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Background:

- CAPO Education Committee identified gap
- Targeted to Educators and Health Care Providers
- Expert subcommittee formed
- In partnership with and funding from de Souza
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• LeftRight Strategic Learning Consulting
Why is mommy losing her hair?

We know that the effects of cancer in the family are many; we know that most individuals and families benefit from some measure of emotional, psychological, spiritual and practical support. This resource is a guide for health care professionals and educators to support children and teens when a family member has cancer.

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This resource has been developed by the Canadian Association of Psychosocial Oncology (CAPO) with support from the de Souza Institute.
Overview

• You be able to apply learning from the modules into practice
• You can choose between two parallel streams – Educator (School based) and Health Care Provider – depending on your role
• Offers strategies, tools, tips and examples considering the different aspects of these roles and their capacities to help
Some Guiding Principles

1. Family as a unit
2. Support the parent(s)
3. Each family is unique
4. Family needs and involvement may change as the family goes through the illness trajectory
5. You will not be able to ‘fix’ all of the problems that the child and family face
6. Be realistic about what you can do and how you can provide support
7. “Small things” can make a difference
Dad is sick, is it my fault?

Learn more

The Canadian Association of Psychosocial Oncology (CAPO) is an organization of clinicians, researchers, educators, and others dedicated to the understanding, treatment and study of the social, psychological, emotional, spiritual and quality of life aspects of cancer.

CAPO has partnered with the de Souza Institute to create an engaging e-learning resource to guide health care professionals and educators to support children and teens when a family member has cancer. We know that the effects of cancer in the family are many; we know that most individuals and families benefit from emotional, psychological, spiritual and practical support.

The resource is divided into four modules. Each module takes about 15 minutes to view. We encourage you to navigate through the modules as you wish to find the information you need.

Module 1: What is Cancer

This resource begins with a basic introduction to cancer as a disease and the psychosocial impact it can have on children, teens and families. This information is intended for those who do not work in cancer care (such as teachers, coaches, or nurses and other health care providers working with other populations) and would like to know more about cancer.

What is Cancer?

- What are the basic characteristics and terminology of cancer
- What are the phases of cancer
- What are the common physical and psychological effects at each phase of disease
This resource has been developed by the Canadian Association of Psychosocial Oncology with support from the de Souza Institute.

Module Viewing Tips

The modules are best viewed in Full Screen mode. This command can be found in your browser menu.

To navigate between modules, use the back button, found in the top left corner of you browser.

The modules contain audio segments, so please ensure that your computer’s speakers are turned on and that you can adjust the volume as required.

Module 1: What is Cancer

This resource begins with a basic introduction to cancer as a disease and the psychosocial impact it can have on children and families. This information is for those who do not work in cancer care (such as teachers, coaches, personal support workers, cardiac nurses) and would like to know more about cancer.

Module 2: Children’s and Teen’s Responses to Cancer in the Family

This module will increase awareness of the common responses children and teens may have to cancer in the family. We present the most current knowledge about effective ways of providing support at all phases of the cancer trajectory, including when a family member dies.

Module 3: Preparing to Help

This module addresses how educators and health care professionals can support children and families, given that all families are unique and face different challenges. This resource is not intended as a course in counseling children or families but in helping educators and health care professionals consider the boundaries of their role in providing basic support.

Module 4: Communicating and Providing Support

This module provides two separate ‘streams’ of information, one for educators and one for health care professionals. The module offers practical tips and suggestions about what you can do to actively support children and teens through a family member’s illness, how to talk with children and teens, and how to support children and...
Module 1: What is Cancer

- What are the basic characteristics and terminology of cancer
- What are the phases of cancer
- What are the common physical and emotional effects of each phase of disease
- How social factors shape family and individual experiences with cancer
This resource has been developed by the Canadian Association of Psychosocial Oncology with support from the de Souza Institute.
What is Cancer?

Click on the numbers below to learn how cancer forms.

1. CELLS
2. TUMOURS
3. CANCER

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### What is Cancer?

**Q:** Which of these do you think is TRUE and which is FALSE?

- **TRUE** Cancer is contagious
- **FALSE** Cancer can be caused by negative thoughts or anger toward the ill person
- **TRUE** Cancer is a death sentence

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Depending on the type and stage of cancer, oncologists will recommend a course of treatment. The goals of treatment vary according to the stage and grade of the cancer, for example, cure, long-term control, or symptom control in cases where a cure or control of the cancer is not possible.
Module 2: Children’s and Teen’s Responses to Cancer in the Family

• What are common responses?
• What are effective ways of providing support?
Supporting Children and Teens When a Family Member Has Cancer
A Guide for Educators and Health Care Professionals

Children's and Teens' Responses to Cancer in the Family

Diagnosis
Treatment
Survivorship (The "New Normal")
Recurrence or Metastases
Advancing Illness and Dying
Death and Bereavement

Click the images to learn about needs and concerns of children and teens during the different phases of the family's experience with cancer.

What is Helpful to Children and Teens?

This resource has been developed by the Canadian Association of Psychosocial Oncology with support from the de Souza Institute.
What Teens Understand

Teens are able to understand the complexities of disease, illness, and death in ways similar to adults.

Quote from Brandon, age 15:

"After Mom got cancer, I got mad at everything. It wasn't fair that I had to watch my little brother and clean. I felt like I was going to lose it, but tried to stay cool and told my mom how hard things were. Now I still have chores, but my little brother goes to a friend's after school, so that I can go to soccer. My mom's awesome. She really understood."
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Module 3: Preparing to Help

- How can educators and health care providers support families?
- What are the boundaries in your role in providing support?
Prepared by

A formerly enthusiastic student appears withdrawn
A young child lingers behind
A teacher has asked you to meet with a student
A child in your nursery school has just experienced a death
Preparing to Help

Professionals often feel that they must know the correct things to do and say, or exactly what actions to take. However, understanding and helping a child or family can be extremely complex. It is important to know your own limits and to have realistic expectations about how you can help.

Your Role

Encourage parents to communicate openly about cancer with their children and suggest resources that can help them do so. That's right. If you are in a position to discuss this with the parents, this is an appropriate thing to do.

Guide or refer a child or family member for help as needed. That's right. If the family requires help in areas beyond the scope of your role, it is important to refer them to other services.

Not Your Role

Answer a child or teen's questions about the illness in an area in which you are not a specialist. That's right. You can refer a child or teen to another health care professional whose scope of practice and responsibilities better position them to answer the questions.

Share information that is new to the child without the parents' knowledge. That's right. You can always seek approval from the parents or guardians before you share new information.
Preparing to Help

In addition to the help you provide, families need to know what other resources exist. At times, your role may be to ensure they make those connections, especially when you can see the family struggling.

All families benefit from information about how to access cancer-specific counseling offered through the local cancer centre or hospital. Available professionals may include social workers, psychologists, spiritual care workers, specialty nurses, and specially trained volunteers. Don’t assume the family knows about these services. Many cancer centres have support programs for children and teens who are dealing with cancer in the family. Staff can also direct you to services available in your community. Even if the family chooses not to access these programs, the specialists working within these programs are available for consultation to you. Do not hesitate to call.

Click on each of the images to learn more.
Module 4: Communicating and Providing Ongoing Support

“I am afraid that I may say or do something that will upset the child or family.”
Communicating and Providing Ongoing Support

Quote from an Oncology nurse:

"That's the thing I'm most afraid of, causing conflict in the family by saying the wrong thing. The family's going through enough already."
What you can learn in this module:

1. How to open and maintain communication with the family
2. How to assess the family’s needs
3. Ways to support children and teens in educational and health care settings
4. Suggestions for helping children and teens prepare for and cope with death
Opening and maintaining communication with family and assessing needs:

Effective support begins with parents
- How to open a conversation with parents
- Examples of questions you can use
- Some ways that you can respond
Communicating and Providing Ongoing Support

Educator

Health Care Professional

Both are well positioned to provide support to children

Explore Support Role
Considerations for Specific information for Educators:

1. Educators have an ongoing role as a daily part of the child’s life
2. More likely to have background knowledge of the child
3. May be familiar with the child’s personality, interests, etc, as well as the family’s strengths and challenges
4. In a better position to support the child academically and with extracurricular activities and interests
5. Less likely to be in a position to answer health-related questions
6. School can provide opportunities for normalcy, routine and healthy sources of diversion and social support
Considerations for Specific information for Health Care Providers:

1. Most likely new in the child’s life and may see the family only during this time of intensified stress
2. In a unique position to support parents and children by answering questions, within the scope of their roles, and to prepare parents to speak with their children about illness
3. Depending on their role and situation, they may also be able to respond more directly to children’s concerns or responses (physical, psychological, emotional, spiritual)
4. Inpatient, treatment and outpatient visits
Communicating and Providing Ongoing Support

Once the family has indicated that they are comfortable with your involvement and support, there are four key areas where you can take action.

1. Maintain Communication Within The Health Care Team
2. Learn about the Family
3. Support The Parents In Being Open With Their Children
4. Be Familiar With Resources You Can Access

Click here for more guidance on how to take action in these four key areas.
Helping Children and Teens Prepare for Loss and Grieving and When a Family Member Dies:

1. Explaining death
2. Encouraging communication
3. Respecting family’s approach
4. “Red Flags” – when to seek professional help
5. Information for educators and health care providers about actions they can take
Helping Children and Teens Prepare for the Death of a Family Member and Supporting Grieving Children and Teens:

Mount Sinai Hospital Materials

• Supporting Grieving Students in School
• Talking with Young People About Illness and Dying
• Attending Funerals, Memorials and Other Rituals
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What support do we have at BCCA?

- Patient and Family Counselling Services at each of our cancer centres
- Children’s Support Groups and Parent Group
- BCCA website – Coping with Cancer (Fact sheets)
- [www.cancerinmyfamily.ca](http://www.cancerinmyfamily.ca) website
- A Guide for Parents: Reaching Out to Your Children When Cancer Comes to Your Family (Online bookstore)
- Time for Me Booklet for children and parents (Online bookstore)
- Up and coming – Teen site