



Candlelighters Simcoe
Parents of Children with Cancer
6 Emily Court Barrie Ontario L4N 6B4
Phone: 705-737-4296 Fax: 705-737-4836

Candlelighters Simcoe School Program

What is Candlelighters Simcoe?

Candlelighters Simcoe Parents of Children with Cancer was founded in 1990 by Barbara Johnson, a Pediatric Occupational Therapist in Barrie and the mother of three, one who is a long term survivor of childhood cancer.

Candlelighters Simcoe is a volunteer driven, not for profit organization that is supported entirely by community donations. It is a group of parents whose children and teens have been diagnosed with cancer; some cured, some on treatment, and some who have lost their battle. It provides support for families in Simcoe County and surrounding areas. Our support programs have been designed to positively impact and improve the quality of life for children with cancer easing the burden faced by their families. All of our programs are free of charge for our families.

Some of our support programs include:

- *Monthly support groups for parents and an expressive art program for the children*
- *Care package for families at diagnosis*
- *Weekly art therapy for a small group of children (with cancer or the siblings)*
- *Monthly social events for teens (including the siblings)*
- *Christmas care program which provides Christmas care packages for the families whose child or teen is on active treatment.*
- *School support program for classmates, schools and teachers*

Candlelighters Simcoe is part of a provincial organization called Ontario Parents Advocating for Children with Cancer (OPACC) that serves families by providing information, engaging in advocacy and encouraging and assisting in the development of parent support groups. The provincial website is www.opacc.org

Who is Candlelighters Simcoe Parent Liaison?

The Parent Liaison is a paid parent professional funded by Candlelighters Simcoe, who facilitates a family's journey through the childhood cancer experience. Barbara Johnson is currently in this role as the parent liaison.

What is the Candlelighters Simcoe School Support Program?

The School Support Program was developed by Candlelighters Simcoe to support children with cancer and their siblings in the classroom. The Parent Liaison brings the perspective of one who has personally faced the challenges of childhood cancer in the family. She has knowledge of the medical terminology and procedures; can share her personal stories and feelings about having a child diagnosed with cancer, and how a child is impacted by treatment in daily life.

It is a peer support model empowering parents to advocate for their child/teen in the educational system. Since 2001 Candlelighters Simcoe has had representation on SEAC (Special Education Advisory Committee) for the Simcoe County District School Board and the Simcoe Muskoka Catholic District School Board. Knowledge attained through SEAC includes updates on Individual Educational Plan (IEP) and Identification Placement Review Committee (IPRC) process, awareness of educational resources available to students with exceptionalities such as Educational Assistants, technology (Laptops, I Pads) and adaptive programming.



What services does the School Support Program include?

1. PRESENTATIONS

- Presentations to students whose classmate has cancer (usually only at the Elementary level). This may include viewing the video “Why Charlie Brown Why”, discussion about cancer, its treatment, side effects and emotions related to a diagnosis of cancer. Presentations are tailored to the wishes of the parent and student with cancer. This may include the participation of the student in the presentation e.g. photos/DVD of their personal experience, bravery beads or special medical equipment used by the student.
- *Similar presentations to students whose classmate has a brother or sister with cancer.*
- *Presentations are not limited to one class but can be done for large groups of students by division: primary, junior and intermediate.*
- *Presentations are also available for schools during fundraisers such as Terry Fox runs or for students learning about the science of the body in Grades 5 and 6.*

2. Information Sessions

- Information sessions with teachers, principals, special education consultants and school board personnel to share information about Candlelighters Simcoe; what it is like for a family going through the journey of childhood cancer; and how the school community can support families during the cancer process.

3. SUPPORT AND RESOURCES

- Support for parents during IEP, IPRC and transition meetings with school principals, teachers, special education consultants, guidance counselors, therapists etc. This is a step by step process that is available at diagnosis, during treatment, after treatment and long term. The needs of the siblings are also identified.
- *Candlelighters Simcoe helps to identify long term effects from cancer treatment that will affect educational outcomes by providing resources for the teachers (e.g. relevant childhood cancer websites). Resources are available that can be loaned to the school for use in the classroom (e.g. DVD's, books and games for children relating to illness and cancer).*
- Candlelighters Simcoe helps to advocate for home instruction during the treatment process.
- *At the high school level, Candlelighters Simcoe supports the parents and teen at case conferences with the high school staff at diagnosis, during treatments and post treatment. Information is shared about Candlelighters Simcoe programs, resources for long term effects of cancer treatment and educational outcomes.*
- Should a child become palliative, support for the school is available during the last stages of illness and after a student dies. In most cases there has been an ongoing relationship with the school, therefore the support continues in the form of a dialogue with the students about their feelings and what the school/classroom may want to do in memory of the student that has died.



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Additional Notes:

Parent Role in the School Program:

Candlelighters Simcoe empowers parents to participate in school support for their child/teen with cancer and their siblings with the following guidelines and suggestions:

- Parents have the right to decide what medical information is shared with the school and what information will be put in their child's OSR (Ontario Scholastic Record)
- Parents are encouraged to write their own information letter to the school with pertinent medical information such as diagnosis, treatment schedule, side effects, safety concerns within the school and emergency contact information (sample letters are available through Candlelighters Simcoe)
- Encourage the parent to have an initial meeting with the administration and teachers at the school to discuss what is happening, what the impact will be in the future and how this information will be shared with the school and students. Candlelighters Simcoe Parent Liaison can be part of this process and be there to support the parents in this meeting. The parent liaison can meet with the staff to share information about Candlelighters Simcoe programs, resources available to the staff, discuss the impact on the family and how the school can help
- Encourage parents to have frequent follow-up with the school during the treatment process, off treatment and post treatment through semester based or yearly case conferences
- Ensure an IEP is in place for a "medically fragile" student determined by the students individual needs (e.g. need for EA support, decreased course load, balancing courses in high school semesters, use of scribes, oral exams, use of laptops or I Pads, photocopied notes, accommodations for physical education classes, extended time for tests, access to resource centre for classroom work or tests etc.)
- Requesting accommodation or exemption for EQAO testing done at grade 3, 6 and 9
- Ensure that home instruction is in place during the treatment process. A student may still attend school at times, but due to the treatment and side effects this may be sporadic thus having the home instruction concurrently ensures a continued learning process
- Parents can help the older child self advocate for their needs and wishes particularly at the high school level.

Role of Special Education Advisory Committee (SEAC) Representatives:

- SEAC representatives for the designated school board represent students with cancer on behalf of Candlelighters Simcoe, at the school board SEAC meetings on a monthly basis during the school year.
- Through our SEAC representation and school program Candlelighters has forged relationships with key personnel at the school board level such as Principals of Special Education/Program and Services, Special Education consultants, Superintendents and Trustees. As a result of more than 20 years in the community working with schools, Candlelighters Simcoe has established rapport with school principals, vice principals, special education teachers and classroom teachers. This building of community is important ground work for the support and understanding needed when a student is diagnosed with cancer.
- Candlelighters Simcoe has made presentations at the School board level for Professional Development Days, Area Principal Meetings, Special Education Consultants, Guidance Counselors, and Chaplains. Candlelighters Simcoe has also been involved in information booths at Educational Workshops for teachers and parents.