all their caregivers. When the doctors at the Mexican clinic told the Duecks they could cure an osteogenic sarcoma without surgery - they were lying. No such cure is possible. For this advice, plus therapy that included laetrile, the extract of apricot pits, which is the most disproven cancer treatment ever, the Mexican clinic charged a minimum of \$6,000 per week. Many families, like the Duecks, are spending huge amounts of their own money on totally unproven remedies.

Studies show that at least 50% of families are turning to complementary therapies such as special diets, massage therapy, aromatherapy, music therapy and faith healing to accompany the conventional therapies their children are receiving. While there is no evidence that these therapies impact at all on cure rates, they may improve the quality of the life of the patient. However, all treatments, including those given to improve quality of life, must be substantiated.

Alternative and complementary therapies need to be put to the same standard of proof, including controlled studies, as conventional treatments. In the end, we need to be sure they are doing good, or at least not causing any harm.



A Welcome bouquet for Corrie Messerer

Candlelighters New National Teen Co-ordinator

We are starting the new century with new energy and exciting new plans. Corrie Messerer has enthusiastically taken over the reins from Paula Clark as the new teen co-ordinator for Candlelighters Canada. Corrie will be working closely with the Candlelighters Director in Newfoundland. Thank goodness for e-mail!

It is up to all of us to make the teen network a huge success. We hope that as many of the teens as possible will be in Toronto at the conference this August. Representatives from Canteen Australia will be there to meet with you.

Please contact your CanTeen Canada reps:

Nova Scotia - Norma Jean MacPhee, Eastern Region Co-ordinator, mcph@mta.ca

New Brunswick - Jill Allen 506 847-9627

Québec - Pierre-David Letourneau, odett@globetrotter.qc.ca

Ontario - Matt Parker, matt.parker@hwcn.org

Ontario - Nikki Parkinson, 7ncp@qmlink.queensu.ca

Ontario - Kevin Rabjohn, 905 727-6485

Manitoba - Patricia Dubeau, 204 257-5914

Saskatchewan - Vanessa Mollier 306 949-3318

Saskatchewan - Devan Brisebois, dbrisebois@hotmail.ca

Alberta - Tina DaSousa 403 948 9865

Alberta - Karen Bourgeois, Western Region Co-ordinator

British Columbia - Pamela Finnie, candlebc@rockies.net

British Columbia - Corrie Messerer, lynnm@unixg.ubc.ca

If you want to be part of this teen network, or to learn more about it and how to get involved, please contact your provincial co-ordinator, or Corrie. It is a chance to meet other teens, make friends and have a great time. The next big get-together will be in Toronto at the Candlelighters Year 2000 conference, but there is a good chance that lots will be happening in each of the provinces before then. The teen network promises to be a great success and there is a lot of energy behind getting the network up and running really well.

Please let Matt Parker know of your ideas for a newsletter. Please take this opportunity to reach out and meet other teens. As former national teen co-ordinator, Paula Clarke, said at her first meeting *"We have each braved a lot in our lifetimes - chemo, radiation, hair loss to name a few ... and we have many challenges to face in establishing this network for teens."*

Corrie will be moving. To contact her for now, please e-mail her at lynnm@unixg.ubc.ca. You can also contact Candlelighters National Office and we will forward your information to Corrie. The next issue of Contact will include Corrie's new address and phone number.

My Fight For Life

By Justin Arneson Grade 8

Some say a fight is a messy
thing,
Sometimes you lose and
sometimes you win
You're given a challenge, sort
of a test,
And pray everyday it will work
out for the best.

The fight I speak of does not
involve fists
Instead it involves your heart,
mind and wits,
It's easier to fight against
something you see,
But the fight that I fight is as
hard as can be.

I fight for my life, my very
being, my soul,
It's an illness inside me, that I
can't control.
I believe I'll get better and one
day be well,
Then the fight would be over
and that would be swell.

So because I have so much
living to do,
It doesn't matter what I have to
go through.
I'll fight the fight that is required
of me,
And I'll win back my life, you
just wait and see.

Candlelighters Mission ...

The Childhood Cancer Foundation~Candlelighters Canada is a national volunteer charitable organization dedicated to improving the quality of life for families experiencing the effects of childhood cancer, through the provision of resources, parent support and the promotion of research.



A Special Gift

- From A Special Person for Another Special Person

Hi! My name is Renata. I would like to share with you how a wig came to be here at Candlelighters.

On my 18th birthday I was told that I would have to have cranial surgery to remove a tumour from my brain. I was shocked and scared and one of many concerns was that if I went back to school with a shaved head everyone would notice, gossip and ask painful questions. I wanted to make a smooth transition back into school and everyday life after my operation. So, I went wig shopping with my sister at various malls. I came home very distressed because we were unable to find anything that looked at all like my own hair. Through the grapevine we heard of a place called the **Hair Prosthesis Centre**. Custom making hairpieces is their specialty. They were able to obtain a wig of a colour similar to mine and they told me to come in after my surgery to have it cut and styled. Believe it or not this wig was originally 16 inches long!

The wig being hand woven was too great an expense for my family. The Starlight Children's Foundation came to my rescue and granted my wish for the hairpiece. I cannot explain the extent of relief and happiness I felt when I found out I would be able to have the wig. At that point in time, it was as if someone had told me that I would be able to get on with my life normally after such a devastating occurrence.

And the wig was very convincing! When I went back to school everyone complimented me on my new haircut. I even had it styled for my High School Formal and my sister's wedding – no one suspected a thing!

After my hair grew back I stopped wearing the wig. Everyone just thought I had another haircut! I no longer need this wig and I only hope that it can bring you as much happiness as it brought me. I also hope it can bring you a bit of hope that perhaps, one day, you also will no longer need it.

Best wishes from the bottom of my heart. Love, Renata

Editor's Note. Renata has donated this beautiful wig to Candlelighters Canada. The Starlight Foundation arranged for Renata's donation, had the wig cleaned and arranged for us to pick it up. The wig is at Candlelighters National Office. If you or someone you know would like to use this wig to help over a difficult time (i.e. during chemotherapy) please contact our office at 1-800-363-1062 or 416 489-6440.

Thinking of travelling out of Canada?

But your child or teen has cancer...

Insurance is no longer a problem

Medical Coverage is now available for your child. The Childhood Cancer Foundation~Candlelighters Canada is pleased to confirm out-of-country medical coverage can be arranged through:

INGLE Health
438 University Ave., Suite 1200
Toronto, ON M5G 2K8
Phone: 416 340-8115
or 1-800-216-3588

The process is very straightforward:

- call their number
- ask for a medical questionnaire
- complete the questionnaire
- obtain a letter from your paediatric oncologist regarding your child's medical history
- send the completed questionnaire and the letter to INGLE Health for underwriting
- allow 4 weeks for processing and confirmation

Candlelighters Vision ...

The Childhood Cancer Foundation~Candlelighters Canada:

- is a recognized leader in a national childhood cancer network
- ensures that all children and their families have equal access to resources throughout their experience with childhood cancer
- works collaboratively towards a cure



Music Therapy in a Paediatric Haematology/Oncology Setting

Music therapy is the skilful use of music and musical elements by trained therapists to promote, maintain and restore physical, emotional and spiritual health.

It is based on the relationship between the therapist and the child using music as the primary mode of communication.

Music Therapy helps children with cancer in many ways:

- ♪ provides comfort in a strange environment
- ♪ helps the child express feelings non-verbally
- ♪ enhances developmental tasks
- ♪ increases social interactions with others
- ♪ reduces pain and anxiety
- ♪ promotes creativity
- ♪ provides opportunity for choice and control by the child
- ♪ improves quality of life
- ♪ provides comfort during the palliative stage

When a child is referred to the Music Therapist, an informal assessment is conducted during which the child's strengths and greatest needs are identified. I have several interventions available for the child depending on his needs and feelings at the moment. Through singing, instrument playing, games, movement, listening and improvising, a child is invited to explore and express freely in a safe, accepting environment.

Peter, a 6-year-old boy with stage four neuroblastoma, was admitted to the Bone marrow transplant unit. He was referred by social workers for music therapy to assist in developing his coping skills for the upcoming treatment and isolation. Over the

course of the next three weeks, we had seven music therapy sessions together. Peter enjoyed exploring the sounds of the tapo drum and glockenspiel and singing favourite songs. On days when he was too ill to participate actively, he often chose to listen to 'soft songs', which I played and sang on the guitar. Once we made a tape of Peter singing a favourite song "It's a Small World" and a second piece playing the drum in a rhythmic improvisation with me. He was discharged from the hospital with hopes of a full recovery.

Sadly, his disease relapsed and he died at home three months later. His mother sent a letter saying how proud Peter was of his music, and during his final weeks at home he invited friends to listen to his tape. The music was later played at his funeral as part of a final tribute to his short life.

Stories like this are not uncommon in my work. It is humbling and deeply rewarding to see the vibrancy and beauty in each of these children at such difficult times in their lives. It is equally wonderful to know that in many ways, some not even anticipated, that music therapy can and does make a difference to the children.

The current three-day position of Music Therapist on the Haematology/



Oncology Unit at the Toronto Hospital for Sick Children was initiated in February 1999, and is funded by Families of Children with Cancer, the local Parent Support Group for families with a child with cancer. The instruments and equipment were purchased with a \$2,000 grant from the Canadian Music Therapy Trust Fund.

Four Canadian Universities offer a degree in music therapy. To enter, students who have competence over 9-10 years in a musical instrument and who will, over the term of their studies, become competent with at least two other instruments. The focus of the education is on music, therapy models, psychology and research. Following graduation, a 1,000-hour internship must be completed.

The Canadian Association for Music Therapy was established in 1994 and has over 400 members with several provincial chapters. Music therapy is practised in 70 countries worldwide, including the U.S., where the association has been active for 54 years.

Send your Reader Mail to:

Candlelighter's Reader Mail
552 Dalglish Drive Regina, SK S4R 6L8

Want to communicate with others who have the same diagnosis? Want to find a pen pal? Need to obtain information or share your thoughts with others? Simply send a note explaining what you would like published in **Contact**, include your name and address. You will be assigned a number and only that number will be printed - your name will not appear. Your replies will be sent to you and you can answer all your mail.

Nortel Networks Community Volunteers help out Candlelighters Canada

Nortel Community Volunteers have been working with Candlelighters Canada to help support children with cancer and their families across Canada. This picture captured a holiday donation made to Candlelighters Canada on behalf of the Nortel Networks Community Volunteers.

Candlelighters looks forward to working with Nortel and the Community Volunteers in the future, and we are very grateful for all of their support.



Grateful for support:
Georgia Phair, Mgr. of Marketing and Communication for Nortel, Renae Addis, Dir. of Development for Candlelighters, and Duncan Ratcliffe Business Director Wireless Solutions for Nortel.

The Nortel Community Volunteers have given monetary donations and dedicated their time by supporting the Candlelighters Angel programme. To date, Nortel and their employees have sold over 300 Angel pins. Way to go Nortel! And thank you.

Holiday gift drive for families a smashing success

This year was amazing -- 1999 was a record year for Candlelighters Canada. We supported over 60 families, and approximately 150 children, with our Holiday Toy Drive. We met our goal of helping families across Canada thanks to your support!

Each of these 60 families received a holiday tin of cookies and chocolates. As well, we sent a Revlon package and candles to the moms in every family. Every child in the family received at least two gifts. Most of these were what they had asked for on their Holiday Wish List! We were also able to give the families food coupons for the grocery stores and movie passes.

Thanks to the kind support of the following Corporate Angels. Without their support and donations, we would not have been able to help so many children and families this past season:

The following companies donated \$5,000 for our holiday drive:

- General Motors of Canada
- Sterling Commerce
- Scotiabank

These companies donated \$1,000 for the holiday drive:

- Procor Limited
- Rio Algom
- TrizecHahn Corporation
- MDS Health Group

The following companies donated product and time to our toy drive:

- Bell Mobility
- Bell Canada employees
- Revlon Canada
- Scholastic Canada
- Caldwell Partners

A huge thanks to our friends at Total Health Chiropractic Centre. They created a toy drive for our families called the 1999 Chiropractic for Kids Toy Drive. The toy drive ran for one month and raised over 250 toys. Wow!

Thanks so much to all of our volunteers and the companies who supported the 1999 Candlelighters Holiday Toy Drive for our families across Canada.

It's all about Compassion.

Children with cancer need research too.

The Childhood Cancer Foundation~Candlelighters Canada is pleased to announce that we have officially launched the partnership with the Medical Research Council of Canada (Canadian Institute of Health Research).

The launch took place in Toronto at the Courthouse restaurant on Thursday, March 2, 2000. It marks the beginning of increased funding through Candlelighters for childhood cancer research in Canada. The evening "***It's all about Compassion***" was a wonderful success.

The event brought together childhood researchers, clinicians, parents, survivors, donors, representatives from the corporate world and the Medical Research Council.

Candlelighters Canada is excited to embark on this new journey into the area of childhood cancer research, and is pleased with the support that has been shown by the medical community. "Paediatric research has been the orphan of cancer research in Canada," says Dr. Sheila Weitzman, Senior Oncologist and Associate Director Clinical Services at The Hospital for Sick Children, ON. This new partnership is dedicated to ensuring increased funding for childhood cancer research.

Childhood cancer research helps to find cures.

"The promising outcome for many children with cancer is essentially the result of endless hours of clinical and basic research," says Dr. Max Coppes, Director of the Children's Program at the Alberta's Children's Hospital, AB. "Despite the limited resources that have been made available to childhood cancer researchers, we have designed numerous successful strategies to cure children with cancer. There are some battles, however, that we still cannot seem to win. The only proven way

to move forward is through further research. If anybody knows how to do so without research, please step forward. If not, let us finally get serious about supporting clinical and basic childhood cancer research, and together resolve the remaining challenges for children with cancer and their families."

PIC
INSERTED
LATER

PIC
INSERTED
LATER

Untitled but Wise

(This poem was given to us by the owner of the Blue Begonia restaurant in Toronto, ON. The poet is unknown at this time.)

There are days and times
when it has been cloudy
But don't forget
your hours in the sun.

Forget about the times
you have been defeated
But don't forget
the victories you have won.

Forget about mistakes
that you can't change now
But don't forget
the lessons you have learned.

Forget about the misfortunes
you have encountered
But don't forget
the times your luck has turned.

Forget about the days
when you have been lonely
But don't forget
the friendly smiles you have seen.

Forget about the plans
that didn't seem to work out right
But don't forget
to always have a dream.

Childhood Cancer and the Family: Together in 2000, Candlelighters Childhood Cancer Foundation Conference

August 18 - 20, 2000 in Toronto, ON

The fourth international conference is co-hosted by the Parent Groups of Ontario and the Childhood Cancer Foundation~Candlelighters Canada. Dr Bernie Siegel will give the opening keynote address. Other well known speakers include: Sr. Frances Dominica, an international expert on children's palliative care and hospice care; Dr. Lauren Woodhouse, a laughter therapist, Dr. Mark Greenberg, who will speak on long term effects. This child and family conference will bring Candlelighters into the new century. Events are planned for the children who will enjoy a special outing, as well as having informative sessions during the conference. This is a conference for everybody -- parents, survivors, siblings, professionals and volunteers.



Please review the information in the attached Preliminary Programme. Complete the attached registration form and return it as soon as possible to the conference office. ***A special message for all Parent Groups:*** please contact your Provincial Director for tips on raising funds to assist families to come to the conference.

The International Confederation of Childhood Cancer Parent Organizations

October 4-7, 2000 in Amsterdam, The Netherlands

The ICCPO is holding a one-day parent conference in conjunction with The International Society of Paediatric Oncology and the American Society for Paediatric Haematology/Oncology. Sessions for parents will be held throughout the SIOP conference. The conference provides a unique opportunity to meet and exchange ideas with parent from around the world.

Attending to the Spiritual Needs of the Dying and the Bereaved

May 15-17, 2000 in London, ON at the King's College Centre for
Education About Death and Bereavement

Spirituality is the ability of a person to choose the relative importance of the physical, social, emotional and intellectual stimuli that influence him and thereby create meaning. A group of distinguished experts discuss the many ways of thinking about spirituality. The many aspects of spirituality will be revealed through drama, language, music, humour, the wisdom of traditions, and the support of one another coming together. For information about this conference please contact the Centre, 266 Epworth Avenue, London, ON N6A 2M3, Tel: (519) 433-3491

For additional information, contact Candlelighters Canada, 55 Eglinton Avenue East # 401
Toronto, ON M4P 1G8, Tel: (416) 489-6440, Fax: (416) 489-9812, email: staff@candlelighters.ca

Upcoming
Conferences

Our Story...

by David Madeley

Our story begins in July 1997 when James, my 5 year old son, started vomiting and was diagnosed by the family doctor as having chronic sinus infection.

We went on holiday to Minorca in September 1997, where, on the second week of the holiday, James became very ill - vomiting and complaining of pains in his head and stomach. The doctors in the Minorca hospital diagnosed gastroenteritis. Toward the end of the second week of our holiday, James seemed to get a little better and we were allowed to fly home to Manchester as scheduled. James returned to school. He continued to vomit and then feel fine again.

We returned to our family doctor, but this time saw a different doctor in the practice. She stated that 5 year old children generally do not suffer from chronic sinus infections. It was then alarm bells started to ring. She did say he had a chest infection. Two weeks later, the vomiting had become much more frequent and James complained of neck ache, headache and had a temperature. My wife took him to hospital and was told he had virus and to take him home. James was not well enough to attend school now and developed a squint.

We took him back to our family doctor who told us it was quite normal for 5 year old to develop squints over night. Still not happy with how poorly James was, we once again took him back to our GP where James was almost falling asleep standing up in the doctors' surgery. The doctor said, "Oh look at him; he is shattered; he needs a good night's sleep." We then took him back to hospital where this time they listened.

Sally (my wife) even said I think he has a brain tumour. Nine a.m. the following morning (7th November) James appeared to fall asleep. He made a most awful grunting noise and began stretching his arms and legs. Sally knew something was seriously wrong. I buzzed for the nurse and she summoned several doctors who fortunately were in the next room doing their rounds. James was in a coma, he had stopped breathing and his pupils were fixed and dilated. Together, the doctors and anaesthetist worked on James while another doctor tried to arrange a CT scan. By the time the scan was ready for James, the anaesthetist said it was too late and took out the hand-operated breathing equipment.

We began the short trip down to scan not really knowing if our son was still alive. The CT scan revealed a large brain tumour, and we were soon on the way to the Royal Manchester children's hospital. Unfortunately, there wasn't enough room in the ambulance for either of us to travel with James. Reaching the children's hospital before the ambulance was a strange, almost hollow, feeling. James arrived 10 minutes later and was taken to the intensive care unit. We walked through the doors of I.C.U. at the same time as the neurosurgeon.

James had emergency surgery to relieve the pressure and then surgery to remove 99 per cent of a tumour, which had been growing, and causing pressure for some time. We spent the next four days by his bedside in I.C.U.

Day 4 in I.C.U. was time to do another scan. Back in I.C.U., they switched off all the drugs and we were told that all the tubes and wires didn't matter so much now, and not to worry if he did wake up



and disturb anything. This is exactly what he did. First a few flickers from his eyes and then he woke up taking out his own tubes and wires. The neurosurgeon was called and arrived with the scan results. The results from the MRI couldn't have been better; it showed no spread.

James spent one more night in I.C.U., and then went on to the high dependency unit for a couple of days. James moved on to the main ward where he encountered some problems with infection and received IV antibiotics. He later had his VP shunt, a device fitted internally from the head down to the abdomen, to regulate the pressure within the head. This meant that James was now able to move around without dragging a drip stand with him.

James started his radiotherapy four weeks after the surgery that removed the tumour. Six weeks after treatment the effects of the radiation began to show. James was sleeping more and eating less and less. It got to the point where James had lost so much weight that his paediatric oncologist said he would have to come back to hospital to be fed via a tube. James, horrified by the thought of returning to the hospital, began to eat. May 1998 came, and time for his first scan, the results were clean and from this point on James started to improve. James is now back in school full time and is looking forward to his seventh birthday.

To contact David & Sally Madeley, please send an e-mail to: dmadeley@tinyonline.co.uk

David now has an internet mailing list for Medulloblastoma and PNET's. The list is for parents, patients, caregivers and professionals to share and exchange experiences and information. You can find the free subscription URL at <http://www.onelist.com/subscribe/medulloblastoma>.

Be a special angel



Buy an Angel pin and support the Candlelighters' Angel Programme

The **Candlelighters' Angel Programme** is a special fund dedicated to help the families living with childhood cancer. The funds raised are directed to two programmes: Family Assistance and the Candlelighters/Interlink Community Cancer Nurses. Each Angel pin is carefully handcrafted and is available in either a gold or silver tone. Please complete the order form and return it to Candlelighters, 55 Eglinton St. East, Suite 401, Toronto, ON M4P 1G8. Or fax your order to us at 416-489-9812.

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Method of Payment

(please circle one):

Cheque enclosed

Visa MasterCard

My mom says angels
are all around us
they show
us how to care,
and how to share,
and fill our hearts with love.

Giving Children Tools to Manage their own Health Care

by Yanni Hamdani, Occupational Therapist

(Permission has been granted to reprint this article initially published by Bloorview–MacMillan Centre, Toronto, 1999)

Many skills for independent living seem obvious: a young child wants to dress himself or teenager asks to go to the mall alone. A skill that is often overlooked, because it's natural for parents to assume the responsibility, is the ability to manage health and medical needs.



Giving children the tools to manage their own health care will ensure they have a solid understanding of their disability and how to get their needs met in the medical system as adults.

Following is a list of tips to help children learn how to communicate with doctors and to understand and describe their medical history.

- ✓ Prepare children for appointments by explaining who the doctor is and what will happen during the appointment.
- ✓ Have your child answer as many of the doctor's questions as possible.
- ✓ Ask the doctor to explain information in ways that your child can understand.
- ✓ Ask older children if they have questions for the doctor ahead of time. Help them to practise asking the questions by role-playing, with you acting the doctor.
- ✓ Allow teenagers and young adults to gradually become more independent in going to medical appointments. You may want to start by having teenagers call to book their own appointments. Next, try dropping your teenager off to register for a clinic while you find parking or get a coffee.
- ✓ Help teenagers prepare questions for appointments. Encourage them to ask the doctor to explain medical terms in simple, everyday language. Teenagers can also ask to tape-record the meeting or have the doctor write down information if they have difficulty remembering details.
- ✓ Encourage teenagers and young adults to ask about medical and health services for adults with disabilities. Your doctor or clinic nurse should have information about the transition to adult medical services when a young adult is no longer eligible for all services at a children's treatment centre.
- ✓ Have children practice explaining their diagnosis or disability. Help them find the words to explain clearly.
- ✓ As children get older, show them how to keep track of medical and health appointments, as well as surgeries and major illness. Be a role model and show how to write down appointments in a calendar and keep reports in a file or binder.
- ✓ Ideally, teenagers should be in charge of their own medications. They should know what each drug is for, when to take it, and how much to take. You may want to assist your teenager in organizing a pill box. Young adults should also be encouraged to find out about the effects of alcohol and illegal drugs on their medications.



New Resources for You and Your Family

Cancer Clinical trials: Experimental treatments & how they can help you

by Robert Finn price \$21.95

This is a unique and indispensable guide for families who want to understand the many aspects of clinical trials. The structure, administration and ethical guidelines of clinical trials are discussed. How to read an informed consent document and a trial protocol are addressed. A list of questions to ask yourself and your doctor about clinical trials is very helpful. This book does not describe individual trials.

Childhood Cancer - A Parent's Guide to Solid Tumor Cancers

by Honna Janes-Hodder and Nancy Keene price \$36.95

This book written by parents who have experienced the journey of childhood cancer provides detailed information and support. It offers a basic understanding of medical terms, chemotherapy and side effects of treatment. It offers practical advice on how to deal with procedures, hospitalization, school, family and friends, as well as social and financial issues. One of the strengths of this resource is the stories by parents who describe their emotional ups and downs as they coped with hospitalizations and their child's illness.

Supporting Sick Children and their Families

by Penny Cook price \$31.95

A practical, sensitive and supportive book for parents describing guidance related to the provision of emotional, psychological and spiritual support for sick or dying children and their families. In addition to covering the practical aspects, the book covers a variety of coping strategies. Some chapters focus on the range of emotions that children and their family members may feel or express; another is devoted to the issues facing siblings of sick children.

Cancer pain relief and palliative care in Children

Published by the World Health Organization in collaboration with the International Association for the Study of Pain price \$29.95

The first statement of the book says the "Children with cancer do not need to suffer unrelieved pain." Several chapters of this resource deal with the nature of children's pain, the extent of the problem, assessment, supportive, cognitive, physical and behavioural management of pain as well as drug therapy. The ethical and spiritual effects of children's pain are addressed. This excellent resource although primarily written for professionals will be of

benefit to parents who want to understand the nature and treatment of their child's pain.

Finding Strength - A Mother and Daughter's Story of Childhood Cancer

by Juanne Nancarrow Clarke

with Lauren Nancarrow Clarke price \$19.95

A medical sociologist whose daughter was diagnosed with leukaemia wrote this extraordinary book. Two years in the lives of both the mother and daughter are detailed from the early symptoms and denial, through diagnosis and two years of treatment. Chapters highlight such topics as acknowledging diagnosis, having to deal with health care professionals who are blunt and (in the eyes of the family) insensitive, discovering the importance of family, friends, food and faith. Throughout the book Lauren, the daughter, adds her own footnotes to her mother's comments where she felt the need to clarify or amplify what her mother had written. All family members will appreciate this resource

In May, **Finding Strength** will be launched in British Columbia and Alberta. Highlight of all events and dates will be forwarded as soon as they are confirmed to Children's Treatment Centres and Parent Groups. Please watch for further details.

All these books are available from the Candlelighters Resource Centre at 55 Eglinton Ave. East, Suite 401, Toronto, ON

Candlelighters Catalogue

New Flyer and New Listings

Recently reviewed resources and other new books and videos are highlighted on a new flyer. The flyer will be available in all catalogues sent out in the future. If you learn of resources which you feel would be of benefit to other families, please let us know and we will make it available through the resource centre. Many thanks to those readers who have informed us of valuable resources. The new enlarged and revised catalogue is available. If you have not received yours, please let us know. You can also receive your catalogue from your treatment centre or Parent Group.



**The Childhood Cancer Foundation
~Candlelighters Canada**

55 Eglinton Ave. East, Suite 401
Toronto, ON M4P 1G8

It is better to light one candle than to curse the darkness.

- Candlelighters Canada

Please add me to Candlelighters Canada mailing list.

Name: _____

Address: _____

Institution (if any): _____

City: _____

Province: _____

Postal Code: _____

I would also like to make a donation to Candlelighters
Canada in the amount of \$ _____ (cheque enclosed)

Please indicate if you are:

A parent of a child
with cancer

A patient with cancer

A health professional
(please specify)

Other (please specify)

As part of its free services, the Childhood Cancer Foundation~Candlelighters Canada is pleased to offer you *Contact*, a quarterly Canadian newsletter featuring articles for families of children with cancer. You will also receive information on new resources and upcoming events. Simply complete and return this form.