



Where there's light, there's hope.

INTRODUCTION

Candlelighters Childhood Cancer Support Programs Inc. was established in 1988 as part of the Candlelighters Childhood Cancer Foundation of Canada network of local and parent support groups. Candlelighters is a not-for-profit organization and the only group at the local level that exists to give childhood cancer patients and their families the kind of support and resources that are so vital in a time of crisis.

Mission

Candlelighters mission is to enrich the lives of children, and their families, coping with childhood cancer and to raise awareness and understanding of the impact of childhood cancer on the children and the families.

Vision

That every child and family affected with childhood cancer enjoys the best quality of life possible, from the time of diagnosis, through to the completion of treatment and beyond.

Values

Volunteers and donors are essential to the work of Candlelighters. Their talents and resources, time and energy are directed to the fulfillment of the organization's mission. All actions of those associated with Candlelighters programs are conducted with a high degree of professionalism, integrity and compassion.

The work of Candlelighters is complementary to that of the medical community treating children and their families.

THE NEED

In Canada, today, 10,000 children are living with childhood cancer. Over 400 children will be diagnosed in the province of Ontario in 2006. In Ottawa alone, 65 kids a year are diagnosed with cancer. That is more than one child per week. They are your neighbors, they are your children's classmates and teammates. They could be your children, or your nieces, nephews or grandchildren. Childhood cancer does not discriminate and affects children regardless of race, religion or social economic background. Cancer is the leading cause of death by disease in children. More children will die this year of cancer than anything other than accidents. 25% of children diagnosed with cancer will not survive. One in four.

The impact of a diagnosis of childhood cancer in a family is enormous and far reaching. In 2003, the Pediatric Oncology Group of Ontario (POGO) reported "approximately 1/3 of parents' after tax income" goes to cover out of pocket expenses that families are faced with when a child is undergoing cancer treatment. Costs associated with spending day, weeks and sometimes even months in hospital. Children do not get to appointments and treatment on their own and a parent usually either stays in hospital with the young child or spends a tremendous amount of time at the hospital. One parent usually stops working. Parents incur expenses like parking costs, food costs while in hospital (they need to eat) and childcare for other children.

Over time, paying for groceries, rent, utilities can become a financial strain if family incomes drop from double to single. At times, children require treatment outside of this region for procedures and travel costs (including transportation, lodging, food and even long distance phone calls) place added burden on an already strained financial situation. All this in addition to the emotional upheaval the uncertainty of childhood cancer places on patients, parents and families.

Candlelighters Childhood Cancer Support Programs provides real tangible support to these families through the provision of Support Services, Financial Assistance and CyberKids programs.

In 2007, we had 250 families in our membership. Through our innovative Parking Program we provided 268 parking passes to our members to cover the cost of parking during their treatment at the Children's Hospital of Eastern Ontario in 2007. 15 families traveled outside of Ottawa for medical procedures and Candlelighters provided parking passes, food vouchers, long distance phone cards and other certificates for them. Through our CyberKids program, 27 laptops were placed with children being treated for cancer in 2007.

Member families benefit from the strong relationship Candlelighters enjoys with the Children's Hospital of Eastern Ontario. In addition to having a pediatric oncologist sit on the Board of Directors, the Program, Service and Delivery sub committee is comprised entirely of staff from the multi-disciplinary oncology care team.

PROGRAM OVERVIEW

Candlelighters' programs and services are aimed at the needs of the entire family, and deal mainly with alleviating both the emotional and financial stress that families of children with cancer deal with on a daily basis.

In order to achieve its mission of enhancing the lives of children and their families coping with childhood cancer, Candlelighters provides a variety of services, delivered through three core programs;

- Support Services
- Financial Assistance
- CyberKids

Support Services

For most people, a diagnosis of cancer is an overwhelming experience, intensified when a child is involved. Fear of dying, worrying about medical treatment, concern over role changes at home or at work can make people feel isolated and alone at a time when they most need support from other people.

Realizing that others have experienced similar reactions and fears reassures those involved that their own reactions are normal. Exposure to several viewpoints and shared experiences help individuals find a way of managing their own fears as well as dealing with those of friends and family. Learning positive coping methods and regaining a sense of control gives those affected a more positive outlook toward life and a sense of well-being and hope.

Candlelighters coordinates the provision of the following support services to young people with cancer and their families:

- "Coffee Talk" weekly drop-in
Wednesday mornings in the Sens Den on 4 North, parents and caregivers are welcome to join in an informal chat with other parents dealing with similar circumstances while enjoying coffee and snacks. These meetings are facilitated by Child Life, Social Work staff and the Interlink Nurses on a rotating basis.
- Bereaved parents support group
This is an 8 - 12 week program which is professionally facilitated. This program, offered once a year, is for parent whose children have not survived a diagnosis of cancer.
- Workshops/Seminars
Candlelighters brings in health care professionals or others from the childhood cancer community to make information/educational presentations to our families. Smiling Siblings Watercolour Workshop is a monthly outing offered to siblings of childhood cancer patients.
- Resource materials
Candlelighters' provides families with diagnosis specific resources including books and videos as well as binders to keep a systematic reference to medical information when received. These books include, but are not limited to: Childhood Leukemia, Childhood Cancer "A Parent's Guide to Solid Tumor", Childhood Brain & Spinal Cord Tumors, Non Hodgkin's Lymphoma, Childhood Cancer Survivor, Living with Childhood Cancer, Des enfants comme les autres, Autologous Stem Cell Transplants, Childhood Hodgkin's Disease.

Candlelighters' also engages in a number of other initiatives, which include:

- **Annual Christmas Party**
Each year, Candlelighters hosts a holiday gathering for our member families in a festive atmosphere offering a myriad of fun-filled activities. This has been a highlight for many families over the years, and will be open only to those families who are Candlelighters members.
- **Family Membership**
Families of children with cancer usually become Candlelighters Members shortly after diagnosis. Families are asked to join Candlelighters and sign a release of information form. In order to maintain your membership, Candlelighters mails our annual membership renewal forms to families in the fall of each year. Families must complete the forms and they must be received in the office for processing. Only Candlelighters' member families are eligible for our programs and services, so it is very important that you return your membership form each year.
- **Ottawa Senators Alumni Suite Seats**
The Ottawa Senators Alumni generously provide Candlelighters with tickets to TEN of the Ottawa Senators Hockey Club home games; welcoming us into the exclusive Ottawa Senators/Molson Alumni Suite.
- **Birthday Greetings**
Birthday greetings from Candlelighters sent to your child recognizing their special day!
- **Candlelighters' Courage Beads**
Candlelighters Courage Beads are designed to document, honour and recount the journey that each child takes by providing an array of beads; each representing some facet of treatment.
- **Tree of Life Memorial Ceremony**
A bi-annual, non denominational ceremony for families of children who have succumbed to their illness. A beautiful wall hanging is present on the in-patient ward at the Children's Hospital to recognize these youngsters. The next ceremony will be held in 2009.

Financial Assistance

Families of children with cancer experience an immense financial burden. In its 2003 Annual Report, the Pediatric Oncology Group of Ontario (POGO) reported that the out-of-pocket costs faced by families of children with cancer is estimated to be approximately 1/3 of after tax income. Treatment for cancer in a child can come at a high price for families, as often their quality of life is compromised by the financial and socio-economic impacts that result from a child literally "fighting for their life" while enduring cancer treatment.

Candlelighters provides the following financial assistance to the families of children with cancer:

- **Patient Amenities**
This program offers financial assistance to families in a crisis situation where other funds are not available.
- **Parking Program**
All member families are eligible for parking passes for the entire duration of treatment which can be redeemed for either a Frequent User or a Monthly parking pass.
- **Ottawa Senators Alumni Bursary**
Candlelighters is very pleased to offer a bursary in the amount of \$1,000.00 to a Candlelighters' childhood cancer patient (meeting the eligibility criteria) in their academic pursuits of post-secondary education.
- **Kathleen Elizabeth Ward Sibling Bursary**
Candlelighters offers a bursary to a sibling of a childhood cancer patient in the amount of \$1000.00 in their academic pursuits of post-secondary education.

CyberKids

Candlelighters can help a child/youth who is being treated for cancer stay plugged in to schoolwork and teachers, friends and the outside world, whether they are in hospital or at home, through the provision of laptop computers equipped with age-appropriate software programs, Internet access and email capability. When cancer throws school timetables out the window, "CyberKids" gives children the opportunity to learn when they feel good. Helping them keep in touch academically and socially can go a long way to boosting patients' self confidence and positive outlook.

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