

## WHAT ABOUT RESEARCH STUDIES?

AfterCare clinics will record information about their patients to be included in a provincial research record. None of this information is identifiable. If we need to provide information that could identify your child for a research study, a Research Ethics Board would have to approve it, and we will ask your permission. We will not do this without 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 separated from the data used in these studies.

Some research benefits greatly from a follow up contact with survivors, or from the addition of patient health information stored in other health records and databases. When we do need personal information, researchers will seek your consent.

## **LEARN HOW TO PROTECT YOUR CHILD'S HEALTH.**

### **PARTICIPATE IN AN AFTERCARE PROGRAM**



## WHERE TO FIND AN AFTERCARE PROGRAM

### **Kingston**

Cancer Centre of Southeastern Ontario  
at Kingston General Hospital  
613-544-2631 • Ext. 6625

### **Hamilton**

McMaster Children's Hospital,  
Hamilton Health Sciences  
905-521-5014

### **London**

Children's Hospital of Western Ontario  
519-685-8500 • Ext. 52192

### **Ottawa**

Children's Hospital of Eastern Ontario  
613-737-2470  
The Ottawa Regional Hospital Cancer Centre  
oncologyaftercare@cheo.on.ca

### **Toronto**

The Hospital for Sick Children  
416-813-8321  
Princess Margaret Hospital  
416-946-2127

The provincial network of AfterCare programs for survivors of cancer in childhood is the result of support and funding from Ontario's Ministry of Health and Long Term Care (MOHLTC).

Provincial Pediatric Oncology AfterCare Program  
(416) 592-1232  
info@pogo.on.ca • www.pogo.ca  
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## **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 follow-up care program for your child. AfterCare provides 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 child's health. The health care team is trained to:

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

## WHAT ARE THE ADVANTAGES FOR MY CHILD OF ATTENDING THE AFTERCARE PROGRAM?

When you participate in an AfterCare program, you help your child and others because:

- AfterCare arranges services your child needs such as neuropsychology testing, dietary consultation, etc.
- The program keeps you up to date on new information about childhood cancer and those who survive it.
- By participating, you can contribute to our growing knowledge base about the long-term health of survivors.

## WHO SHOULD ATTEND AFTERCARE CLINICS?

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

## WHAT HAPPENS WHEN MY CHILD PARTICIPATES IN THE AFTERCARE PROGRAM?

One or more years (as indicated by your child's oncologist or clinic nurse) after active treatment ends, you will receive 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.

There will be an interview and assessment, to collect information about your child's health and treatment, in order to help plan your child's AfterCare needs. Your child's health care team then meets to develop a visit plan and arrange any required tests.

When your child transfers to an adult AfterCare clinic he/she will receive a new 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?

You should expect to bring your child 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 give your child a clinical assessment, arrange required tests, and refer for required treatment. You will be welcome to discuss any concerns with the experts.

You may also gain access to other information of interest, and opportunities to talk to other survivors and their families.

We ask teens, adult survivors and parents to fill out a questionnaire providing information essential to planning future care, and to our research on survivor health and late effects. AfterCare visits may take 1-4 hours.

## WILL WE BE TOLD TEST RESULTS?

Yes. We also send them to your family doctor. If the visit shows something is not normal, we may ask you to bring your child to the clinic for further assessment or arrange referral to an appropriate resource or 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: \_\_\_\_\_

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AfterCare Clinics are a project of POGO, the Pediatric Oncology Group of Ontario. Through POGO, all of Ontario's childhood cancer program partners work together to protect the health of survivors of childhood cancer into adult life.

