



Website for Children When a Family Member is Diagnosed with Cancer

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-
- No conflict of interest to disclose



Today's Presentation

- Why we developed it?
- How we developed it?
- What is it?
- How is it being used?
- Next steps



www.cancerinmyfamily.ca

- Launched in August 2009
- 2009 Canadian Applied Arts Interactive Award, Educational Category



Why did we develop a website?

- Cancer impacts children in a family
 - 30% of new cases and 17% of cancer deaths in Canada occur in young and middle-aged adults (20-59yrs) – JRobinson & LLabelle (Environmental Scan Report on Programs for Kids whose Parents have Cancer – 2010)
- Face to face programs are not readily accessible and/or acceptable to many
- Web is 'kid friendly'
- Resource for professionals working with families who have young children



How did we develop it?

- Interdisciplinary team
 - Mix of clinical and website/multimedia
- Defined our audience
- Literature review from 3 perspectives
 - Oncology
 - Child development – cognitive & learning
 - Digital behavior of children
- Current program review
- Defined objectives
- Designed website and Tested
 - Children & adults



Website Project Team

- Content (BCCA)
 - Carly Fleming, MEd, Counselor
 - Karen Janes, RN, MSN, Regional Professional Nursing Practice Leader
 - Gina MacKenzie, MSW, Provincial Director, Psychosocial Oncology
 - Susanna Ruebsaat, BFA, T.Ed, DVATI, MA, Art Therapist
- Website (BCCA &PHSA)
 - Ruth Hartnup, BCCA & PHSA, Specialist Web Communications
 - Hilary Horlock, User Experience, PHSA Web Strategies
 - Yvette Smith, Former PHSA Web Strategies & Communications
- Design
 - Fjord design team, including project management (now known as DARE)
- MultiMedia (BCCA)
 - Jane Rowlands, Graphic Artist, Medical Illustration
- Communications (BCCA)
 - Nicole Adams, Former Director



Who is this for? – Phase 1

- **Primary:** Children ages 6 to 12.
- **Secondary:** Parents, grandparents, aunts and uncles (adults), who are looking for tools to help child(ren) communicate and understand about cancer.
- **Tertiary:** Health care professionals who can use this site as a learning tool for dealing with children and families that are living with a chronic illness. Others working with children, eg, school based personnel.



Literature Review: Learning Characteristics of Children

- Need a **safe** space in order to explore their feelings
- Looking to find answers to the questions they are **afraid to ask**
- Respond to more **visual** versus words
- **Interactive**, less intellectual
- Motivated by **fun**, interaction and desire
- Like to **physically interact** with their world

From Fjord Research



Literature Review: Digital Behavior of Children

- Very **comfortable** with computers
- **Access** Internet from home and school
- Use computers as both an **educational tool** and entertainment resource
- 58% of 8 – 12 yr olds reported spending at least 1 hour **online per day**
- Top online activities for 8-10 yrs are: online **games** (79%); **school research** (67%); hobbies/interest search (51%); email (46%); listen to music (33%); IM chat (18%)

Research from Fjord



Review of Current Program Activities

- Individual, couple and family **sessions**
- Children and Parent Support **Groups**
- **Education** Materials
 - Activity booklet – "*Time for Me*" (J Slakov, K Janes)
 - Parents' Guide – "*Reaching Out to Your Children When Cancer Comes to Your Family: A Guide for Parents*" (J Slakov)
- **School** based workshops/consultations
- **Web** based education – Coping with Cancer section of the BC Cancer Agency website (www.bccancer.bc.ca)

Time for Me



An activity book for kids when
someone in the family has cancer

by
June Slakov
Karen Janes



BC Cancer Agency
CARE & RESEARCH

Contents

Chapter 1	About Me.....	1
Chapter 2	About Cancer and its Treatment	7
Chapter 3	About Family.....	26
Chapter 4	Feeling Better	40
Last Page	Your Comments	50





Underlying Conceptual Themes

- **Therapeutic** but not therapy
- **Holistic**
- **Expressive** modalities
 - 'Kids like to do; adults like to talk'
- **Learning** focused
- **Personalized** journey experience
- 'Cancer is a **family** affair'
- Builds on **strengths** and builds confidence
 - Kids will feel strong enough to take action



Website Objectives – Content/Support

Children can learn:

- that other families are going through a similar experience.
- coping skills through interactive, expressive and playful activities.
- basic information about cancer and treatment (not meant to be a science course!).

To encourage communication in families.

To provide support for parents and others working with children.

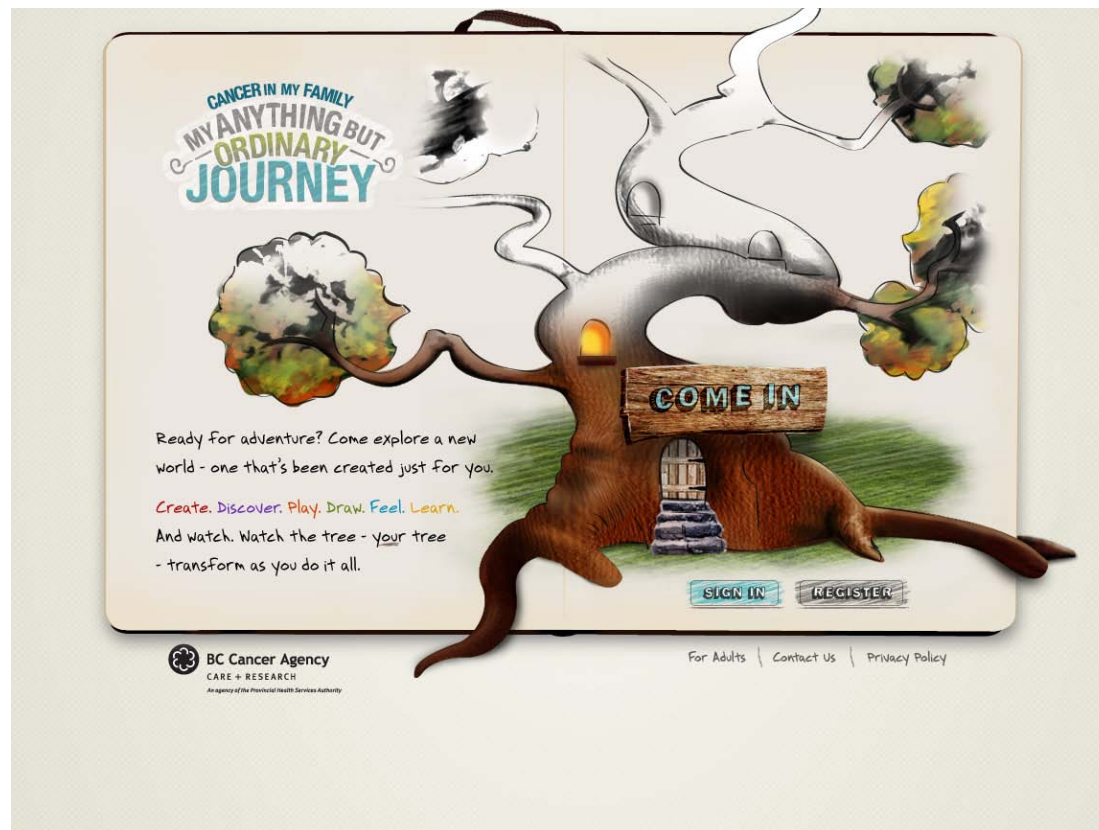


Website Design Objectives

- Kid friendly
- Kid focused learning
- Real time
- Safe
- Intuitive – easy to use
- You can go back to it again and again

Site overview - Activities

- Home tree





Key Messages in Site

- You are not alone
- It's okay to talk about cancer
- It's okay to express your feelings
- You can cope
- There is support for you
- You didn't cause your family member's cancer
- Your family member isn't to be blamed for their cancer

CANCER IN MY FAMILY
MY ANYTHING BUT
ORDINARY
JOURNEY

Create an EXPLORER to take on your journey.

HEADS

BODIES



Name your Explorer

OK



Explorer



Buddies



Weather



Journal



SIGN IN

EXIT



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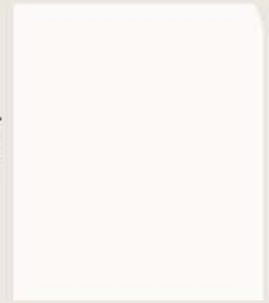
[For Adults](#) | [Contact Us](#) | [Privacy Policy](#)

CANCER IN MY FAMILY
MY ANYTHING BUT
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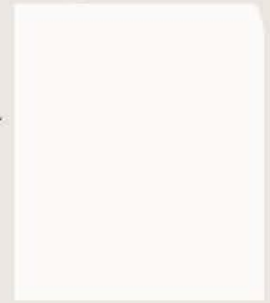
TRAVEL JOURNAL

Keep a travel journey of your adventure. You can start by printing off a cover and an "about me" page. Add pages as you complete activities.

FRONT
COVER



ABOUT
ME



OK



Explorer



Buddies



Weather



Journal



SIGN IN

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Site overview – Activity Examples

- Submarine
 - Matching game
 - Assuring messages related to cancer
 - There are no silly questions, etc.
- Rock Wall
 - Healthy and cancer cells
 - Children can draw each

Site overview – Expressive Art Activity

- Sandcastle







Parent's Section on the Site

- Overview of site
- Guidance about using the site
- Links to resources
- Recommended readings
- Download Parent's Guide/Pages from Time for Me



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Reaching Out to Your Children When Cancer Comes to Your Family: A Guide for Parents



by June Slakov

Chapter 1 – Finding Out About the Diagnosis

Talking with your children about your diagnosis

Why tell your children?

Why are children less anxious, and function better in the long run when they are told the truth?

- Your children will realize they can trust and count on you.
- It is not usually possible to hide a serious diagnosis.
- Secrets use up valuable energy.
- Your children can sense that something is wrong even when nothing is said.
- Your children are often more aware than you realize, and your teens are very observant.
- It is inevitable that your children will overhear something.
- When your children don't understand what is happening, they will likely become anxious.
- Without the truth, your children are likely to imagine something far worse.

It is natural to want to protect your children from distress.

Why would not telling the truth make things worse?

- Your children may feel excluded.
- While you may want to avoid your children's sadness, anger, or questions about death, there is a serious risk of losing your child's trust.
- Not telling the truth can lead to additional family stress for you to cope with.

When do you tell your children?

- As soon as you are able to do this, talk with your children.
- Give yourself time to absorb the news of your diagnosis. You may experience some of the following: shock, worry and fear for the future, guilt over lifestyle or diet or letting the family down, anger at this happening, sadness or grief.
- When you feel ready, talk with your partner or other adult support person about what you would like to say to your children.



Webtrends Data

August 2009 – May 2011

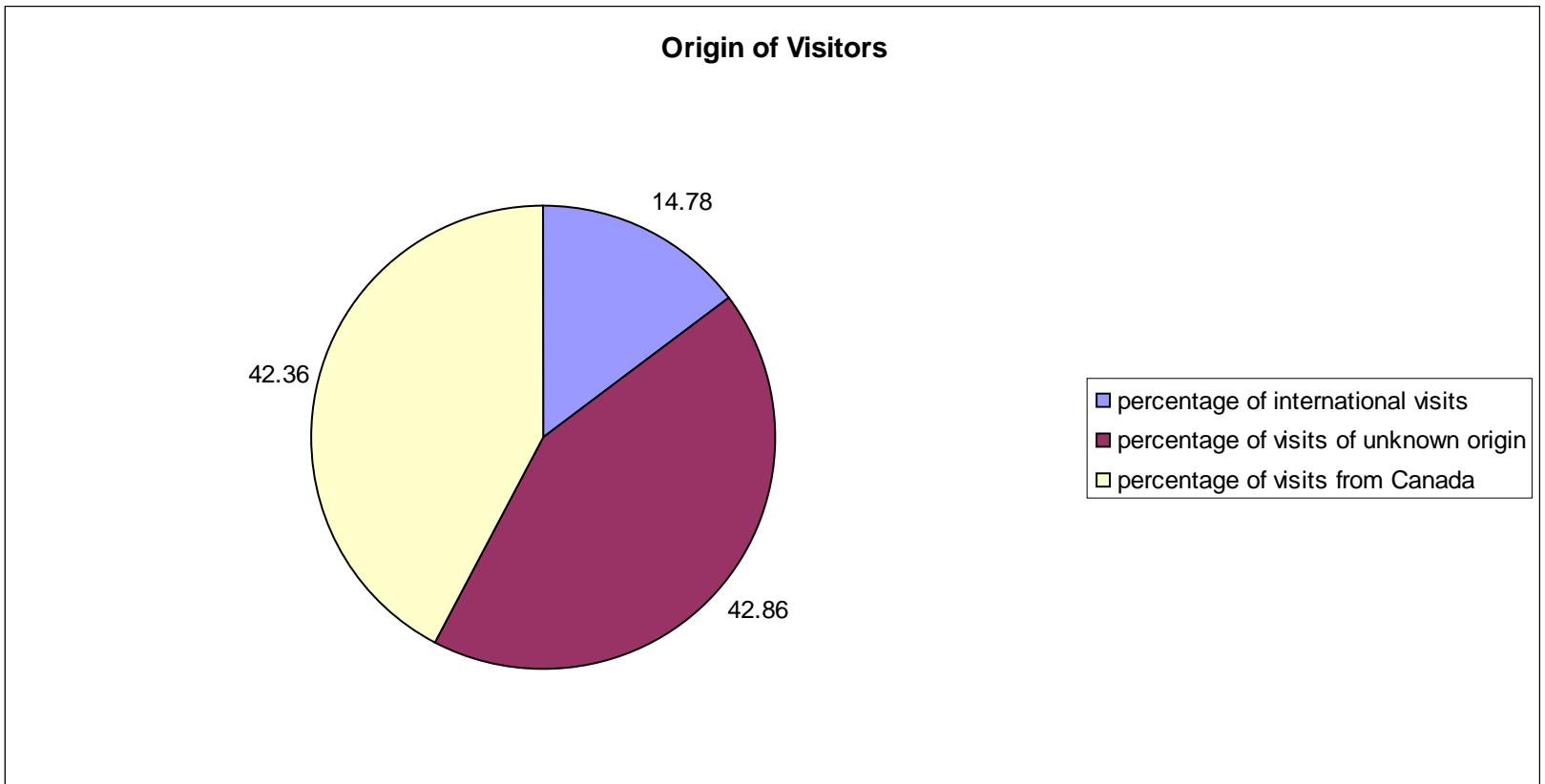
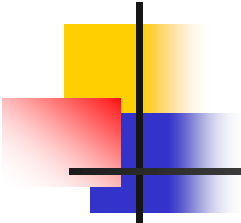
- Visitors per month – 262 average
- Visits per visitor – 1.30 average
- Duration of visits – 7.51 minutes average



Parents' Guide Downloads

- Downloads of Parents' Guide – 320.5/month/average
- Range - 30 to 1381
- 2011 Downloads
 - January – 234
 - February – 514
 - March – 921
 - April – 650
 - May - 1381

How is the website being used?





Next Steps

- Phase 1 is completed
- Phase 2 to be developed
 - Tweens and teens
 - Funding support
 - New sites



Acknowledgements

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