

What about Research Studies

Your AfterCare clinic will record information about you to be included in a provincial research record. None of this information is identifiable. If we need to identify you for a specific research study, a Research Ethics Board will approve it, and we will ask your permission. We will not give information that can identify you without your permission.

But if you allow it, 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. Information that could identify you will be separated from the data used in research studies.

Sometimes researchers may benefit greatly from a follow up contact with you, or from the addition of your health information stored in other health records and databases. When we do need personal information, researchers will ask for your consent, along with approval from the Hospital Research Ethics Board.

**LEARN HOW TO PROTECT YOUR
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



Are you a Childhood Cancer Survivor?

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



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

What is the Childhood Cancer AfterCare Program?

It's a follow-up care program designed to provide you with these benefits:

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

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

- Protect health
- Promote quality of life
- Detect problems early, including social or psychological ones
- Provide referrals, so you and your family can find the help you need
- Prevent disease

What are the advantages of attending AfterCare?

When you participate in an AfterCare program you help yourself and others because:

- You may be able to access services you need.
- The program will keep you up to date on new information about cancer and those who survive it.
- You can contribute to our growing knowledge base about the long-term health of survivors.

Who should attend AfterCare Clinics?

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

What happens when I participate in the AfterCare Program?

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

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

Once you become an adult, you 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 medical history and past treatments.

How often should I attend?

You should expect to come in at least once a year for the first five to 10 years, and every second year after that.

What happens at the clinic?

The AfterCare clinic staff are specialists, focused on childhood cancer survivors. They will assess your health, arrange required tests, and refer you for required treatment.

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

We will ask you to complete a questionnaire that will provide us with information that is essential for planning your 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 test results and we also send them to your family doctor. If results show that something is not normal we may ask you to come back to clinic for further assessment or refer you to an appropriate specialist.

What do I do if I have health concerns related to cancer between visits?

Call the nurse on your health care team:

Nurse: _____

Telephone: _____