Information for childhood cancer survivors and families

Read this booklet to learn about:

- Ontario’s Childhood Cancer AfterCare Program
- how it can help
- what you can expect at your appointments
- where to find a program near you
What is Ontario’s Childhood Cancer AfterCare Program?

Ontario's AfterCare Program is a follow-up care program for childhood cancer survivors. The program will:

- provide regular contact with a health care team. This team is specially trained to understand cancer and its treatment.
- try to find and treat any problems you may have as soon as possible. These include:
  - health
  - social
  - and psychological problems
- provide on-going health care
- give you up-to-date information about different cancer survival topics
- provide referrals to other services (as needed)

How will the program help?

When you participate in an AfterCare program, you help yourself and other childhood cancer survivors. The program is designed to:

- protect your health
- improve the quality of your life
- and prevent disease

Being in the program can help us increase our knowledge about the long-term health of cancer survivors.

Going to just 1 AfterCare appointment a year could reduce the side-effects of your cancer treatment and help you stay healthy.
When can I join the program?

You can join the program 2 or more years after your final cancer treatment or after at least 4 years from your diagnosis.

What happens when I’m ready to join the AfterCare program?

We will give you information about how the AfterCare program works and who will be on your AfterCare team. You can then make an appointment for your first visit.

We will review your medical and treatment history to help plan your AfterCare needs. Your health care team will meet to develop a plan and arrange any required tests.

As part of the AfterCare program, you will receive a Passport to Health. This is a wallet-sized card that lists all the important details of your medical history and treatments.

What happens at the appointment?

- You will meet with a health care team who are experts at helping childhood cancer survivors.
- We will write down your medical history and use it to design a follow-up plan for you. Your plan will include:
  - medical tests to check for any problems
  - referrals for any medical or psychosocial specialists you may need to see
  - strategies to help prevent late side-effects of your cancer treatments
- If you are interested, we can help you find other information or meet with other survivors and their families.
- We will ask you to fill out a questionnaire. Your answers to this list of questions will help us plan your future care. Also, the information gathered from the questionnaire will help us with our research about health and late side-effects of childhood cancer survivors.

Note: AfterCare appointments may take between 1 to 4 hours.
Will you tell me my test results?

Yes. You can also call us to find out results that weren’t ready until after your appointment. We will also send updates to your family doctor.

If the tests show something is not normal, we will ask you to come back for further tests or treatment.

How often should I come to appointments?

You will have a check-up either once a year or once every 2 years. This will depend on your cancer treatment risk factors.

What if I have health concerns between visits?

If you have any questions or concerns, call:

Mona Pedlar, Coordinator of the Pediatric Cancer AfterCare Program

Telephone: 416-946-2121
Fax: 416-9464586

What about research studies?

We will ask you if you will let us add your health information to a provincial research record. We will not add your information without your permission. But if you let us, you will be helping us to:

- improve care by focusing on important research areas
- plan changes to cancer treatment for future childhood cancer patients

You will not be identified in most of the information we collect. Information that could identify you will be separated from the data used in these studies.
Follow-up contact with you or adding your health information from other health records and databases could really help certain research studies. When we do need personal information, researchers will first ask for your consent (agreement) and approval from the Hospital Research Ethics Board.

**Where can I find an AfterCare Program?**

**Toronto**

Princess Margaret Cancer Centre
 Telephone: 416 946-4501, extension 2127

The Hospital For Sick Children
 Telephone: 416-813-8321

**Hamilton**

Children's Hospital, Hamilton Health Sciences
 Telephone: 905-521-5014

**London**

Children's Hospital of Western Ontario
 Telephone: 519-685-8500, extension 52192

**Kingston**

The Cancer Centre of Southeastern Ontario at Kingston General Hospital
 Telephone: 613-544-2631, extension 6625

**Ottawa**

Children's Hospital of Eastern Ontario
 Telephone: 613-737-2470
 Website: oncologyaftercare@cheo.on.ca

The Ottawa Hospital Regional Cancer Centre
 Telephone: 613-737-7700, extension 70294
Ontario’s Childhood Cancer AfterCare Program is a project of POGO: The Pediatric Oncology Group of Ontario.

Learn how to protect your health. Participate in an AfterCare Program.

Provincial Pediatric Oncology AfterCare Program

📞 Telephone: 416-592-1232
✉️ Email: info@pogo.ca
🌐 Website: www.pogo.ca

Through POGO, all of Ontario's childhood cancer program partners work together to protect the health of survivors of childhood cancer into adult life.

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