



The First Annual Childhood Cancer Parents' Educational Seminar, Workshop & Retreat

Harrison Hot Springs Resort & Spa – March 27th, 28th & 29th, 2009

(Sponsored in Part by: BCCCPA - Balding for Dollar\$ - BC Children's Hospital)

Group (Roundtable) Discussions Saturday March 28th, 2009

**Notes on material gathered during discussions which
were presented and discussed in an open forum -**

On the following subjects:

**Relationships
Financial Strategies
Stress Busters
Shortfalls & Opportunities
Beyond Cancer
Advocacy**

RELATIONSHIPS

(Group presenter: Susan Kerr)

***Note – Although I really enjoyed this discussion and my group agreed on the opinions shared, I realize that this is a very personal topic. The opinions expressed may or may not relate to everyone else's journey.**

- 1) **Husband and Wife put aside their own relationship.
Focus on tasks to be done.**

When a child is seriously ill, the relationship between the partners is put aside, evolves, or disintegrates. Coping abilities are put to the test as well as the ability to understand the different stresses of each partner, especially if they are providing support in different ways. In most circumstances the partners are not together – one is usually with the child undergoing treatment and the other is at home taking care of sibling(s) and providing an income. The need to focus on tasks to be done is easier when a family has a good support network of extended family and friends to provide emotional, & if possible, financial stability. This benefits the entire family unit.

- 2) **Emotional needs are “shelved”.**

In some cases the emotional needs are put aside to better focus on the medical aspects of the disease - the need to be educated regarding medications, side effects, not to mention other scenarios that may or may not happen. This is a huge output of energy and worry, and emotional needs are sometimes better off “pushed under the rug”. I think that at some point it is beneficial to access the emotional needs, understanding that everyone has a different time frame for this undertaking.

- 3) **Time should not be wasted on trivial things (minor misunderstandings).**

***Easier said than done when your family is under the most stressful of circumstances, but time in itself is precious. When the life of your child is an unknown, the minor misunderstandings seem unnecessary and unfortunate. These minor misunderstandings can also be stress related and not so trivial – not unlike the small earthquakes, providing relief and reprieve of the “big one”.
(Testing the strength of the relationship)***

- 4) **Men feel the need to “Fix” the situation.**

***Women focus on talking, validating, emotional needs.
In some cases there is frustration at the lack of control that the diagnoses of cancer brings about. Typically men like to be able to problem solve and “fix” things that have gone wrong. Women tend to seek emotional support through communications, even though these may not solve any one particular problem. This provides a sense of validation that the diagnosis is life altering and it is OK to be thoroughly changed by it.***

RELATIONSHIPS

(Continued...)

(Group presenter: Susan Kerr)

5) **Stage of pre-existing marriage relationship impacts post diagnoses'.**
Chances are that if a marriage is rocky to begin with, the added stress of a childhood cancer diagnoses will destroy it completely. I am sure there are situations that a sick child will bring a couple closer – forcing them to work together as a team. Other factors would definitely be important as well – alcoholism, drug abuse – these pre-existing problems would certainly be tested along with the diagnoses, challenging the marriage further.

6) **Gained through this experience:**
an appreciation for life (living in each moment).
To live each moment in the moment is the ultimate gift. Supporting a child through the diagnoses of cancer forces you to think moment to moment. Day to day is sometimes not an option. Our lives slow down, we think in terms of timing. Bloodwork, results, ANC counts, RBC counts, platelet counts etc. Days are definitely broken down and we embrace the good tests results, the moments we can go “out”, the times our child feels good enough to eat, the opportunities to go home for a while. The good moments with our sick children are definitely cherished with the knowledge that we may not have many more. Knowing that life is fragile, and it can be taken at any moment. Not just your child, but you become aware of your own life and what you have taken for granted.

7) **Lost through this experience:**

- a sense of safety, innocence
- loss of a piece of yourself
- loss of a parents' health

The life one leads prior to their child being diagnosed with cancer is a different life altogether. How we took things for granted, how we worried about trivial things, how we focused on insignificant “problems”.
The plain and simple knowledge that your child may lose his/her life through the diagnoses of cancer is a total loss of safety. Knowing families and being the family that has lost a child is a loss of innocence. A piece of yourself is lost through the worry, sadness, and fear. Through the stresses is a loss of health. How can we deny the fact that the lack of proper sleep, eating, and stress in itself leads to the destruction (at some level) of the human body. This is something the body has to withstand sometimes for years.

8) **Effective communication is important to avoid misunderstandings and feelings that the other spouse is not doing enough.**

FINANCIAL STRATEGIES

(Group presenter: Kellyann Clark)

- 1) **ISSUES:**
 - ~ credit card
 - ~ increased interest rate (rate needs to come down)
 - ~ job loss
 - ~ leave of absence
 - ~ compassionate care time – 6 weeks only (needs to be increased)
 - ~ relates to EI (employment insurance)
 - ~ long term disability (stress related) – affects medical insurance
 - ~ lone parent
 - ~ travel expenses
 - ~ childcare for siblings

- 2) **Short answer = NO**

Mortgage – BMO (ie., forgoing payments program – see Manager)
BCCCPA (British Columbia Childhood Cancer Parents' Association)
Consultant
Disability Tax Credit – Retroactive (approach Revenue Canada)

- 3) **NGO's (Non-Government Organizations)**
 - Children's Wish Foundation
 - Balding for Dollars
 - BCCCPA
 - Canadian Cancer Society
 - Family & Friends – Fundraising

- 4) **ADVICE:**

I would say very simply that the first thing anyone should do if their child is diagnosed with Cancer is to Consult the Professionals

 1. An Accountant, Financial Advisor, and follow their suggestions.
 2. Contact the Cancer Society for help and advice.
 - Keep all receipts
 3. Keep all receipts and diarize, with lots of notes. When offered help, always say yes. Have your key financial people in place to help you. My accountant, and bankers, and financial advisor were my saviors.
 - Keep a diary of events / dates / mileage, etc.
 4. Keep a good diary of day-to-day expenses with phone numbers & contacts.
 - Access Counseling & other Resources to relieve stress from financial burdens
 5. Social Workers at the BCCH should also help... and at Surrey Memorial.
 - Seek out programs to help with points / credits (ie., Air Miles)
 - Network with other Families
 - **DON'T BE AFRAID TO ASK FOR HELP !!**
 - Find out who your Social Worker is and find out about resources available to you

STRESS - BUSTERS

(Group presenter: Paul Clark)

MEDICAL COMMUNITY: Child Life

Medical Staff

Social Workers

Controlled, Quiet Environment

Free Parking / Passes

Connecting with other Families

PERSONAL:

- Utilize the Answering Machine
- One line of Communication (Advocate)
- Sleeping Pill ~ a Good Night's Sleep
- www.CaringBridge.org
- Family Support / Network
- Assigning an Advocate / Checklist
- Baking / Cooking
- The "Never-Ending" Project!
- Establishing Boundaries / Limitations
- Soap Box Derby
- Quality Time with Child
- Bucket List / Dreams
- Keeping a Daily Journal
- Men & Women have different Needs and Wants
- Humour!!

The monotony of long hospital stays can be very difficult if not stressful. To help pass the time, try reading trivia books like the Uncle John's Bathroom Reader series. The stories & articles cover a wide variety of topics and many are very informative. Most are from one paragraph to one page long so the child only has to concentrate for a short period of time if they are not feeling well. Some of the stories may not be appropriate for young children though. So you should pre-read them first.

SHORTFALLS & OPPORTUNITIES

(Group presenters: Kelly May & Tracey Dolling)

- initial meeting with Social Worker to discuss finances, family relationships
- shortfalls...? Is this a staff resource problem
- should each family have a survey to see if they need support?
- self advocacy? Setting up support service, what is the role in the hospital?
- Parent Handbook – too much info – old info needs to be streamlined
- An Oncology “greeter” – show the ropes... parking, laundry, the ins and outs of the Hospital... volunteer position? Grandparent? – someone safe
- Bridge between Pediatric and Adult Care:
 - pediatric care in adult hospital outside of Children's
 - Ward – standard of care within Children's – 3M, 3R? Not the same as 3B
- Comfort level outside of 3B / 2B – Very Stressful!
 - infection control
 - laziness
 - central line care
 - VAD access – horror stories
 - kids are not comfortable
- **There is a real lack of organized activities on weekends to help pass the time**

Moments, Quotes, etc., that “Stand Out”:

- Staff being sincere... “Is there anything I can do for you?”
- “You are part of the Team”
- Allowing families to be a family at the Hospital - ie., sleepovers, special “furry” visitors, movie nights, fun !
- “If something is bothering you, ask us.”
- Oncologists being accessible - e-mails, phone numbers, etc.

SHORTFALLS & OPPORTUNITIES

(Continued...)

(Group presenters: Kelly May & Tracey Dolling)

Oncology Clinic:

- segregation of families - follow up and treatment
 - miss the connection with other kids and families
 - New families might be missing out, without "experienced" support
 - Networking
 - "Pill swallowing Coach"
-
- We love Allen! (The Crazy Brit)
 - a sense of humour is essential
 - water fights, BBQ's on the deck, snowball fights
 - Fun activities - focus on some kind of positive
 - Good Staff! above and beyond being a doc or a nurse

BEYOND CANCER

(Group presenter: Kathryn McDonald)

- ~ Support
- ~ Anxiety when visits are more spaced out
- ~ Old Friends / New Friends
 - ↑ lose
 - ↑ special people
- ~ Let go of what stresses you!!
- ~ Not worth the energy
- ~ New perspective
- ~ More faith in humanity:
 - every person has a story
 - help from every corner
- ~ Values - some have changed
 - why put off things for the future

Repair & build relationships with siblings of the cancer patient. They can be deeply hurt or emotionally damaged when all the focus is on the child with cancer. Saturate them with quality time when the opportunities arise. Find an activity that they love or have a passion for & get involved with them in it. Quality time with them, doing something enjoyable, is priceless.

Don't dwell on the negative aspects of the past. It cannot be changed. Focus on the positive aspects of the future. Look for things that will enhance the quality of life for the entire family.

ADVOCACY

(Group presenter: Dave Dunbar)

◀ FAMILIES OF KIDS WITH CANCER ▶

ISSUES: - Financial - With many families, one parent has to quit their job for the full time care that is required for their child - Loss of income - cost of Parking, eating out, care for siblings, additional drug costs that may not be covered by our Provincial Health Plan, extended health plans, or even other private plans - other "non-drug" medical supplies, home equipment, even liquid nutrition (when a child is on a feeding tube as they're too ill to eat, etc.) isn't covered in British Columbia! Costs are overwhelming! - Even more extreme for a single parent. Here is where BCCCPA and other groups can help!

- Travel & Accommodation - over 45% of children are from outside the lower mainland, airfare, other travel costs and accommodation (hotels, motels, etc.) add up quickly. Some children require special treatment in the United States that may last for several months or more at a time. Within BC, groups like the Shriners have a bus to help with transportation of children to Children's Hospital. Groups like "Hope Air" can fill the need for "free" airfare to a child & parent traveling for treatment, when & where needed.

Another conference note: Safeway gives 7X the AirMiles when you fill your prescriptions with them! Did you know that you can use your AirMiles through other travel agencies, as well? And, AirMiles can also be used for other items, gifts, needed goods, etc.

- Anxiety - about everything, from every angle - re: fear of the unknown
- Treatment Plan (and the) Department(s)
 - ... Consensus (everyone on the same page!)
- Family Impact - fear of unknown, denial, blame, inattention to siblings, the "Why?"
- Social Impact - friends, extended family - some rally & support, others lose touch (still others fear and feel uncomfortable visiting or calling / asking).

At times like these, a www.caringbridge.org website is invaluable, as it may relieve awkwardness.

ADVOCACY

(Continued...)

- @ the Hospital - *Social Workers/Counselors/Staff - too many are unused and let some "proud" families slip through the cracks - re: directing families to the types of support available to them - as families are overwhelmed in the beginning, it would be worthwhile to go over areas of support again & again throughout their difficult journey. Here is where a "checklist" would be invaluable to ALL groups involved - repeatedly!

◀ PARENTS ROLES AS ADVOCATES ▶

- Organizations:

- BCCCPA - British Columbia Childhood Cancer Parents' Association -

(www.bcccpa.org) Share with others about BCCCPA, the real (unfortunate) need for their existence. Look through their website. Become a Member, host a fundraiser, support a fundraiser, become a volunteer, donate online - help is most appreciated!

- Gaby Davis Foundation, etc. - an organization that helps families like BCCCPA does

- view their website: www.gabydavisfoundation.com

Also suggest the variety of other groups that can be looked into, to help families in other ways, as well: Make a Wish, Children's Wish, Variety Club, the Starlight Starbright Foundation, Candlelighters, the Shriners' Bus, Hope Air, etc.

- Hold large "Cancer" related groups and organizations "accountable"

(ie., fair funds (%) for Pediatric Cancers - Research) - Why is it that many "Large"

Cancer related groups/organizations use such a high percentage of Children's

images in their fundraising brochure, posters, ads, etc., when there is such a small

percentage of their dollars raised going to pediatric cancer research??? WE MUST

ASK THEM ALL TO BE ACCOUNTABLE! ... and explain their actions.

- Media - consistent & constant awareness... \$, needs, etc. - most everyone in our

"rich" western society/culture are appalled when they learn of the incredible financial crises that most families face when they have a child with cancer in BC. Only

awareness and public support will grab the attention of our government and the groups that need to come to the table and support these struggling families - we must voice these needs, wherever and whenever the opportunity arises, as children don't vote, don't work and don't pay taxes... **BUT WE PARENTS DO!**

- **Government - BC (Provincial) & Nationwide (Federal) - write your MLA about this incredible need, and tell them they need to have ALL medical expenses for children stricken with cancer in BC to be covered under their basic medical plan!**

- **New Hospital - input from Parents, etc! - ensure we meet with the right planning departments and personnel so that we have a say as to the needs of the families that have to go through this unfortunate ordeal in the "new" hospital(s). Re: the environment and the necessities to make the stay that much more comfortable!**

- ***Social Workers "Checklist"... go over multiple times! - express this very real need.**

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Thank you to everyone that has made this conference a memorable success - the BCCCPA, Balding for Dollars, Children's Hospital, the Harrison Hot Springs Resort and Spa, David Norton (Family Counselor), Dr. David Dix (Pediatric Oncologist - Children's Hospital), Mr. Dan Mornar (Parent/Patient Advocate - Children's Hospital), Mr. Syd Birrell (author of "You can't let cancer ruin your day."), and all other caregivers from a variety of hospital positions and disciplines.

To the families who attended, a special thank you to "you" - the families of children with cancer that are starting on their own fearful journey, the families that are ongoing in their struggle with their child / siblings' cancer, those that have won their battles - yet fear their follow-up check ups. And most of all, to the families that have lost a child to this dreadful disease yet had the courage to share their stories and their insights to others, we salute you. May everyone's input be recognized and become a valuable tool for families and caregivers in the future fight on cancer.

(Dave Dunbar)