

What about Research Studies?

AfterCare clinics record information about patients to be included in a provincial research record. None of this information is identifiable. If we need to collect information that could identify your child for a research study, we will not collect this information without your permission. A Research Ethics Board would have to approve the study, and we would ask your permission.

If you allow your child to participate in the research, you will be helping us to:

- Improve care by focusing attention on key research areas
- Plan changes in cancer treatment for future generations of children.

Most of the information we collect does not require identification of the patient or family. Information that could identify your child personally will be kept separate from data included in the provincial research record.

Some research benefits greatly from follow-up contact with survivors, or from the additional health information stored in other health records and databases. If we need personal information about your child, researchers will seek your consent.

Learn how to protect your child's health.

Participate in an AfterCare Program



Where to find an AfterCare Program

Ottawa

Children's Hospital of Eastern Ontario
613-737-7600 • Ext 2760
The Ottawa Regional Hospital Cancer Centre
613-737-7700 • Ext 70294

Hamilton

McMaster Children's Hospital,
Hamilton Health Sciences Centre
905-521-2100 • Ext 73430

Kingston

Cancer Centre of Southeastern Ontario
at Kingston General Hospital
613-549-6666 • Ext 3834

London

Children's Hospital,
London Health Sciences Centre
519-685-8500 • Ext. 52192

Toronto

The Hospital for Sick Children
416-813-8321
Princess Margaret Hospital
416-946-4501 • Ext 5437

Pediatric Oncology Group of Ontario
480 University Avenue, Suite 1014, Toronto,
Ontario, Canada M5G 1V2
(416) 592-1232 www.pogo.ca



Is your child a Cancer Survivor?

Ontario's AfterCare Program helps protect the health of survivors.



Attending just one AfterCare Clinic per year could reduce side effects of treatment and help your child stay healthy

What is the AfterCare Program?

It's a long term follow-up program that provides your child with the following benefits:

- Regular contact with caregivers who understand cancer and its treatment
- Access to information related to cancer survival
- Early detection of any late effects from treatment

Ontario's Childhood Cancer AfterCare Program teaches you how to protect your child's health. The AfterCare team is trained to:

- Promote health and prevent disease
- Promote quality of life
- Detect problems early, including social or psychological problems
- Provide referrals such as neuropsychology testing, dietary consultation, etc so that you and your child can find the help you may need

Why should your child participate in the AfterCare program?

The program keeps you up to date on new information about childhood cancer and those who survive it.

By participating, your child can contribute to our growing knowledge base about the long term health of survivors

Knowledge helps us to improve care for the next generation of childhood cancer patients.

Who should attend AfterCare Clinics?

All survivors of childhood cancer who have been off treatment for two or more years may be eligible to attend an AfterCare Clinic. Your child's oncologist or clinic nurse will talk to you about when AfterCare clinic should start for your child.

What happens when my child participates in the AfterCare Program?

Once your child has been off active treatment for at least one year your child's oncologist or clinic nurse will provide you with information about how AfterCare clinics work and who will be on your child's AfterCare team. You can then make an appointment for your first AfterCare visit.

During your child's first clinic visit, the AfterCare team will meet with you to collect information about your child's health and treatment. This information will be used to develop a long term follow-up plan for your child.

Once your child becomes an adult, he/she will transfer to an Adult AfterCare clinic and will receive a Passport to Health – a wallet size document containing all the important details of your child's medical history and past treatments.

When should we attend?

The frequency of clinic visits depends on your child's diagnosis and how long it has been since active treatment. Most children attend clinic once a year.

What happens at the clinic?

The AfterCare clinic staff are specialists, focused on childhood cancer survivors. They will give your child a clinical assessment, arrange required tests, and refer for required treatment.

You will be able to discuss any concerns with the experts. You may also gain opportunities to talk to other survivors and their families.

We ask teens, adult survivors and parents to fill out questionnaire that will provide us with information that is essential for planning your child's care in future. This information is also essential to our research on survivor health and late effects from treatment of Childhood Cancer.

AfterCare clinic visits may take 1-4 hours.

What about test results?

We will tell you your child's test results and we also send them to your family doctor. If results show that something is not normal we may ask you to bring your child to clinic for further assessment or refer your child to an appropriate specialist.

What do we do if there are health concerns related to cancer between visits?

Call the nurse on your health care team:

Nurse: _____

Telephone: _____