Module « Parlons-en » – Soutenir les enfants et les adolescents qui ont un proche atteint de cancer

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Outline

• Challenges and Educational needs of Oncology Nurses
• International and Canadian Statistics
• Children’s development and response
• Challenges
• Research current and past
• Recommendations for support of children and their families
• Presentation of Rossy Cancer Network project:
  – The Start the Talk Modules
• Some other resources
Acknowledgements

• Members of CAPO Education Committee who developed the “Start the Talk” modules. including
  – Andrea Warnick, RN, MSc, Grief Counselor
  – Linda Corsini, Social Worker, Ottawa, Ontario

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• Valerie Lok, BScN student, Ingram School of Nursing and Junior Assistant McGill University Health Centre
• Asma Compaore, BSc. Student, Sciences infirmières, Université de Montréal
Challenges and Educational needs of oncology nurses

• Limited knowledge and professional training;
• Fear of making things worse;
• Lacked confidence in their communication skills;
• Nurses felt burdened when unable to respond to families’ needs;
• Wanted support in relation to the emotional strains of working in oncology.

### Barriers & Educational Needs for Oncology Nurses when providing Psychosocial Care

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<tr>
<th>Barriers to Psychosocial Care</th>
<th>Educational Needs</th>
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<tr>
<td>• Time</td>
<td>• Confusion about clinical guidelines</td>
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<td>• Nurses’ lack of emotional energy</td>
<td>• Not knowing how to approach sensitive topics</td>
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<tr>
<td>• Lack of experience with screening tools</td>
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<td>• Poor communication among team members</td>
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<td>• Lack of patient privacy</td>
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Parental cancer is more common than previously suggested:

- Annual incidence of parental cancer for children under 18 years of age is 0.3%

- Approximately 4% of children aged 0–25 years have or have had parents diagnosed with cancer, corresponding to a population prevalence of 1.4%.
  - Around 20% of these children experienced parental death

About cancer patients with children and adolescents

- At least 18% of cancer patients diagnosed in past 2 years, and 14% of all cancer survivors, are parenting minor children.

- More than 1.5 million cancer survivors have close to 3 million children at home and that more than half a million of these children are living with a parent in the early stages of cancer treatment and recovery.


More than 40% of Canadians will develop cancer during their lifetime, and among them, more than 25% will die from their illness.

- 30% of new cancer cases and 17% of cancer deaths will occur in young and middle-age adults aged 20 to 59, in the critical period when they are raising their families.

- Cancer incidence is rising among young adults, particularly among women age 20 to 39 (Canadian Cancer Society’s Steering Committee, 2009).

- It has been estimated that 22% of women affected by breast cancer have children at home (Lewis, Casey, Brandt, Shands, & Zahlis, 2006).

Child Development and Response
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<tr>
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<th>PARENT’S POSSIBLE RESPONSES</th>
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<td><strong>Newborns/Infants/Toddlers</strong></td>
<td>Learning to Trust</td>
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<td></td>
<td>- focused on self &amp; on maternal caregiver</td>
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<td>- dependent on caregivers</td>
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<td></td>
<td>- do not understand time</td>
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<td>- do not understand illness</td>
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<td>- do respond to emotional states of caregivers</td>
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<td>Sense of Self</td>
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<td>- focused on parents as most significant relationship</td>
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<td>- can recognize differences between ‘I’ and ‘you’</td>
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<td>- moods fluctuate with adjustment to new situations</td>
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<td>- understanding is based on what they see directly</td>
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<td>- limited grasp of time</td>
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<td>- limited understanding of illness/treatment apart from what they see</td>
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<td>- may believe they can catch your illness</td>
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<td>- parents main focus</td>
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<td>- begin to state feelings</td>
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<td></td>
<td>- good at picking up on non-verbal information</td>
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<td>• Little awareness of illness.</td>
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<td>• Infants are aware of feelings parents show including anxiety.</td>
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<td>• Aware of periods of separation from parents.</td>
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<td>• Can get upset when loving parent is missing.</td>
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<td>• Toddlers may react to physical change in parent or presence of side effects (e.g. vomiting).</td>
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<td>• Provide consistent caretaking by maintaining baby’s schedule.</td>
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<td>• Ask family members and friends to help with household tasks and care.</td>
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<td>• Give plenty of physical contact (patting, hugging, holding).</td>
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<td>• Observe play for clues to their adjustments.</td>
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<td>• Provide daily contact to help them feel secure.</td>
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<td>• Express your feelings and fears with others.</td>
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<td>• Use relaxation tapes, music, or baby massage.</td>
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<tr>
<td>Preschool (3-5 years)</td>
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<td>Sense of Personal Responsibility / Guilt</td>
<td>• Beginning level of understanding about illness.</td>
<td>• Thumb sucking</td>
<td>• Talk about the illness with pictures, dolls, or stuffed animals. Read a picture book about illness.</td>
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<td>• Magical thinking: Children may believe that they caused the illness (e.g. by being angry with parents, thinking bad thoughts)</td>
<td>• Fears of the dark, monsters, animals, darkness, strangers, and the unknown</td>
<td>• Read about nightmares or other problems (e.g., There’s A Nightmare in my Closet).</td>
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<td>• Children may think they can catch the same thing.</td>
<td>• Nightmares</td>
<td>• Explain what they can expect; describe how things may change regarding routine, activities, and schedules.</td>
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<td>• Children consider themselves the center of the universe.</td>
<td>• Sleepwalking, Sleep-talking</td>
<td>• Reassure them that they will be taken care of and will not be forgotten.</td>
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<td>• They are egocentric and think everything is related to them.</td>
<td>• Bedwetting</td>
<td>• Provide brief and simple explanations. Repeat explanations when necessary.</td>
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<td></td>
<td>• Fear of separation from significant others (especially at bedtime or going to preschool)</td>
<td>• Stuttering</td>
<td>• Encourage them to have fun.</td>
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<td>• Aggression (e.g., hitting, biting)</td>
<td>• Baby talk</td>
<td>• Show emotion with some caution.</td>
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<td>• Hyperactivity</td>
<td>• Assure them that they have not caused the illness by their behavior or thoughts.</td>
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<td>• Apathy</td>
<td>• Paraphrase for children what their behavior might mean.</td>
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<td></td>
<td>• Fear of separation from significant others</td>
<td>• Continue usual discipline and limit setting. Provide outlets for aggression that are positive.</td>
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<td>• Be sure children get physical activity to use up excess energy and anxiety.</td>
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<td>• Assure them that they cannot catch the illness.</td>
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| **School Age Children (6-12 yrs)** | - They are able to understand more complex explanations of cancer diagnosis. Can understand what cancer cells are.  
- They still may feel responsible for causing illness because of bad behavior.  
- Nine years old and older understand that parents can die. | - irritable  
- sad, crying  
- anxiety, guilt, jealousy  
- physical complaints: headaches, stomach aches  
- separation anxiety at time of going to school or away to camp  
- hostile reactions toward sick parent, like yelling or fighting  
- poor concentration, daydreaming, lack of attention  
- poor grades  
- difficulty adapting to change  
- fear of performance, punishment or new situations  
- sensitivity to shame and embarrassment | - Use books, web sites to explain illness, treatment, and potential outcome (e.g., Our Mom Has Cancer).  
- Assure them that they did not cause the illness by their behaviors or thoughts  
- Reassure them about their care, routine & activities.  
- Tell them they are not alone: identify other adults who can offer them care  
- Let them know how they can help, give them a job  
- Take time to listen and let them know you care about their feelings.  
- Address issues of parent dying if children do not bring up topic. |

**Self Exploration & Turning Outward from family, school take on more importance**

- develop friendships  
- learn from peers  
- develop strong sense of morality (good and bad)  
- concepts of time and space are still developing (e.g. Time feels slower for them if you are away.)  
- likely to have heard of ‘cancer’ and may associate it with death  
- view illness in terms of how it affects their lives  
- may wish the other parent were the ill one

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<td>Teenagers (13-18 yrs)</td>
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<td>Attempts at Consolidation of Identity; Move towards Independence</td>
<td>They are capable of abstract thinking; can think about things they have not experienced themselves.</td>
<td>want to be more independent and treated like adults</td>
<td>Encourage them to talk about their feelings, but realize they may find it easier to confide in friends, teachers, or other trusted people.</td>
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<td>- peer groups, friendships are a main focus</td>
<td>Able to begin thinking more like adults.</td>
<td>anger and rebellion</td>
<td>Provide plenty of physical and verbal expressions of love.</td>
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<td>- romantic relationships become important</td>
<td>Able to understand that people are fragile.</td>
<td>may criticize how parents handle illness situation</td>
<td>Provide privacy as needed.</td>
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<td>- reasoning and abstract thinking capacity develops significantly</td>
<td>Able to understand complex relationships between events</td>
<td>depression</td>
<td>Encourage them to maintain activities and peer relationships.</td>
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<td>e.g. better understanding of cause and effect, serious vs. simple illness question the meaning of life</td>
<td>Able to understand reasons for symptoms</td>
<td>Anxiety</td>
<td>If problems are noted, provide opportunities for counseling.</td>
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<td>- see selves as “invincible”: believe that death won’t happen to them uncertainty about how to express and handle their strong emotions</td>
<td>More likely to deny fear and worry in order to avoid discussion.</td>
<td>worry about being different</td>
<td>Set appropriate limits.</td>
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<td>12-14: Quiet</td>
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<td>poor judgment</td>
<td>Don’t rely on them to take on too many added responsibilities.</td>
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<td>14-16: Self-focused, angry</td>
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<td>withdrawal</td>
<td>Provide resources for learning more about the disease and getting support.</td>
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<td>16-18: Greater ability to empathize &amp; make decisions based on others’ needs not just their own</td>
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<td>Apathy</td>
<td>Adapted from J. Hamilton, When a Parent is Sick, 2001</td>
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<td>physical symptoms: stomach aches, headaches, rashes</td>
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<td>more likely to turn feelings inward (so parents are less likely to see reactions)</td>
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Research: Past and Present
PARENTS (N=66) REPORTED CHILDREN’S QUESTIONS

- 64% Does it hurt?
- 41% Will you die?
- 36% How do you get cancer?
- 18% Would they get cancer?
- 18% Is it catching?

RESPONSES OF CHILDREN (6-18) TO A MOTHER’S BREAST CANCER

CHILDREN (7-10 YEARS)
• FEELINGS OF SADNESS, FEAR, AND LONELINESS WITH WORRY OVER THE INTEGRITY OF THE FAMILY UNIT

CHILDREN (10-13 YEARS)
• FOCUSED ON CHANGES IN THEIR OWN LIVES chores, responsibility, get along with rest of family

TEENAGERS
• WANT TO HELP THEIR MOTHERS AS WELL AS DO THEIR OWN THING

(Issel, Ersek, & Lewis, 1990)
Behaviour Changes: Possible Symptoms of Distress

- Young Children & Pre-Adolescents
  - Loss of toilet training
  - Night terrors
  - Refusal to sleep alone
  - Withdrawal from peers and playing
  - Academic skills
  - Aggression
  - Appetite disturbance
  - Stealing, fire-setting

- Adolescents
  - Stealing
  - Running away
  - School performance
  - Drug abuse
  - Promiscuity
  - Withdrawal from friends and family

Wellisch, 1981
Is early stage parental cancer associated with an increased risk of psychosocial difficulties amongst children and adolescents?

• Overall, evidence suggests children and adolescents do not generally experience elevated levels of serious psychosocial difficulties compared to reference groups, but they are at a slightly increased risk for internalising type problems.

• Adolescent daughters appear to be the most negatively affected group.

IMPACT ON CHILDREN and ADOLESCENTS

• Adolescents = **group most susceptible to negative psychosocial outcomes** when faced with a parent’s illness
  – Findings suggest that adolescents dealing with parental cancer demonstrate **greater anxiety, depression, and emotional distress** than school-age children
  – Developmentally, adolescence creates fundamental changes in the family structure as youth strive for increased autonomy.

• Adolescents express a need for information and support related to their parent’s cancer.
  – A lack of this support is consistently associated with negative psychosocial adjustment

• Recurrence of parental cancer has been associated with **high rates of distress and stress** response symptoms (SRS) in adolescents
IMPACT ON CHILDREN and ADOLESCENTS

- Children whose parents were receiving treatment for advanced cancer reported:
  - significantly higher levels of depression, anxiety, and lower self-esteem than peers (Siegel et al.)
  - In a follow-up study, Siegel et al. found that children’s levels of depression and anxiety prior to their parent’s death were significantly higher than it was 7–12 months after the loss of their parent.

- Adolescents living with a parent’s advanced cancer showed significantly higher levels of distress and depression compared with the general population (Rainville et al.)

- Depressive mood or negative affect in the parent with cancer is associated with emotional and behavioral problems in children

- Behavioral problems were also reported in children by parents who did not have open communication styles.

How children coped when parent had advanced cancer?

- Children described being distressed by their parents diagnosis and having concerns related to their parents and their own health.

- Parents did not recognise the impact on children to the same degree as described by children and focused on limiting the impact by maintaining normality.

Are there differences in reactions if child facing parental cancer versus parental death?

- Youth dealing with parental cancer exhibited lower levels of PTSS than children who had experienced the death of a parent, but both groups exhibited similar levels of anxiety and depression.

- Expressive coping was associated with lower levels of PTSS, anxiety, and depression across both groups. An interaction effect revealed that for the bereaved group only, positive parental reinforcement and supportive caregiver communication were inversely associated with PTSS.

Family Functioning in Families of Palliative Cancer Patients

• Between 15% and 36% of family members reported problems with family general functioning
  – Parents indicated more problems with Roles
  – Adolescents reported problems with Communication

• For adolescents with parents in palliation, incidents because of the disease tend to become more dominant, and spending time with the family tends to become even more important.

Positive Gains

Evidence of resilience or protective factors that have led to positive outcomes for these families dealing with cancer.

• Parents and children reported a greater sense of appreciation for their family and a sense of ‘being grateful for what they have’.
• Many adolescents seemed to search for meaning in the cancer experience as a way to cope and maintain hope.
• Parents also reported witnessing positive outcomes in their children such as increased independence, learning to prioritize, and improvements in relationships with family members.
• Learning how to care for others, being prepared for adult life, and learning to appreciate their family.
• Parents and adolescents spent more time together, increased intimacy, and continued to foster a sense of attachment after the parent’s death.

References
Recommendations to Support Children and Adolescents

• Be honest
• Use simple and correct language
• Foster an environment so the child can ask questions
  – Did I cause it?
  – Can I catch it?
  – Can I cure it?
  – Who is going to take care of me?
  – Anything else on their mind?
  – Also about routines?

• Be prepared to not have answers and explore possibilities and/or help them find someone who may have an answer
• Jill Taylor-Brown MSW, RSW, Project Lead, CancerCare Manitoba
• Linda Corsini MSW, RSW, Ottawa Hospital Breast Health Centre
• Mary Jane Esplen PhD, RN, de Souza Institute, University of Toronto and University Health Network
• Joan Hamilton RN, BN, MSc(A)N, QEII Health Sciences Centre, Halifax
• Laura Labelle PhD, R.Psych(Provisional), Tom Baker Cancer Centre, Calgary
• Andrea Laizner PhD, RN, McGill University Health Centre, Montréal
• Gina MacKenzie MSW, BC Cancer Agency
• Deborah McLeod PhD, RN, QEII Health Sciences Centre, Halifax
• Shane Sinclair PhD, Spiritual Care Specialist (CASC), Tom Baker Cancer Centre, Calgary
• Andrea Warnick MA, BScN, Mount Sinai Hospital, Toronto
• CARDINAL CONSULTANTS (Laura Cleghorn and Jennifer Nelson)
• LeftRight Strategic Learning Consulting
The Rossy Cancer Network Funds Quality Improvement Initiatives

• The « Start the Talk » project is part of quality improvement initiatives funded by the Rossy Cancer Network (RCN), which were created to empower health care teams within the network and improve patient care.
PROJECT GOAL:
Increase patient awareness and accessibility to information to communicate about cancer with people who are close to them (especially children)

OBJECTIVES:
- Increased access to modules
- Increased awareness
  - Patients
  - Information gate keepers

STRATEGY/INTERVENTIONS:
- Create links on RCN sites web pages
- Remove password/log-ins on CAPO webpage
- Translate STT modules in French
- Dissemination tools (bookmarks, pamphlets...)
- Dissemination (workshops, lunch and learn conferences...)
  - Patients’ resource centers
  - Available on screens (waiting areas...)

OUTCOME INDICATORS:
- # of patient hits on STT page
- AOPSS satisfaction % in the “information domain” (questions 62, 63 and 67)
- % of patients’ awareness
- % of health care providers’ awareness
Funding Initiatives to Improve Quality of Patient Care within the Rossy Cancer Network

• This project is a collaboration between RCN institutions.

• The goal is to increase access and awareness of resources developed to help patients diagnosed with cancer to talk about this difficult topic with their children and those close to them.

• In 2014, the AOPSS found:
  Only 24.3% of patients reported having received enough information about changes in relationships and 33.8% reported having received enough information about changes in emotions. Results indicate a gap in the health care teams’s ability to provide support in this area.

| Question 62.3 : Did you get the help you wanted to cope with social/family issues |
|---------------------------------|-----------------|-----------------|
|                                  | YES             | BLANK           |
| SMH 2014/15                     | 9.2% (n=8)      | 90.8%           |
| MUHC 2014/15                    | 7.9% (n=13)     | 92.1%           |
| JGH 2014/15                     | 4.1% (n=7)      | 95.9%           |

| Question 67 : In the past 6 months, has someone at ___ put you in touch with other care providers who could help you with anxieties and fears |
|-------------------------------------------------|-----------------|-----------------|
|                                  | YES             | NO              | I HAD NO ANXIETIES OR FEARS |
| SMH 2014/15                         | 28.0% (n=21)    | 22.7%           | 49.3%            |
| MUHC 2014/15                        | 28.1% (n=45)    | 28.8%           | 43.1%            |
| JGH 2014/15                         | 32.7% (n=52)    | 22.0%           | 45.3%            |
The Modules

• What is the Canadian Association of Psychosocial Oncology (CAPO)?

• Impact of cancer on the family

• Individuals and families benefit from emotional, spiritual and practical support

Gingerbread Man - Teen
Objective of the Modules

• Increase awareness about the reactions of children and teens when dealing with cancer in the family

• Increase awareness about the different strategies that can be used to help across the cancer trajectory

• Help professionals know their roles and the recognize the boundaries of their roles of support

• Provide professionals with resources and strategies when working with teens
The website

- **Home page**
  - Details about the modules, informations about developers and rationale
- **Modules**
  - 15 minutes each
- **Ressources**
  - Oriented towards professionals, parents as well as children and teens.
- **Credits**
- **Help**
  - Contacts and tips
- **Feedback**
  - Your comments are importants!
Module 1: What is cancer

- An overview of cancer
  - Characteristics and treatments
  - Myths
  - Recurrence and palliative care
  - Psychosocial impacts
  - Social factors
  - Inequalities
Module 2: Children and adolescents

- Needs of newborns, infants and toddlers, school aged children and teens
- Reactions of young children and teens
- Strategies of response with these age groups
Module 3: Preparing oneself to help

- Each family is unique
- Guiding principles of support
- Our role
- Limits of social support
- When to refer?
- Taking care of self
Module 4: Communication and support

• Start with the parents
• Review the role of support and its boundaries
• Prepare for the possible death of the ill family member
• Support children and teens during periods of grief and loss
• Role of the professional in times of death
Conclusion

• A resource that can be used at diagnosis
• A resource that can help open the conversation …« start the talk » with your patients and respond to their needs
• It is possible that individuals and families can use this resource at their own pace
Responding to Parents’ Needs Other Ressources in Montreal, QC

- CanSupport
  - cansupport.ca
  - « Jouer ensemble: Un atelier de fabrication de masques en famille »
    - April 30th, 2016
    - Jennifer.finestone@muhc.mcgill.ca
- NOVA West Island
  - www.novawi.org
- Hope & Cope
  - hopeandcope.ca
- VOBOC
  - voboc.org
- West Island Cancer Wellness Centre
  - wicwc.com
Questions ?