

## **Interprofessional Practice Symposium**

**Sick Kids, Monday, November 12, 2007**

This afternoon, I'd like to comment on the ways that Interprofessional Practice can support good family-centered care and offer you some examples from my own experience with my three children.



**Anna, Natalie, Madeleine**

The Family Advisory Committee at Sick Kids works to support and improve family centered care at the hospital. Family-centered care happens when

- Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.
- Health care practitioners communicate and share timely, complete, and accurate information with patients and families in order to effectively involve them in care and decision-making.
- Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
- Health care leaders collaborate with patients and families in policy and program development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care.

In short families are involved as active members of the interprofessional practice team.

Key qualities of a well-functioning team, from my perspective are:

- Communication
- Collaboration
- Coordination

My eldest daughter, Madeleine, is now 19, in grade 12 and loves dancing. Anna, now 14, just started high school. She's a competitive synchronized swimmer.



**Anna (14), Madeleine (19)**

Natalie, our middle daughter was the peacemaker and artist in the family. She would have been 17 but died of leukemia when she was 9.



**Natalie (7)**



**Girls at the cottage**

As a baby Madeleine had eye surgery to correct strabismus, along with several operations for tubes in her ears. She has a mild intellectual delay, speech language and motor delays. When she was six, she was diagnosed with Burkitt's Lymphoma. When she was 11 she was diagnosed with epilepsy.

Natalie was diagnosed with leukemia just one month after my mother died of lung cancer and one day before her 7<sup>th</sup> birthday. She relapsed on treatment, died at home in August 1999.

Anna wears a brace for scoliosis.

## **Communication**

One of the most key features of effective family-centered care and of effective interprofessional practice is good communication and yet communication can be the biggest challenge. Effective communication allows health care providers, families and patients to share what they know about the patient in order to make decisions and develop a plan of care.

It is a real challenge to you as health care providers to inform partners who have no background in health, may not speak English and are overwhelmed, exhausted and terrified. But most families that I've met learn to welcome or seek out information they need to help them make decisions and feel less afraid of what's happening. The problem for you is that it's very hard to know who is ready to receive the information you have to offer.

I found the information about the cancer diagnoses overwhelming. With each of our daughters, there was a "disclosure meeting." We were introduced to our team, given information about the particular cancer, and the recommended course of treatment. I couldn't absorb any of it. Then on the floor, the nurses would come in with blood counts and information sheets about the drugs. Initially, I ignored them because I didn't want to hear it. But my husband was a much better partner in that regard. He seized the information and started researching the protocols and the drugs. It was his way of coping.

My suggestion to you is to offer important information over again when the families are not quite as overwhelmed. Our nurses gently persisted in offering information that I needed to know. Sometimes, they provided it in other forms, such as a brochures or books or through contacts with another family.

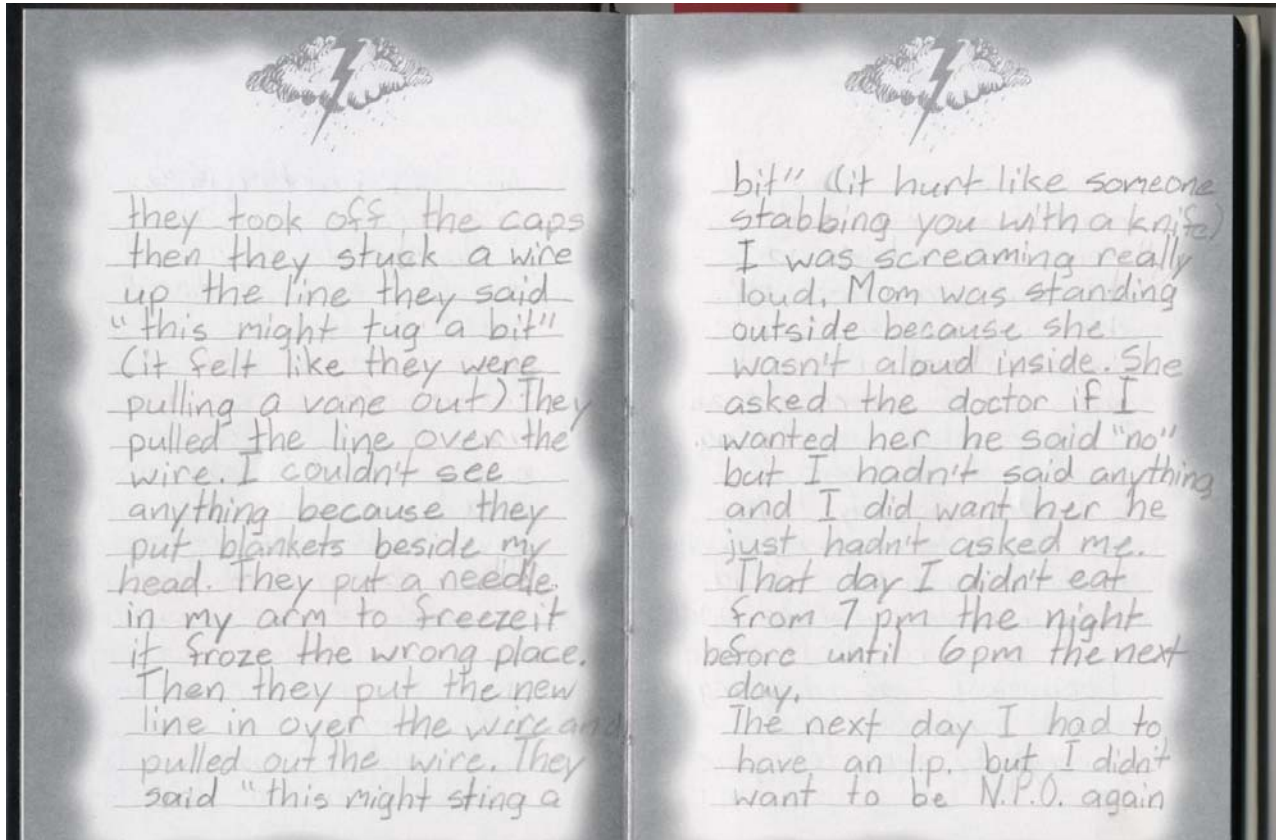
I see the partnership between health care providers and families as an exchange of knowledge. You have knowledge about illness and treatment and I have knowledge about my child and how she reacts to illness and treatment.

I know that my eldest daughter is terrified of needles of any kind. Even though she is now nearly 18, she still hates them. It's not worth reasoning with her or asking her to count to three or giving her choices. With her agreement, my pediatrician and I have developed a routine. Until she grew taller than me, I would hold her on my lap, wrap my legs around hers to keep her from kicking him, and pin her arms, while he jabbed her with the needle. It might sound cruel, but it makes her too anxious to know ahead of time that she's going to get a needle. Because he respected my understanding of my own child, we were able to collaborate to find a way to help her.

My daughter, Natalie, on the other hand, had very clear ideas about all aspects of her treatment. With her, my role was to explain her preferences to the staff and to advocate for her because she wouldn't speak to anyone except a few nurses. Most of the time, the staff at Sick Kids showed remarkable respect for her preferences and went out of their way to collaborate with Natalie to include her in as a participant in her own care.

She helped with dressing changes, worked out an effective practice with her clinic nurse and the phlebotomy team to get blood from her wonky picc line and had strong preferences about whether her oral medications were in liquid or tablet form.

However, this excerpt from her diary shows what happened when her choices were not respected.



**Natalie's diary: "Today, yesterday and the day before were so far, the worst days of my entire life...."**

### **Collaboration**

Like Natalie, I did learn to find ways to become an active participant in her care. With the support of the staff, and lots of clear information and training, I learned many new skills.

- Change a sterile dressing
- Check sugar levels with a finger poke
- Mix and inject insulin
- Inject a line with heparin
- Give a complete history
- Monitor fever
- Administer eye drops
- Run portable IV pump

- Support child during induction, Lumbar Punctures, insertion of central venous lines, CT scans, bone scans, x-rays, ultrasound, EEG, ECG, MRI scans
- Administer complex regime of oral medications

The nurses helped me to understand the significance of blood tests, vital signs, reactions to chemotherapy and to keep track of the complex protocols that each of my children followed. I learned that no one else kept track of the impact of the treatment on my children the way that I did and that was particularly important when we went off for treatment in other areas of the hospital or when we came in through emerg and had to give detailed histories. Here's a sample from my binder:

Revised 2/8/84

A.L.L. PROTOCOL C  
PHASE II - CNS INTENSIFICATION

Name Natalie I.D. No. \_\_\_\_\_

Surface Area (at diagnosis) \_\_\_\_\_

Cyclophosphamide 1000 mgm/sq m day 0, 14 = mgm Cyclo

6MP po 60 mgm/sq m day 0-27 = mgm 6MP

AraC IV 75 mgm/sq m day 1-4, 8-11, 15-18, 22-25 = mgm AraC

Methotrexate IT 8 mgm <2; 10 mgm <3; 12 mgm >3 = mgm MTX  
day 1, 8, 15, 22

Septra 3 mgm/kg/day in 2 divided doses = mgm Septra

CNS Radiation

Date due	Date given	Day	Medication	Notes
April 29	T April 29	0	Cyclo	6MP
	W April 30	1	AraC	IT MTX Radiation
	Th May 1	2	AraC	
	F May 2	3	AraC	
	S May 3	4	AraC	
	S May 4	5	AraC	
	Th May 6	7	AraC	
	May 6	8	AraC	IT MTX
	May 7	9	AraC	admitted May 5-9
	May 7	10	AraC	
	May 9	11	AraC	
	May 12	14	T. Cyclo	needs 4 hours hydr. - go in
	May 13	15	AraC M	IT MTX Th
	May 14	16	AraC T	no Septera this am
	May 15	17	AraC W	
	May 16	18	AraC F	
	May 17	19	AraC Th	
	May 20	22	AraC T	IT MTX
	May 20	23	AraC W	YES END Ther W
	May 21	24	AraC T	LP/Port - NO END
	May 22	25	AraC F	Thurs a
	May 27	27	foot w/p	
	June 1	31/0	Start interim maintenance	

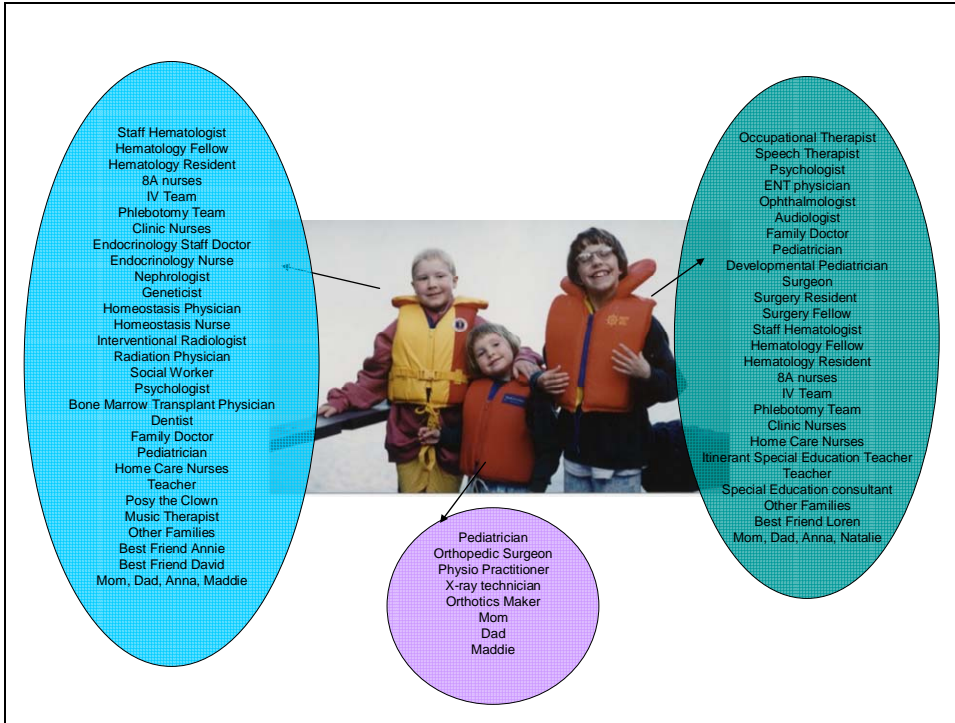
(4-6 wks) mid-may Page 4 of 7

**Natalie's treatment protocol**

Research into patient safety shows that family members can play a key role in preventing medical errors because they may notice things that staff do not. The other reality is that families play a key role in coordinating the care of their children, particularly when the child is dealing with many complex issues.

### Anna, Natalie, Maddie and their teams

The slide below shows the teams that helped each of my children at a particular point in time. It was often hard for me to remember who everyone was and what their roles were, but because my children and I were ones who ever met all the members, I had to assume the role of coordinating care among the team members here at Sick Kids, and in the community.



## Natalie and Posy—her favourite team member



I think that the staff at Sick Kids tries very hard to include families as active partners in the teams that care for children. However, there are also initiatives that involve families in working to improve policies, programs and services that affect all families and

children. There are a growing number of committees and work groups that include parents and patients as members. For many years the Family Advisory Committee at has worked to support and improve family-centred care by

- offering advice to the Hospital Board and Administration;
- providing feedback on specific policy and program changes; and
- sharing our stories with the hospital's medical students, residents and newly recruited nurses as part of our education program.

### **Some initiatives**

Here is a list of some of the initiatives parents and patients have been involved with:

- Advocating for adequate funding for the Hospital
- Improvements and renovations to the Emergency Department
- Changes to the Playroom policy
- Revising the Visitors' Policy
- Improving Ambulatory Care
- Developing a Diversity plan for Sick Kids
- Developing a strategic plan for Sick Kids
- Supporting parental presence at induction in surgery
- Improving to the inpatient food delivery services
- Improving patient safety
  - Making the hospital 100% smoke-free (initiative of the Children's council)
  - Initiating a hand hygiene campaign.

By being involved as a partner in my children's care, I was able to make their experience less stressful and more effective. I think my involvement allowed us to spend less time in hospital and to free up resources. As a member of Hospital Committees like the Patient Safety and Family Advisory committees, I think that I have had some impact on the care of all children. However, it took time and commitment on the part of the staff to foster both sorts of partnerships with effective information, training and support. I welcome any questions or comments.