



# **Family Centred Care Learning Vignettes**

**Family & Community Resource Centre  
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It can also be downloaded under the *Publications* tab at:

[www.sacyhn.ca](http://www.sacyhn.ca)

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## Family Centred Care Learning Vignettes

The cornerstone of family centred care is real partnerships between children, youth, families, staff, professionals, and health organizations. We share the responsibility for providing the best patient care possible. We build on the strengths and knowledge of families and make programs and services better by working together. Family centred care is relevant in all settings and to people of all ages and cultures. Working in a family centred way results in the delivery of high quality, safe health and related services.

The **Family Centred Care Learning Vignettes** resource consists of three parts:

**Part 1: “How to Use the Family Centred Care Learning Vignettes”** provides facilitators with guidelines to create a learning opportunity for family centred care concepts using the **Facilitator Reference List** and strategies for group discussions.

**Part 2: “Family, Child & Youth Stories”** consists of short excerpts from family, child and youth interviews that help demonstrate the philosophy and concepts of family centred care. Each story includes salient themes, learning elements and discussion questions to help the participant explore the application of family centred care to their personal life and professional practice. There are separate discussion questions for health provider participants and patient / client, parent and family participants.

**Appendix: “Family, Child & Youth Interviews” - Full Transcriptions** consists of fully transcribed patient, family and youth interviews. Parents, children and youth volunteered to be interviewed in order describe their family’s health care experience. The interview was guided by four questions:

1. What do children and families want to tell health care professionals?
2. What worked well in their patient, their child’s or their sibling’s health care experience?
3. What could have gone better?
4. What are their ideas and suggestions for improvement?

You are encouraged to read the full transcriptions in order to gain a more comprehensive understanding of a particular family’s health care experience.

## Part 1: How to Use the Family Centred Care Learning Vignettes

The **Family Centred Care Learning Vignettes** have been designed to assist facilitators to create an opportunity to learn about family centred care concepts through the voices of parents, child patients and their siblings.

This tool may be used for at least two different audiences:

- ✓ professional and nonprofessional health care employees, students and volunteers
- ✓ patients / clients, parents and families

The **Facilitator Reference List** (pgs. iv - vii) outlines seven pertinent family centred care themes and the family stories that reflect those themes. Some family stories reflect more than one theme and they have been cross referenced within other family centred care theme categories. These family centred care themes include:

- I Communication**
- II Roles**
- III Collaboration**
- IV Information Sharing**
- V Support**
- VI Patient Safety**
- VII System Policies and Procedures**

The facilitator will select appropriate family stories that will meet the learning needs of the audience. For example, if the audience wants to learn more about the communication process between health care professionals and families including *how to communicate*, *what to communicate* and *how to listen to the voices of children and youth*, the facilitator may select stories from the Communication, Roles and/or Collaboration categories.

It is important to note that discussions about the family stories are not limited to the discussion questions provided. It would be beneficial for facilitators to initiate group discussions with introductory comments from the participants including:

- What is your initial reaction to this story?
- What made this such a good experience for the family?"
- Why is this not an example of family centred care?
- What could a health care professional do to make this experience more family centred?
- What could be done at the system level to make this experience more family centred?

The goal for facilitators is to lead discussions by having participants apply and integrate the family centred care concepts reflected in the family story to their personal life and professional practice.

**According to principles of adult education, learner directed education generates better outcomes than teacher directed education.**

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## Part 2: Family, Child & Youth Stories

### Family Interview with Victoria

The Smither family consists of Victoria, her husband Jon and their two children, Samantha, 12 years and Emma, 6 years. Emma has special needs due to encephalitis. Jon's parents live in a rural community and Victoria's parents are deceased. Victoria has one sister in Winnipeg and Jon has four siblings. They do not have a lot of family support in the city, but have a good network of friends. Victoria works part time at a hospital as a nurse.

Emma has accessed a variety of health services and has had many hospital admissions. Her recent admission was for bladder surgery. Victoria explains more regarding Emma's health care experience.

### Salient Themes:

#### I Communication

1. Communication with patients and families
  - a. patient with special needs

### Learning Elements:

- Exploring past experiences with people with special needs
- Gathering information regarding abilities of special needs patients

Victoria stated she was frustrated regarding how Emma was sometimes treated by health care professionals because she had special needs.

"Sometimes, even nurses feel uncomfortable when they see a child with special needs because they do not know what to anticipate regarding their abilities. Can they express themselves? They tend to look at the mother or father for answers. That can be stressful because the child needs to be able to feel that she is part of her care too. Everybody from health care professionals to support staff need to treat children with special needs with respect and dignity, no matter what their abilities or disabilities are. The child life worker helped us all because she brought masks and talked about dealing with the surgery. She talked to Emma which was really appreciated."

### Health Provider Discussion Questions:

1. Why are we sometimes uncomfortable with people with special needs?
2. How can we invite patients with special needs be active participants in their care?
3. What experiences have you had with people with special needs?

### Parent Discussion Questions:

1. Why are some health care professionals uncomfortable with people with special needs?
2. What have been your experiences with health care professionals looking after your child with special needs?

Did you know?

Family centred care practices often improve the clinical outcomes for patients.

## **Family Interview with Victoria**

The Smither family consists of Victoria, her husband Jon and their two children, Samantha, 12 years and Emma, 6 years. Emma has special needs due to encephalitis. Jon's parents live in a rural community and Victoria's parents are deceased. Victoria has one sister in Winnipeg and Jon has four siblings. They do not have a lot of family support in the city, but have a good network of friends. Victoria works part time at a hospital as a nurse.

Emma has accessed a variety of health services and has had many hospital admissions. Her recent admission was for bladder surgery. Victoria explains more regarding Emma's health care experience.

### **Salient Themes:**

#### **I Communication**

1. Communication with patients and families
  - b. family member who is a health professional

### **Learning Elements:**

- Understanding the dynamics regarding assumptions about skills and knowledge between the health professional and the parent who is also a health care professional

"Post op was a very tough time for us. Not only were we upset, but as a nurse, I saw things differently than perhaps a layperson. Emma had problems with the epidural, insufficient morphine and a bit of a bleed that freaked me out. Everyone treated me like a hypochondriac nurse/mother!"

"The people did not really listen to me. I think when you are a nurse it sometimes colors the staff's opinions of what you are telling them. I said, "She seems really uncomfortable because she's squirming around the bed." The nurse examined her and said "We'll get the anesthetist here. Something is probably wrong". We then waited and waited. Finally I paged the nurse and she said the anesthetist couldn't be here for another three hours. No one came to support us during this time. It was difficult to see Emma moan in bed and I was very upset and angry. I know the nurse did feel bad and I felt she was caring but at the same token, she didn't offer another analgesic. That bothered me."

"I told them there was a big surge of blood and she had drained about 200 ml of fresh blood in a short time. They said, "Yeah, yeah, don't worry about it." It kept coming and I kept calling the nurse. I was almost hysterical. No nurse would even come into the room, so then I called the OR on my own cell phone to talk to the surgeon because I felt no one was listening to me."

"I never had any experience with this. I think other health care people have to be aware that when you are a nurse, you are a mother still and when you are a mother and your child is ill, you are no longer a nurse in many regards. You are very frightened and scared and you think you know stuff and maybe you don't. And you panic at things that you perhaps shouldn't. Much later when things had settled, a nurse said, "That often happens. They get a pocket of blood in there and it just comes out".

**Health Provider Discussion Questions:**

1. Is it easier or harder to be a health care professional when your child needs care?
2. How do you feel as a health professional when the patient's family member is also a health professional? Are there any assumptions that need to be explored when the parent is a health care professional? If your child needed help, would you tell a health provider that you too are a health care professional?
3. Being a health care professional, what are some strategies you can use to promote collaborative family centred care in this family situation?

**Parent Discussion Questions:**

1. What would it be like to be a parent and also a health care professional when dealing with your child's health issues?
2. What would it be like for a health care professional working with this parent? Are there any assumptions the caregiver might make when in this situation?
3. Being this parent, what are some strategies you can use to promote collaboration between you and the health care professional?

## Family Interview with Brigitta

Brigitta is Finnish and Carl is Canadian. They are married and have three children; Jennifer 21 years, Robert 16 years and Meg 14 years. They moved from Finland in 1997 to Pincher Creek. Carl is a farmer. Carl's siblings are in Pincher Creek, Calgary, Maine, Peru, and San Francisco. Brigitta's family is in Finland. Robert had a motorcycle accident resulting in him having a severely broken arm along with significant complications. Brigitta described Robert's health care experience.

### Salient Themes:

#### I Communication

1. Communication with patients and families
  - c. language barrier

#### IV Information Sharing

3. Sharing information with patient and family
  - b. informed choices – consent forms

### Learning Elements:

- Communication process
- Language barrier

“Dr. Carson said Robert needed more manual setting and some surgery. You thought you were just taking your kid for a check up and now he is going to surgery.”

“Written information would have been helpful to know what is going on. I understand that doctors do not have time to do that. There are a lot of things I could have looked up on the computer if they wrote key words. There were even computers at the hospital I could have used while waiting. It was hard when I phoned home and I couldn't tell my husband much except what Robert had started with the letter C! I don't know what it is. I am very confused. I know they are very busy and doing their best. It is not about taking care of me but it would help to get some information or to have it explained.”

“I signed the papers. There were lots of papers with very good explanation but when you are in a state of mind that your kid is going to surgery, you can't think and you forget. It would be nice to later sit down and read a copy of all the papers you signed. What did I read and what did I really sign? They said there were three or four options and I signed those papers. When I walked away from the room, I wondered which one I had chosen. You were told what was to happen but you remember only two and not the rest. If I could only read and understand it better. You are alone and your husband is somewhere else.”

“It would be nice to later sit down and read a copy of all the papers you signed. What did I read and what did I really sign?”

**Health care professional Discussion Questions:**

1. As a health care professional, what concerns come to mind when you read this family story?
2. What would you do in this situation to promote better communication? What would you say to Brigitta?
3. Are there any system impediments to family centred care in this story? Do you have any suggestions to alleviate them?

**Parent Discussion Questions:**

1. As a parent, what is it like to feel overwhelmed by the paperwork?
2. What would you do to improve the communication between you and the health care professional?

## **Family Interview with Brigitta**

Brigitta is Finnish and Carl is Canadian. They are married and have three children; Jennifer 21, Robert 16 and Meg 14. They moved from Finland in 1997 to Pincher Creek to farm. Carl's siblings are in Pincher Creek, Calgary, Maine, Peru, and San Francisco. Brigitta's family is in Finland. Robert had a motorcycle accident resulting in him having a severely broken arm along with significant complications. He required surgery and is now recuperating postoperatively. Brigitta described Robert's health care experience.

### **Salient Themes:**

#### **I Communication**

1. Communication with patients and families
  - c. language barrier

### **Learning Elements:**

- Communication process

"I waited all the time in the hospital to talk to the doctors and when I just went to the bathroom, that was when they came and I missed them! Robert said the doctor was in and he told me this and that and then they left. The doctor has his few minutes and then he has to go. I thought maybe the next morning I would talk to him. It is very hard to talk to them and get the information. That was always a problem which I don't know how to solve. It would be nice to get information on paper, especially for me as a foreigner, it is hard to understand. I mean when you are worried, you do not feel and think the same way."

"When there are four patients in the room it is very hard to concentrate on what the doctors are saying. You know you always have this fear of time and the doctors have to go soon. They are always on the run and you are keeping them with your stupid questions. Many times even when they are important questions you feel like you are stupid if you ask them. You are worried about your kid and how to get your questions answered."

"Doctors like to talk in doctor language which is very hard to understand. They are very calm when they explain but the problem is not theirs because it is not their kid they are talking about. I do not need anyone to pat me on the shoulder or hug me, I just need to have information that I can understand in a language that makes sense. Many times when the doctor was here, I would ask myself, what did that doctor say? He talked but I think he looks at this as his project. He talks about this very technically and I am more emotional and how this is affecting our life. How is this working in reality? The main doctors were excellent but when Robert went home, I wondered why did I not ask these questions?"

**Discussion Questions:**

1. As a professional, how do you deal with the challenge of keeping parents and family members informed regarding your patient's health status?
2. In order to improve communication with your patient and family, what personal and perhaps system changes need to be addressed to accomplish this?

**Parent Discussion Questions:**

1. As a parent, have you experienced problems communicating with doctors?
2. What did you do in your situation?
3. What suggestions do you have for Brigitta?

### **Family Interview with Tara (French interpreter used during interview)**

Tara is 48 years old with two sons, 6 years and 5 months old. She came to Canada from the Congo because she was persecuted and was not able to have any contact with her husband or family. Tara has no family here. For support she has the Congolese community and her church but it is still very difficult for her. Her 5 month old son was having breathing problems and needed medical attention. Tara speaks French and with the help of an interpreter she shares her family's health care experiences.

#### **Salient Themes:**

##### **I Communication**

1. Communication with patients and families
  - c. language barrier

#### **Learning Elements:**

- Communication process when dealing with a language barrier
- Resources to assist communication when there is a language barrier

“My baby was having problems breathing. We first went to 8<sup>th</sup> and 8<sup>th</sup> Clinic. They put oxygen on him because he was not breathing well and then they called an ambulance. There were no problems with me speaking French and very little English because the staff at 8<sup>th</sup> and 8<sup>th</sup> Clinic called the hospital to see if there could be a doctor that speaks French when we arrived.”

“After the doctor saw the baby, there was a young woman that spoke French and told me more information. When I went home, I was comfortable and understood what I was told. I was given the phone numbers for the ambulance, and 8<sup>th</sup> and 8<sup>th</sup> Clinic. I was later told about Health Link. Someone said they would have someone who could speak to me in French and answer my questions. I did not have the number for Health Link. There were no problems and they were helpful.”

“Tara had no communication problems when she had the baby. “My baby was born premature at 34 weeks. It was helpful to find people around me that spoke French. There was a social worker that spoke French and she was able to arrange for me to get bus passes because I needed to go and breast feed the baby. I would phone all the time to see how the baby was. I felt like I was always told what was happening. I felt that I was welcomed and treated well.”

“When the baby was discharged I received information. Even though the information was in English, I found ways to better understand it like looking words up in a dictionary. I am in an English speaking country and therefore I need to learn how to speak English better. I ask them to speak slowly and I am able to understand. Many of the words are similar to French. Overall, the health experiences for me and my children have been good.”

**Health Provider Discussion Questions:**

1. What have been your experiences dealing with language barriers when working with patients and families?
2. Do you have suggestions to improve communication with patients and families when English is a second language?

**Parent Discussion Questions**

1. What have been your experiences communicating with health care professionals when English was not your first language?
2. What was done to resolve this communication problem?

## Family Interview with Cara

Cara and her husband have three children; a daughter 20 years, a son 16 years, and another daughter 4 years. They moved from New Delhi in 2000. Her husband's family lives in Canada; a brother in Toronto, a sister in Winnipeg, a brother in Calgary, a sister in India, and his father lives with them for 6 months of the year. Cara's parents and siblings are in India. We don't have many friends. I meet with some people but they are not really friends. Their youngest daughter Suneet was diagnosed with leukemia and soon relapsed after her treatment was completed. She had a bone marrow transplant. Suneet has recovered well though still has some feeding problems. Cara describes her daughter's health care experiences.

### Salient Themes:

#### I Communication

1. Communication with patients and families
  - c. language barrier

### Learning Elements:

- Resources for parents with language barriers

"I was so worried because my English was not as good as it is now. I always arranged for someone to be with me who spoke English. I speak Punjabi and Hindi. In Winnipeg, my daughter helped me and when we came to the Alberta Children's Hospital, they arranged for someone from the hospital to interpret. Slowly, slowly, I got better speaking English. If I had a question, I would write it down, and give it to one of the doctors because he speaks Hindi too."

"The doctors and nurses always told me what they were doing but sometimes I didn't understand. Sometimes I do not know what is going on. This is more at the beginning when I did not speak English as well. Often I have to say, "I am sorry, I do not understand. Can you explain it to me again?" Soon, I would be able to understand."

"When Suneet relapsed I could not believe it. I asked the doctor to check the blood tests because maybe they made a mistake. He explained what tests they did and how many people checked the results. I asked how they know. He took me to his lab and let me look in the microscope. He explained what the cancer cells looked like. Sometimes I feel so stupid, asking so many questions. This doctor did not make me feel stupid. I was glad and thankful."

"The doctor explained what was happening. All of the information was in English. I can read it but I may not understand. I feel that if it was in my language, I would understand it better and I could read it later but I know that would be difficult. Maybe taping the conversation when the doctor is explaining would be helpful."

**Did you know?**

**Family centred care practice increases parents' self esteem.**

**Health Provider Discussion Questions:**

1. How have you managed to successfully work with patients and families when faced with a language barrier?
2. What changes need to be made to improve family centred care when there are language barriers?

**Parent Discussion Questions:**

1. What suggestions do you have to help health care professionals, patients and families work together when they don't speak the same language?

## **Family Interview with Don**

My family consists of my wife Vickie and my daughter Jacquie who is almost 4 years old. My wife has her parents, aunts and uncles here. She has 3 siblings of which one is in Calgary. My family is all out east outside of a brother in Red Deer. Don discusses the health care experience they had when Vickie needed to be induced and their daughter was born very prematurely and required lengthy hospitalization.

### **Salient Themes:**

#### **I Communication**

1. Communication with patients and families
  - d. communication - open and honest

#### **III Collaboration**

1. Development of trusting and working relationship between health care professionals, patient and family
  - b. honesty of health professional

### **Learning Elements:**

- Sharing information between professionals and families
- Trusting relationships between professionals and families

“Jacquie is pretty much in perfect health. There were a few challenges on the way. When she was a week old, she developed a serious infection which we were told is common and all of the kids get it. We learned later that this was not the case. It is not common and it is serious. It is probably due to someone not washing their hands well before doing an IV change. That did not instill confidence with us.”

### **Health Provider Discussion Questions:**

1. How have you explained a child's nosocomial condition to the family?
2. What approach did you use with the family? Why?
3. Would you do things differently in the future?

### **Parent Discussion Questions:**

1. How would you feel if this situation happened to you?
2. What might you say to the health care professionals regarding the inaccurate information?

## **Family Interview with Jack**

Jack and his wife Doreen have two daughters, Michelle, 14 years and Allison, 11 years. Jack has his mother and sister in the city but his mother has dementia and is not able to help. His sister is a tremendous support. Doreen's family is all out east. They have support also from Jack's employers and their network of friends. Michelle was diagnosed with leukemia and received a stem cell transplant from her donor sister. Jack reflected on their health care experiences involving their daughter Michelle.

### **Salient Themes:**

#### **I Communication**

1. Communication with patients and families
  - d. communication - open and honest

### **Learning Elements:**

- Approaches when providing open and honest communication

"To his credit, the head of oncology came in that night about 2:00 am in the morning. We were in Q cluster. He arranged to have psychosocial support for us. He had a couple of nurses there too. We went into the conference room and he laid out the facts. They were pretty hard to swallow. It kind of freaked us out. You hear about the expression, "Deer in the head lights", that was us. We did not know how to deal with it and it scared the heck of us. The doctor was very open and honest with us. He said he tells the truth and here are the possible consequences. As hard as it was to deal with, I would rather have an open, honest discussion in a caring way. I want honest communication."

"Staff should keep in mind that when they are dealing with people, they must realize they don't know these folks and have not yet developed any type of a relationship. I think that health care professionals need to gauge families. Some people deal with cold hard facts and numbers very well, but others deal with it in a more abstract way. You have to be prepared to work with people who like statistics. My wife likes statistics and wanted to know about Michelle's chances of survival. I don't like statistics because usually statistics are compiled after something is completed. If Michelle died she would be a statistic, and if she survived, she would be a statistic. In the interim, she is a young lady with cancer. I think you have to be prepared for all those sorts of things."

### **Health Provider Discussion Questions:**

1. What is your approach when you have to present difficult news to patients and families?
2. How have you changed your approach as you've gained greater professional experience?

### **Parent Discussion Questions:**

1. How would you appreciate health care professionals communicate your child's condition and prognosis to you?
2. What is important to you if a health care professional needs to tell you difficult news?

## **Family Interview with Jack**

Jack and his wife Doreen have two daughters, Michelle, 14 years and Allison, 11 years. Jack has his mother and sister in the city but his mother has dementia and is not able to help. His sister is a tremendous support. Doreen's family is all out east. They have support also from Jack's employers and their network of friends. Michelle was diagnosed with leukemia and received a stem cell transplant from her donor sister. Jack reflected on their health care experiences involving their daughter Michelle.

### **Salient Themes:**

#### **I Communication**

1. Communication with patients and families
  - d. communication - open and honest

#### **III Collaboration**

1. Development of trusting and working relationship between health care professionals, patient and family
  - b. honesty of health care professional

### **Learning Elements:**

- Building relationships with good communication

"When you have a patient receiving a lot of medications in a critical situation, part of the family centred care approach is to make sure the families have a lot of the information and they embrace you as a partner. Well if you want this, then you need to treat parents as a partner."

"When we were rookies into the program, my wife had a fall out with one inexperienced nurse who made a mistake but would not tell Doreen what it was. That freaked Doreen out. In that particular incident the nurse just said, "Oops", looked at the syringe in her hand and at the pump. She then left the room. Doreen asked what was wrong when she came back into the room with two other nurses. She said, "Oh nothing." They looked at the pump and kept on saying nothing was wrong and not to worry. Well damn it. Don't do that. You are filling our kid full of chemo drugs and what ever. Just don't do that!"

"Doreen complained to the primary oncologist. He took the nurse aside and said, "Don't ever do that again to my patient. If a mistake was made, tell them. If you see something wrong, then tell them. I want them to know what went wrong and not to be worried." We did not have a trusting relationship with that particular nurse after that."

### **Health Provider Discussion Questions:**

1. What are your thoughts regarding this family story?
2. As a professional, what is your approach when you have made a patient error?

### **Parent Discussion Questions:**

1. Describe any encounters you had regarding possible staff errors during your child's health care experience that were not clearly communicated to you?
2. How was the situation dealt with?
3. How could it have been improved?

## **Family Interview with Kathy and Ray**

Ray and Kathy are married with two daughters, Sandra turning 11 years and Erin 8 1/2 years. Ray's parents live near Edmonton. Kathy has a brother and sister in Grande Prairie. Her mother is in Lethbridge. Kathy had no previous problems during her pregnancy. She had a cesarean section and the staff noticed that Erin had isolated hydrocephalus. She was transported from the PLC to the NICU at ACH. Erin required surgery. Both Kathy and Ray provided information about Erin's health care experience.

### **Salient Themes:**

#### **I Communication**

1. Communication with patients and families
  - e. communication - repetitious

#### **II Roles**

2. Roles of health care professionals
  - b. patient / family knowledge of health care

### **Learning Elements:**

- Health provider identification of role and purpose to family
- Improvement in communication process and documentation

"What I found the most frustrating was that you had to tell the story to every new specialist. When they walk out, in walks in a resident or medical student and then you have to tell the story once again. We sometimes said, "We know this is a teaching hospital but enough is enough. We can't do this right now because we are just too emotional and too wiped out." The problem is when staff comes in they don't say who they are. They say they are Dr. So and So but they do not say exactly who they are, like if they are a resident. Why are they here? Finally we got to the point when we said, "Does that person really have to be here and ask us those questions?"

"It would be great if someone would come in and introduce them self and say what their role actually is. But what they do is come in with their flip chart, sit down and start asking you questions. Early on, you are naïve enough and you see the almighty doctor start asking you questions. Then a few minutes later, in comes another person asking the same questions. As her history got longer and longer, we just said for them to read her chart. There were times we just started to answer because we assumed this person really needed to know. Do not assume you need to talk to every person that comes in. Being in a teaching hospital is great but at the same time there has to be that respect and not feeling compelled that you must do something right now."

"In my career, I would not be where I am today if people didn't take the time to train me, but there has got to be a way to handle it better. I think they should check the chart. If the medical student has already seen the family, than maybe you don't go in. Go and talk to the medical student and go over the questions and answers. We understand that it is important to ask questions, but it does become tiring to answer the same questions. Out of our whole health care experience, that was what we found the most frustrating and overwhelming. We were tired of repeating our story to people."

**Health Provider Discussion Questions:**

1. Being a health professional, what are your thoughts about this family's frustration with having to repeat information to many different people?
2. Do you have any suggestions for improvement?

**Parent Discussion Questions:**

1. What is it like for parents to have to tell their child's story so many times?
2. Do you have any suggestions for improvement?

## **Family Interview with Connor and Lise**

Connor and Lise have a daughter Alexandra. Lise's brother lives with them and helps out. Connor's mother lives in Olds and comes to help. Connor's sister is not from here. Lise has sisters in Calgary and Strathmore. Her mother lives in High River but is sick and unable to help. Lise's father lives in France. They have a network of friends who help out but are scared of Alexandra's fragile condition to care for her. They have hired a student to help with her care.

Alexandra was born premature with genetic abnormalities. She is deaf, has a heart murmur along with feeding problems and seizures. Alexandra has had surgeries for her heart and stomach. Connor and Lise shared their thoughts regarding Alexandra's health care experience.

### **Salient Themes:**

#### **I Communication**

1. Communication with patients and families
  - e. communication - repetitious

### **Learning Elements:**

- Effects of repetitious communication on families

"The health care professionals relied on us for information about Alexandra. It seems like we are going over her history 10 times a day. After about 10 months I got so upset that I actually wrote a request which I bring to the hospital. I attach it to Alexandra's health care summary we personally compiled."

#### *From Our Family to You*

Our family finds it very difficult to come to the hospital! Part of the problem is that we have to explain Alexandra's history to many people every day.

When our family comes to the hospital we are worried about Alexandra's health and many times her life. It is very difficult to deal with the stress of having a sick child. It is even harder to deal with the reality that she is a chronically sick child. The sadness of knowing that our baby may not have a full life is very deep and we cannot get away from it. Unfortunately every visit to the hospital is difficult and having to think back and re-experience every single one hurts us. Having to explain her history multiple times a day leads us to feel hopeless for her future and extreme sadness takes over.

When we are home, we are able to adjust to Alexandra's special needs, and in a way, forget that there are any problems. However when we come to the hospital we usually end up explaining her entire complicated history often making us feel utterly overwhelmed by the stack of issues that we are dealing with every day of our lives.

Our greatest hope during our stay at the hospital is for Alexandra to have a speedy recovery and that we have a quick adjustment to her new special need(s). We really cannot deal with the stress of being in the hospital while remembering and reliving the hardest memories of our lives over and over.

We know better than anyone that Alexandra is a complicated girl and has a lot of health issues. We are also aware that it is important for you to understand her entire history to better help her in the present. So to help you help us, we have compiled some of the most important history into this one document. Please help us have time to adjust and deal with Alexandra's current problems by reading this document before asking us any questions about her history. Thank you.

Connor and Lise

**Health Provider Discussion Questions:**

1. What are your thoughts regarding this family story?
2. What suggestions do you have to reduce repetitious communication with parents in your area of practice?

**Parent Discussion Questions:**

1. Can you relate to this family's story about repetitious communication with health care professionals?
2. How can repetitious communication be addressed?

## Family Interview with Barb

Barb and Jim have two children, Tom 7, and Angelina 2. They live in Calgary. Barb's parents live in Calgary and her siblings live out of the country. Jim's mother lives in Grande Prairie and he has two siblings in Edmonton. Angelina is globally developmentally delayed and also has some kidney abnormalities since birth. Barb provides further details regarding their family story.

### Salient Themes:

#### I Communication

1. Communication with patients and families
  - f. empowerment of families

### Learning Elements:

- Practices used to empower families
- Benefits of empowering families

"When Angelina was first admitted I had lots of questions. What really helped was a doctor who said, "Look. You are her parent and you ask what questions you want. You take whatever notes you want and you get the doctors to repeat things ten times if that is what you need while you write them down. In fact, give me your book and I will write the answers down for you." He was very forthright and said, "Do not feel funny about any of this and ask as much as you can." That was where I took my advice. It was really good advice to give a parent especially for us at the beginning of Angelina's treatment."

"Communication has been really good. I've been told by people at the hospital, that we are unusual in that we ask lots of questions right on the spot. The communication has been fantastic and the professionals will listen to us. For example, I asked for a meeting with the two doctors to discuss separating the two required surgeries. That would not have been done if I did not ask for it. I don't think a lot of parents would have thought to ask for the meeting."

"We do the research. We try to find out as much as we can to know about Angelina's condition. Before we go to meetings with the doctor, we discuss what questions we are going to ask. If we get this answer then what questions are we going to ask? We do not want to have to phone a week later with all our questions that we thought about. We try to do the process of if this is the answer then ask this question. The doctors we had talked to are very open to answering any of our questions."

"We feel a part of the team and what I think and feel matters to them even though I don't know how a kidney works. I feel like it makes a difference and that it matters. Parents know their child the best. That is one of the strengths parents have and they can offer to the health care team."

**"You are her parent and you ask what questions you want. ... You get the doctors to repeat things ten times if that is what you need."**

**Health care professional Discussion Questions:**

1. As a health care professional, how do you empower families in the care of their family member?
2. From your professional practice, what do you see are the benefits of fostering family empowerment?

**Parent Discussion Questions:**

1. Have you had any experiences where health care professionals made you feel empowered and confident in your abilities to care for your child?
2. What suggestions do you have for health care professionals to better enable parents caring for their children?

## Family Interview with Jack

Jack and his wife Doreen have two daughters, Michelle, 14 years and Allison, 11 years. Jack has his mother and sister in the city but his mother has dementia and is not able to help. His sister is a tremendous support. Doreen's family is all out east. They have support also from Jack's employers and their network of friends. Michelle was diagnosed with leukemia and received a stem cell transplant from her donor sister. Jack reflected on their health care experiences involving their daughter Michelle.

### Salient Themes:

#### I Communication

1. Communication with patients and families
  - f. empowerment of families

### Learning Elements:

- Discussion of ways to empower patients and families

"I found the Oncology staff here certainly practice family centred care. We were told up front that they expected us to be partners in treating our daughter because we knew Michelle better than anyone else. It was going to be a long road and they wanted us to work with them. So right away they opened the door for us to feel comfortable to ask questions and they provided us with an open forum so if we had concerns, they would address them right away."

"We were comfortable asking for a meeting with the doctors because we had some questions needing to be addressed. The doctors made themselves available that day or the next day. We met with them privately and the primary nurse scribed the information of the meeting. I even prepared myself with 25 to 30 questions about Michelle's treatment or prognosis. I would photocopy enough to hand out to the people at the meeting. I wanted them to understand what our concerns were, but perhaps that is not the norm."

### Health Provider Discussion Questions:

1. In your professional role, how do you empower patients and families to be active participants of this care team?

### Parent Discussion Questions:

1. What have been your experiences been regarding health care professionals encouraging you to be an active member of your child's health care team?

"We were told up front that they expected us to be partners in treating our daughter because we knew Michelle better than anyone else."

## Family Interview with Connor and Lise

Connor and Lise have a daughter Alexandra. Lise's brother lives with them and he helps out. Connor's mother lives in Olds and sometimes comes to help. Connor has a sister but not from here. Lise has two sisters, one in Calgary and one in Strathmore. Her mother lives in High River but is sick and unable to help. Lise's father lives in France. They have a network of friends who help out in many ways but they are scared of Alexandra's fragile condition to help care of her. They have hired a student to help with her care.

Alexandra was born premature with genetic abnormalities. She is deaf, has a heart murmur along with feeding problems and seizures. Alexandra has had surgeries for her heart and stomach. Connor and Lise shared their thoughts regarding Alexandra's health care experience.

### Salient Themes:

#### I Communication

1. Communication with patients and families
  - f. empowerment of families

#### III Collaboration

- 2.. Family members as part of the collaborative team
  - a. parental involvement with multidisciplinary team

### Learning Elements:

- Parents feeling confident caring for their child

"The palliative care doctors all know that our preferred place is at home and they make our preference a primary goal. They work to help our family get back home soon. Everyone knows us now and they treat us well. For example, in Emergency, they see us so often that as soon as we go in there and say, "Baby seizure. Right this way." They get us in right away and into our own room so we don't have to expose Alexandra to other sick kids. She is so fragile!"

"Neurology allows us to make our own decisions about Alexandra's medication. They tell us all our options and trust us with the decisions. Neurology and Palliative Care Teams really make us feel like we are making good choices. I often hear that we are a pleasure to work with and that our choices are logical. They make us part of the team by including us in the decision making."

### Health Provider Discussion Questions:

1. This family felt empowered in confidently knowing they are doing a good job caring for their daughter. In your professional role, how do you empower your patients and families?

### Parent Discussion Questions:

1. What have your experiences been like working with a multidisciplinary team?
2. Did you feel as a parent you were involved as one of the team members?
3. Did you feel they supported and enabled you as parents to confidently care for your child?

"Neurology and the Palliative Care Teams really make us feel like we are making good choices."

### **Family Interview with Phillip**

Phillip is 18 years old and lives with his parents and two brothers, Michael is 20 years and Andrew is 15 years with Down Syndrome. They have no immediate family in Edmonton but they do have great support from family members in B.C., Manitoba, and Alberta along with many friends in Edmonton. Andrew was diagnosed with leukemia four years ago and is currently in remission. Andrew recently had surgery on his feet due to complications from his chemotherapy and will be in casts for 10 weeks. Phillip's mother is a nurse and understands the medical aspects of Alex's conditions.

#### **Salient Themes:**

##### **I Communication**

1. Communication with patients and families
  - g. patient's siblings

#### **Learning Elements:**

- Health care professionals being knowledgeable of patient's family makeup
- Inclusion of patient's siblings when practicing family centred care

"Most of the time I visited Andrew in the evenings and weekends. I didn't get many opportunities to talk to the doctors about Andrew's condition. I'd see some of the nurses come in to check the monitors and such but there was no real communication. I think they knew who I was but they did not introduce themselves. It would have been nice. I guess I could have introduced myself too. When the health care situation is critical and long term like leukemia as compared to a short term situation such as surgery, I feel it is important for health care professionals to get to know the family better. This makes you feel more included."

#### **Health Provider Discussion Questions:**

1. In your area of practice, how do you gain an understanding of your patient's family make up and dynamics?
2. What experiences have you had communicating and working with the siblings of your patients?

#### **Parent Discussion Questions:**

1. During your child's health care experience, how knowledgeable were the staff regarding the make up of your family? Was this important to you? Why?
2. Did your children feel included by staff when they visited their sibling? Was that important to them? Why?

## Family Interview with Ann

Ann and Robert are married and have two children, Lisa 2 1/2 years and Laura 6 months. Robert works fulltime and Ann is on a maternity leave. Robert's parents are in Calgary. Ann's sister is in Calgary and her parents live about 5 hours from Calgary. She has good family support. Laura has been in the hospital since she was 2 1/2 weeks old. Laura has had surgery to remove her ovary and some of her bowel. She has an ostomy and is receiving total parenteral nutrition. Ann provided information regarding Laura's health care experience.

### Salient Themes:

#### I Communication

2. Communication between multidisciplinary professionals
  - a. variety of settings

#### IV Information Sharing

2. Value/respect patient and family information and requests
  - a. listening to family concerns

### Learning Elements:

- Communication process
- Professionals valuing and respecting family's knowledge of their child

"I had a late ultrasound because they thought the baby was measuring smaller and they also found some abnormalities in her abdomen. They suggested I be induced. After she was born, I thought they were to do an in depth abdominal assessment and investigation. I thought it was done, as I requested. I was misled. It was not done. People did not know that she had abnormalities in her abdomen. They gave her a few palpations and said her belly was fine. I kept asking my family doctor for Laura to have an ultrasound, but she got sick before she had the ultrasound."

"We had huge communication problems. Communication wise, I wouldn't have accepted the doctor's answer that there was no problem. The head of Neonatology implied that they did not have the faxed ultrasound results but my obstetrician disagreed. I'll never know. I specifically informed the pediatrician why I was induced and could he do what was required for Laura. He brushed me off."

"I wish I would have been more persistent with that doctor, subsequent doctors and nurses. I kept asking if they checked everything out and I kept hearing that everything was fine. I should have worded my questions better and ask what they did to determine she was OK. How did they come to that conclusion is what I should have asked. Asking the right question is certainly one suggestion I have for parents who are in this position. Ask very specific questions."

"I should have worded my questions better and ask what they did to determine she was OK."

**Health Provider Discussion Questions:**

1. Can you identify reasons why these communication problems occurred and what is needed to prevent this happening again?
2. How would you as a health care professional communicate more effectively with Ann and other health care professionals?
3. Discuss the benefits of collaboration for both Ann and the health care professionals in this situation.

**Parent Discussion Questions:**

1. Can you identify reasons why these communication problems occurred and what is needed to prevent this happening again?
2. How would you as a parent communicate differently in this situation? What might you say to the health care professional?

## **Family Interview with Lena and Bob**

Lena and Bob are married and have four daughters. One daughter lives in Edmonton, one daughter lives in Calgary on her own and the other two daughters live with them. Bob's mother is in Calgary and sister is in Invermere. Lena's family is out east except for a brother in Red Deer. Their supports also include friends and the people they work with. Sharon, their 17 year old daughter has problems with her spine which has given her lots of pain. Sharon had back surgery and many postoperative complications. Lena and Bob spoke about Sharon's health care experience. They also provided input on Sharon's behalf, who shared her thoughts with them about her hospital experience.

### **Salient Themes:**

#### **Communication**

2. Communication between multidisciplinary professionals
  - a. variety of settings

#### **III Collaboration**

3. Collaboration and coordination of health care professionals
  - a. medication regime

#### **VI Patient Safety**

2. Medication administration / medication experiences

### **Learning Elements:**

- Value family information and requests
- Collaborative process with health care professionals

"Sharon stated that not all of the information was shared with members of the team. There were many incidents of medication confusion which she found very frustrating. The morphine made her very itchy so one of the doctors proceeded to give her Benedryl. She started to get some asthma attacks which the staff thought was due to anxiety. As parents, we did not think that it was due to anxiety. She is not an overly anxious person. A different resident came in a couple of days later and said that Benedryl is often a drug that triggers asthma. When he took her off it, the asthma episodes stopped!"

"There was another incident with Pain Services in that they were going to take her off the morphine and put her on another pain medication. I said to them, "I heard this pain medication also works as an anticoagulant. Did you check with Sharon's hematologist?" Later, they set the pump up and started to give it to her. We assumed since we asked the question, they had followed up. A few hours later the hematologist walks in and says, "Why is she on that? She is already on Heparin. They need to find something else to give her. There are other solutions." We felt we were not listened to at all."

"Sharon was vomiting a lot so she was put on Gravol, which knocked her right out. At this time, they were monitoring her to make sure her blood clot did not travel to her brain. They did not want her to be knocked out like that but we could not wake her up. Pain Services came in the next day and just freaked out. "We have to get all the residents together and talk about what medications she can and cannot be on." There seemed to be lots of confusion."

## **Family Interview with Margaret**

Margaret and Dave are married with three children. Thomas is 8 years old and their twin daughters, Ciara and Maeve are 11 months old. They had another daughter Aileen who died at 24 months of an unknown cause over a year ago. Margaret has parents and a sister in the city and two sisters out on the west coast. Dave's parents and 3 siblings also live in the city.

### **Salient Themes:**

#### **I Communication**

2. Communication between multidisciplinary professionals
  - b. conflict in diagnosis

### **Learning Elements:**

- Resolution process

“The paramedics came and worked on Aileen but couldn't stop the seizure. The paramedics were a lady and man. They appeared to be butting heads. One wanted to work on her longer and the other one said they needed to go to the hospital. They took her to the ambulance. They told us that they had to wait for the fire truck because they both needed to work on her so someone else had to drive the ambulance. They thought she was having heart failure and worried she was going to have a heart attack. The fireman showed up and all I remembered was them talking gibberish to the hospital people.”

“At the hospital we were waiting for results to come back. I remember the neurologist at one stage being quite upset because she did not yet have the lab work back. She was frustrated because she needed answers. The neurologist wanted to give her steroids, but infectious diseases wanted to hold on just in case it was an infection. There seemed to be a fair bit of head butting. That bothered us. It seemed like each doctor was dead set that it was their diagnosis that was the reason for Aileen's problem. You could definitely see there was this power struggle.”

“We requested to meet with the head of ICU and the neurologist to discuss some of our concerns. It was probably 2 ½ days into her care that they determined it was not an infectious disease, so they started the steroids. We always felt that if heads had not butted between the neurologist and infectious disease doctor and the steroids were given sooner, there may have been a different outcome for our daughter.”

### **Health Provider Discussion Questions:**

1. How do you manage differing opinions with other health care professionals regarding patient diagnosis and treatment?
2. When managing this situation, how can professionals still provide support and confidence in their care to patients and families?

### **Parent Discussion Questions:**

1. What is it like when health care professionals have differing opinions regarding the diagnosis and treatment of your child?
2. How did you deal with the situation?

## **Family Interview with Catherine**

The Crocker family is made up of Catherine and her three daughters, Karen 17 years, Ellen 15 years with Down Syndrome and Lily 12 years. Catherine is divorced and Tom, the girls' father sees them on Sundays. Catherine's family lives out east, with her mother in Windsor, her father in Quebec, her two sisters in Toronto and her brother in Quebec City. Tom's parents and seven siblings all live in Edmonton. Lily has experienced medical and mental health issues for the last six years. She has said she wants to kill herself. She has been diagnosed with a nonverbal learning disability, a hand tremor, Tourettes, obsessive compulsive disorder and ADHD. Lily is being further assessed for narcolepsy and possible seizures.

### **Salient Themes:**

#### **I Communication**

2. Communication between multidisciplinary professionals
  - b. conflict in diagnosis

### **Learning Elements:**

- Need for multidisciplinary team meetings
- Parent involvement and recourse

“Another concern I had was health care professionals constantly making conflicting diagnoses. Dr. Wilf, the neurologist diagnosed Lily with Tourettes. Lily sees another neurological psychologist, Dr. Mast and he says she doesn't have Tourettes. We go back to Dr. Frans, and she says Lily absolutely does have Tourettes. Nobody is backing each other up on the diagnosis. Everybody is giving one and then taking one away. Then Dr. Frans tells me that from testing and the observations she's made, Lily absolutely has a nonverbal learning disability. Then Dr. Mast says because Lily passed one test where she could put pegs into a board blindfolded, that no way on God's green earth she has it. Dr. Frans then changes the nonverbal learning disorder to the right information hemisphere function whatever. I then asked Dr. Mast more about the tests he did. I soon found out that he actually never met Lily, he did not test Lily, and he had an intern test her. It was the interns second time doing the test.”

“In the report, Dr. Mast says Lily has no problems. The only problems she has was ADD and OCD, she had no learning disabilities. It totally screwed me over at the school, so I did not release the report and the principal thanked me because they had tested Lily and scored her at a grade 3 in math. The report was so inconsistent with everyone else's report. No one talked with each other. Dr. Frans was to meet with Dr. Mast to discuss the results and get back to me because she couldn't understand the discrepancies in what the school had reported versus what the testing outcomes were. That meeting never happened.”

### **Health Provider Discussion Questions:**

1. What experiences have you had regarding differing professional opinions?
2. How was it resolved in order to best help the patient and family?

### **Parent Discussion Questions:**

1. What suggestions do you have from you personal experiences to help Catherine and Lily deal with this concern?

**Health Provider Discussion Questions:**

1. What would you do in this situation to promote effective communication and collaboration?
2. Are there any system impediments that influence your collaborative practice in family centred care?

**Parent Discussion Questions:**

1. What do you think about this family story?
2. What role can families play if they are involved in similar situations?

## Family Interview with Ann

Ann and Robert are married and have two children. Lisa is 2 1/2 years old and Laura is 6 months old. Robert is working fulltime and Ann is on a maternity leave. Robert's parents are in Calgary. Ann's sister has just moved back to Calgary and her parents live about 5 hours from Calgary. She has good family support. Laura has been in the hospital since she was 2 1/2 weeks old. Laura has had surgery to remove her ovary and some of her bowel. She has an ostomy and is receiving total parenteral nutrition. Ann provided information regarding Laura's health care experience.

### Salient Themes:

#### II Roles

1. Roles of patient and family
  - a. parent involvement defined

### Learning Elements:

- Review of unit routines and their fit with patient and family needs
- Mutual discussion of the roles of caregivers and family members

"For a long term patient, it was frustrating for me to find out that activities such as assessments done every four hours didn't have to always be done at that time, they could be changed. That would have been nice to know a few weeks ago. Let me know what is flexible. Let me know what things I can do on my own time so you don't have to worry about coming and bugging my baby and waking her up. I can do it."

"It would be helpful to know what my role is as a parent and what the schedule is. What can I take on so you don't have to touch my baby as much? I wanted them to not have to disturb her while she was sleeping and they would accommodate me as much as they could. I wish I had known that there were things that I could have been doing. There could have been things that would have made it better if I knew my role."

"Well there were lots of things that did work well. The nurses are helpful and I liked when they started to teach me what they were doing and getting me involved in her care. I didn't even know if I could change her diaper. In ICU there were so many cords coming out of her, I didn't even want to touch her. They helped show me how to touch her. I was not able to hold her but they told me what I could and couldn't do. Everybody told me, "There is nothing here that you have to do. You can do as little as you want or as much as you want." That message was very clear. I appreciated that."

"It would be helpful to know what my role is as a parent."

**Health Provider Discussion Questions:**

1. Family centred care fosters program flexibility rather than program rigidity. Reflect upon your area of practice. Is your work setting flexible in meeting the needs and preferences of patients and families?
2. What are some strategies you use to promote a family centred care collaborative partnership?

**Parent Discussion Questions:**

1. Being a parent, what experiences have you had in regard to your specific role as a parent on your child's health care team?
2. How did it make you feel?

### **Family Interview with Ann**

Ann and Robert are married and have two children. Lisa is 2 1/2 years old and Laura is 6 months old. Robert is working fulltime and Ann is on a maternity leave. Robert's parents are in Calgary. Ann's sister has just moved back to Calgary and her parents live about 5 hours from Calgary. She has good family support. Laura has been in the hospital since she was 2 1/2 weeks old. Laura has had surgery to remove her ovary and some of her bowel. She has an ostomy and is receiving total parenteral nutrition. Ann provided information regarding Laura's health care experience.

### **Salient Themes:**

#### **II Roles**

2. Roles of health care professionals
  - a. family experiences with social worker and child life specialist

### **Learning Elements:**

- Defining caregivers roles to families
- Initiating a plan with families

"I remember a social worker came in the first and second day and asked, "What do you need?" I said, "I'm sorry. I am not there yet. I have no idea what I need. I have not processed this. I don't know how long I will be here. They are telling me I'll be here for two months or six months." The social workers didn't prompt me with questions like how I was going to take care of my other child or provide solutions for me. It just did not work for whatever reason."

"Child life staff was wonderful. I am trying to think what made the difference because I did not get along with the social workers. A child life worker said, "You have a 2 year old child. You have a sick baby and at the moment your baby doesn't need child life, but when she does, we will be here to provide assistance for you. We have a schedule here with resources and this is where she can go. We have staff to help her develop." This was one of my concerns. I thought, "Oh my gosh! Is she going to be lying in a hospital bed for the next 6 months and not do anything?" They totally made me feel so much better telling me what was available."

"The child life staff did get my older daughter Lisa into the playroom every once in a while or toys were brought into my room and it was made clear that the toys were not just for Laura but for Lisa too. The child life worker came in to spell me off. She would hold Laura for a few minutes so I could go for a break. I was a very protective mom and would not leave her side for quite a few months. They tried to make it work. Looking back, I don't know how the child life people and the volunteers did it. They provided me the most support."

**Health Provider Discussion Questions:**

1. What do you think made the difference between the mother's interactions with the social worker and the child life worker? Why was one professional more successful than the other?
2. From your own experience, what do you believe is needed in order to develop successful relationships with new patients and families?

**Parent Discussion Questions:**

1. What do you think made the difference between the mother's interactions with the social worker and the child life worker? Why was one professional more successful than the other?
2. From your own experience, what do you believe is needed in order to develop successful relationships with new health care professionals?

### **Family Interview with Brigitta**

Brigitta is Finnish and Carl is Canadian. They are married and have three children; Jennifer 21, Robert 16 and Meg 14. They moved from Finland in 1997 to Pincher Creek to farm. Carl's siblings are in Pincher Creek, Calgary, Maine, Peru, and San Francisco. Brigitta's family is in Finland.

Robert had a motorcycle accident resulting in him having a severely broken arm along with significant complications. He required surgery and is now recuperating postoperatively. Brigitta described Robert's health care experience.

### **Salient Themes:**

#### **II Roles**

2. Roles of health care professionals
  - b. patient / family knowledge of health care

### **Learning Elements:**

- Health care professionals introducing themselves and explaining their roles to patients and families
- Professional role description is an essential component when developing a trusting relationship

"The other thing we do not know anymore is who is a nurse. Everybody wears their ordinary clothes and come in and say they are Jane and will be Robert's nurse for this shift. Every patient in the room has a different nurse so there are a lot of people coming in and out. I do not find it comfortable to have all these people who you have no clue as to who they are. If I knew that was a nurse, I may ask her different questions but if you don't know who they are, it is hard. Knowing what people do is important to me."

"I did not see any identification. There were some nurses my age that you could tell were nurses by the way they dressed. The young nurses, I do not know if they were students, but by the way they were dressed, it was hard to know. Anybody could walk in and pretend to be anybody."

"That didn't make me feel comfortable. It was hard to trust people. Robert felt the same. I know they dress this way to make kids feel more comfortable but I think kids need to know that there are certain authority figures. You don't have to be a mean person wearing a uniform. Even at the cast clinic you didn't know if that person was the nurse, a secretary or a parent helping out."

### **Health care professional Discussion Questions:**

1. What do you do to communicate your role and team function to the family?
2. What would you do differently to communicate your role more effectively?

### **Parent Discussion Questions:**

1. What experiences have you had in understanding the roles of your health care professionals?
2. What suggestions do you have to help families better understand the roles of health care professionals?

### **Family Interview with Barb**

Barb and Jim have two children, Tom 7, and Angelina 2. They live in Calgary. Barb's parents live in Calgary and her siblings live out of the country. Jim's mother lives in Grande Prairie and he has two siblings in Edmonton. Angelina is globally developmentally delayed and also has some kidney abnormalities since birth. Barb provides further details regarding their family story.

### **Salient Themes:**

#### **II Roles**

2. Roles of health care professionals
  - b. patient / family knowledge of health care

### **Learning Elements:**

- Process of informing patients and families about health care professional's role

"It wasn't till we got used to Angelina having more problems that we started to think about other options we have for support. I did not see a social worker or even know there were any available to us on the cluster. I did not know we had a social worker until we were involved with the Infant Team. Our social worker introduced herself to me and said she was just following up."

"If someone is being admitted to a cluster or starting to attend a clinic, part of the process should be a visit from the social worker. I think people are scared of social workers until they know what they do. I had no idea that social workers did so much. I thought all they did was tell you what you were doing wrong with your child and take them away from you. I did not know that they had any other role. It is really important to have an understanding of people's role in the hospital and the resources they are able to share with us. That is the link that's missing."

### **Health Provider Discussion Questions:**

1. Describe a situation you may have experienced where there was a misunderstanding of what your professional role entailed. How has that experience changed your practice with patients and families?

### **Parent Discussion Questions:**

1. How do you find out about the different roles of health care professionals you are working with?
2. How have your experiences changed the way you interact with health care professionals now?

### **Family Interview with Lena and Bob**

Lena and Bob are married and have four daughters. One daughter lives in Edmonton, one daughter lives in Calgary on her own and the other two daughters live with them. Bob's mother is in Calgary and he has a sister in Invermere. Lena's family is out east except for a brother in Red Deer. Their supports also include friends and the people they work with. Sharon, their 17 year old daughter has problems with her spine which has given her lots of pain. Sharon had back surgery and had many complications post-operatively. Lena and Bob spoke about Sharon's health care experience. They also provided input on Sharon's behalf, who shared her thoughts with them about her hospital experience.

### **Salient Themes:**

#### **II Roles**

2. Roles of health care professionals
  - b. patient / family knowledge of health care

### **Learning Elements:**

- Discussion of the professional's role and purpose to patient and family
- Strategies to help the patient and family know and understand all the professionals involved in the patient's care

"When Sharon was in the hospital with a blood clot complication, she was a rarity. There were lots of doctors, residents, and nurses that came in to see her. It was great that they told us their names but often we did not know where or what department they were from. It would be helpful if they had a business card they could leave with us. You could write on the back of the card their comments. After awhile, you could not remember who said what because there were so many people. When the pediatrician in charge came in, she did introduce herself and tell us what her role would be. She explained who the team consisted of but that was not told to us until a couple of days later. We were not clear who all these people were. After about the third time, the head pediatrician came in and wrote her name on the white board in the room. That was very helpful. I think it would be great to have a white board in every room and when doctors come in, they could write their names on the board so you could then transfer it to your own notebook and have a better chance of remembering them and keeping track of them."

### **Health Provider Discussions Questions:**

1. What suggestions do you have for patients and families trying to learn and understand the names and roles of the various health care professionals they will be encountering?

### **Parent Discussion Questions:**

1. When initially meeting new health care professionals, how do you keep track of the names and roles of all the new people you have met?

## **Family Interview with Kathy and Ray**

Ray and Kathy are married with two daughters, Sandra turning 11 years and Erin 8 1/2 years. Ray's parents live near Edmonton. Kathy has a brother and sister in Grande Prairie. Her mother is in Lethbridge. Kathy had no previous problems during her pregnancy. She had a cesarean section and the staff noticed that Erin had isolated hydrocephalus. She was transported from the PLC to the NICU at ACH. Erin required surgery. Both Kathy and Ray provided information about Erin's health care experience.

### **Salient Themes:**

#### **I Communication**

1. Communication with patients and families
  - e. Communication - repetitious

#### **II Roles**

2. Roles of health care professionals
  - b. patient / family knowledge of health care

### **Learning Elements:**

- Health provider identification of role and purpose to family
- Improvement in communication process and documentation

"What I found the most frustrating was that you had to tell the story to every new specialist. When they walk out, in walks a resident or medical student and then you have to tell the story once again. We sometimes said, "We know this is a teaching hospital but enough is enough. We can't do this right now because we are just too emotional and too wiped out." The problem is when staff comes in they don't say who they are. They say they are Dr. So and So but they do not say exactly who they are, like if they are a resident. Why are they here? Finally we got to the point when we said, "Does that person really have to be here and ask us those questions?"

"It would be great if someone would come in and introduce them self and say what their role actually is. But what they do is come in with their flip chart, sit down and start asking you questions. Early on, you are naïve enough and you see the almighty doctor start asking you questions. Then a few minutes later, in comes another person asking the same questions. As her history got longer and longer, we just said for them to read her chart. There were times we just started to answer because we assumed this person really needed to know. Do not assume you need to talk to every person that comes in. Being in a teaching hospital is great but at the same time there has to be that respect and not feeling compelled that you must do something right now."

"In my career, I would not be where I am today if people didn't take the time to train me, but there has got to be a way to handle it better. I think they should check the chart. If the medical student has already seen the family, then maybe you don't go in. Go and talk to the medical student and go over the questions and answers. We understand that it is important to ask questions, but it does become tiring to answer the same questions. Out of our whole health care experience, that was what we found the most frustrating and overwhelming. We were tired of repeating our story to people."

**Health Provider Discussion Questions:**

1. Being a health professional, what are your thoughts about this family's frustration with having to repeat information to many different people?
2. Do you have any suggestions for improvement?

**Parent Discussion Questions:**

1. What is it like for parents to have to tell their child's story so many times?
2. Do you have any suggestions for improvement?

## **Family Interview with Ann**

Ann and Robert are married and have two children. Lisa is 2 1/2 years old and Laura is 6 months old. Robert is working fulltime and Ann is on a maternity leave. Robert's parents are in Calgary. Ann's sister has just moved back to Calgary and her parents live about 5 hours from Calgary. She has good family support. Laura has been in the hospital since she was 2 1/2 weeks old. Laura has had surgery to remove her ovary and some of her bowel. She has an ostomy and is receiving total parenteral nutrition. Ann provided information regarding Laura's health care experience.

### **Salient Themes:**

#### **III Collaboration**

1. Development of trusting and working relationship between health care professionals, patient and family
  - a. anxiety of parent

### **Learning Elements:**

- Partnership between parents and staff when providing patient care
- Process of developing a good working relationship

"I have a lot of messages to tell health care professionals. Medically, they are experts and I have no doubt that they know what they are doing. However, as a parent I can't be careful enough, so when I watch them and ask them questions I am watching them like a hawk, not that I do not think they know what they are doing, but because mistakes happen. I don't know how they happen, but it is my job to be there and question every darn thing they do and to learn what they are doing and to make sure they do it right."

"Many of the nurses and professionals are OK with that. They know that and understand that. Some of them take offense and that is fine, but I am still going to do it because my job as a parent is to be there and to watch out that she gets the best care available. Most people I meet understand that completely and go to the n<sup>th</sup> degree to help me feel comfortable."

### **Health Provider Discussion Questions:**

1. In your role as a health care professional, how do you develop a trusting relationship with your patients and families?
2. What experiences have you had with families who are wary of the care being provided to their loved one? How did you approach that situation?

### **Parent Discussion Questions:**

1. What is needed in order for you to have a trusting relationship between you and your child's health care professional? How is this relationship developed?
2. Have you experienced a similar situation? How did you approach that situation?

### **Family Interview with Don**

My family consists of my wife Vickie and my daughter Jacquie who is almost 4 years old. My wife has her parents, aunts and uncles here. She has 3 siblings of which one is in Calgary. My family is all out east outside of a brother in Red Deer. Don discusses the health care experience they had when Vickie needed to be induced and their daughter was born very prematurely and required lengthy hospitalization.

#### **Salient Themes:**

##### **I Communication**

1. Communication with patients and families
  - d. communication - open and honest

##### **III Collaboration**

1. Development of trusting and working relationship between health care professionals, patient and family
  - b. honesty of health care professional

#### **Learning Elements:**

- Sharing information between professionals and families
- Trusting relationships between professionals and families

“Jacquie is pretty much in perfect health. There were a few challenges on the way. When she was a week old, she developed a serious infection which we were told is common and all of the kids get it. We learned later that this was not the case. It is not common and it is serious. It is probably due to someone not washing their hands well before doing an IV change. That did not instill confidence with us.”

#### **Health Provider Discussion Questions:**

1. How have you explained a child's nosocomial condition to the family?
2. What approach did you use with the family? Why?
3. Would you do things differently in the future?

#### **Parent Discussion Questions:**

1. How would you feel if this situation happened to you?
2. What might you say to the health care professionals regarding the inaccurate information?

## **Family Interview with Jack**

Jack and his wife Doreen have two daughters, Michelle, 14 years and Allison, 11 years. Jack has his mother and sister in the city but his mother has dementia and is not able to help. His sister is a tremendous support. Doreen's family is all out east. They have support also from Jack's employers and their network of friends. Michelle was diagnosed with leukemia and received a stem cell transplant from her donor sister. Jack reflected on their health care experiences involving their daughter Michelle.

### **Salient Themes:**

#### **I Communication**

1. Communication with patients and families
  - d. communication - open and honest

#### **III Collaboration**

1. Development of trusting and working relationship between health care professionals, patient and family
  - b. honesty of health care professional

### **Learning Elements:**

- Building relationships with good communication

"When you have a patient receiving a lot of medications in a critical situation, part of the family centred care approach is to make sure the families have a lot of the information and they embrace you as a partner. Well if you want this, then you need to treat parents as a partner."

"When we were rookies into the program, my wife had a fall out with one inexperienced nurse who made a mistake but would not tell Doreen what it was. That freaked Doreen out. In that particular incident the nurse just said, "Oops", looked at the syringe in her hand and at the pump. She then left the room. Doreen asked what was wrong when she came back into the room with two other nurses. She said, "Oh nothing." They looked at the pump and kept on saying nothing was wrong and not to worry. Well damn it. Don't do that. You are filling our kid full of chemo drugs and what ever. Just don't do that!"

"Doreen complained to the primary oncologist. He took the nurse aside and said, "Don't ever do that again to my patient. If a mistake was made, tell them. If you see something wrong, then tell them. I want them to know what went wrong and not to be worried." We did not have a trusting relationship with that particular nurse after that."

### **Health Provider Discussion Questions:**

1. What are your thoughts regarding this family story?
2. As a professional, what is your approach when you have made a patient error?

### **Parent Discussion Questions:**

1. Describe any encounters you had regarding possible staff errors during your child's health care experience that were not clearly communicated to you?
2. How was the situation dealt with?
3. How could it have been improved?

## Family Interview with Jack

Jack and his wife Doreen have two daughters, Michelle, 14 years and Allison, 11 years. Jack has his mother and sister in the city but his mother has dementia and is not able to help. His sister is a tremendous support. Doreen's family is all out east. They have support also from Jack's employers and their network of friends. Michelle was diagnosed with leukemia and received a stem cell transplant from her donor sister. Jack reflected on their health care experiences involving their daughter Michelle.

### Salient Themes:

#### III Collaboration

1. Development of trusting and working relationship between health care professionals, patient and family
  - b. honesty of health care professional

#### VI Patient Safety

2. Medication administration / medication experiences

### Learning Elements:

- Using patients and families as safety checks
- Dealing with errors and near miss incidents

"We were more experienced with Michelle's medications. The nurse came in to give her the meds. I asked what she was doing. "I'm giving her meds." I replied, "No, you are too early." She said, "No it is the right time." I asked her what the dose was and she told me and I said the dose and the time of the medication was changed. "No, no, this is the right dose and time." I was insistent and asked her to please check. She didn't argue and she came back to assure me that it was the correct dose and time. Well I assured her it was not correct. I asked her to call the doctor because there was a mistake and to please not give it to her until the orders were clarified."

"She came back and said, "I am glad you pushed it because I would have given the wrong dose. Thanks for pointing that out." She was very open and honest. I appreciated that she respected and valued my opinion. It was not regarded as a mistake or an error but as a near miss. I had less angst over that incident than the "Oops and oh no" episode we previously experienced and not being given any explanation as to what had gone wrong."

"This is something that all parents appreciate, open and honest communication and professionals listening to parents. We know we are not scientists, we are not nurses but we certainly know our kids. We know our meds and we know when they are given. Parents learn that pretty quickly. Give parents credit when credit is due and respect their concerns. If parents say something is wrong, than you need to respect it. We still do not know what happened for the first incident. We did not have a trusting relationship after that episode with the "Oops" nurse. "

Did you know?

Family centred care increases parent confidence.

**Health Provider Discussion Questions:**

1. What are some changes needed to prevent errors and near misses in your area of practice?
2. Do you see a role for patient and family members in being part of a medication checking system prior to the medications being administered?

**Parent Discussion Questions:**

1. Have you experienced similar situations where an error or an error had almost happened to your child?
2. What suggestions do you have to prevent this from happening again?

### **Family Interview with Don**

My family consists of my wife Vickie and my daughter Jacquie who is almost 4 years old. My wife has her parents, aunts and uncles here. She has 3 siblings of which one is in Calgary. My family is all out east outside of a brother in Red Deer. Don discusses the health care experience they had when Vickie needed to be induced and their daughter was born very prematurely and required lengthy hospitalization.

### **Salient Themes:**

#### **III Collaboration**

1. Development of trusting and working relationship between health care professionals, patient and family
  - c. continuity of staff

### **Learning Elements:**

- Relationship building process
- Continuity of care

“Part of the communication problem we found was that the neonatologists rotate between the three hospitals. So you establish a good relationship with a doctor, understand the treatment plan and in two weeks, that doctor is gone. You then have to start all over again with the next doctor, in developing a relationship and rapport. Plus I am sure the new neonatologist has to get up to speed in knowing my child and they often come in with a different treatment plan. The only constant is us but we don’t have the power to really say anything about what is going on.”

### **Health Provider Discussion Questions:**

1. As a health care professional, is the problem of short term rotations a concern for you?
2. How does it influence your practice of family centred care?
3. What can be done to improve this problem?

### **Parent Discussion Questions:**

1. Have you had any experiences regarding staff continuity in the care of your child?
2. Do you have any suggestions to help with this concern?

## Family Interview with Connor and Lise

Connor and Lise have a daughter Alexandra. Lise's brother lives with them and he helps out. Connor's mother lives in Olds and sometimes comes to help. Connor has a sister but not from here. Lise has two sisters, one in Calgary and one in Strathmore. Her mother lives in High River but is sick and unable to help. Lise's father lives in France. They have a network of friends who help out in many ways but they are scared of Alexandra's fragile condition to help care of her. They have hired a student to help with her care.

Alexandra was born premature with genetic abnormalities. She is deaf, has a heart murmur along with feeding problems and seizures. Alexandra has had surgeries for her heart and stomach. Connor and Lise shared their thoughts regarding Alexandra's health care experience.

### Salient Themes:

#### III Collaboration

1. Development of trusting and working relationship between health care professionals, patient and family
  - c. continuity of staff

#### VII System policies and procedures

1. Program changes and flexibility
  - b. assignment and scheduling of multidisciplinary patient

### Learning Elements:

- Parent confidence with safe nursing care
- Policy revision regarding nurse-patient continuity

"We find shift changes to be a very big problem at the ACH. It is rare to get the same nurse twice, it is almost like they try to give you a different one every time. It is hard for us to explain Alexandra's care. She is very complicated and her care is very specific. She is not your normal baby."

"I asked if it was possible to get the same nurse because we wanted to get someone that we have already explained how we wanted her care done, in order to have some consistency in our lives. Most of them are willing to do that and learn her special care, but it takes more than one night to learn. When I ask if that nurse could have her the next time, they said that would not be possible because of the schedule. "It is not in our capabilities." It depends on who you talk to. Some do not want the nurses to get attached to the children. Some of them say it is because the schedule is so crazy. It is not really a part of their policy to have the same nurse over again. You never really get the same story from anyone. I thought that was a dumb policy. That is one of our bigger complaints."

### Health Provider Discussion Questions:

1. What do you see as the advantages and disadvantages for staff-patient continuity in your area of practice?
2. How do you provide continuity of care to your patients?

### Parent Discussion Questions:

1. From your health care experiences, did it matter to you or your child to have staff continuity when they cared for your child? Why?

### Did you know?

Family centred care approach leads to greater parent satisfaction.

### **Family Interview with Moira**

Moira's family is made up of her father, mother and brother. Her parents are divorced and her mother has remarried. Moira lives with her mother, stepfather, brother and stepsister. Her brother and stepsister are both four years older than her. Moira was 12 years old and in grade 7 when diagnosed with leukemia. During the course of her chemotherapy treatment, her mother and stepfather separated. Moira is now 18 years old and is providing information about her health care experience.

### **Salient Themes:**

#### **III Collaboration**

1. Development of trusting and working relationship between health care professionals, patient and family
- d. frustration of teenage patient

### **Learning Elements:**

- Teaching and learning process with teenage patients

"Sometimes doctors came in the room when my parents were there and he talked like I was not even in the room. There were things that I did not understand, but again I did not have the opportunity to ask or get it clarified. When I did ask a question, he would say, "I'll explain that later." I felt he just brushed me off. My mom was good. She would later explain to me to the best of her knowledge but at the same time as a parent, she was trying to censor me from some of it."

"There were times when the doctors tried to explain but other times I did not understand. With some doctors I was comfortable telling them I did not understand. With other doctors, I just was not comfortable. There were some doctors I was really intimidated by and I just tried to have the least exchange with them as possible. There was a dietician that I was more comfortable talking to than I was with any doctor because she would explain everything at my level and I could ask questions. None of my questions to her were silly. Whereas I think my main oncologist thought I was asking totally moronic questions."

### **Health Provider Discussion Questions:**

1. In your professional role, how do you deal with communication and teaching with teenage patients?
2. Is there anything you would do differently?

### **Parent Discussion Questions:**

1. How did your teen feel about the communication and teaching process provided by health care professionals throughout his or her health care experience?
2. What went well? What could have gone better?

### **Did you know?**

**Family centred care respects children and youth by talking to them and not around them.**

### **Family Interview with Cory**

Cory is 14 years old. He lives with his parents Sandy and Greg and his 11 year old brother Nick. His extended family lives in Calgary, Edmonton and Strathmore. He and his family have a good support system. Nick was a healthy and athletic boy who became gravely ill with toxic shock. Nick had a lengthy hospital stay along with numerous surgeries involving him losing both legs below the knees, his fingers and most of his thumbs. After considerable effort from Nick, his family and staff, he has been discharged home. Cory tells about Nick's story and how this experience affected him and his family.

#### **Salient Themes:**

##### **III Collaboration**

1. Development of trusting and working relationship between health care professionals, patient and family
  - e. inclusion of patients siblings

#### **Learning Elements:**

- Discussing the information sharing process between health care professionals, patient, parents and siblings
- Discussing ways for siblings to be included in the patient's health care experience

"Information was usually given to my mother. She was kept very well informed and she told me what was happening. That was a good way for me to know what was going on. If I was curious, I would just ask her and she would tell me. If I had a question when the doctors were there, I would wait and ask my mom. If she did not know, she would ask the doctors. That was the route I went to get information because the doctors were really busy. My mother knew them better than I did because I was only there every evening and she was there during the day. She also knew what they were talking about. I'm not sure if they talked to me I would understand. She put it into words that I could understand."

"When the doctors came in, I would get out of the way when they were doing tests and just watch from a distance. Often I would sit in the corner when the staff came in. My mother calls me her little invisible child. Most of the time the center of focus is always Nick and I usually got ignored. I was alright with that because I could see the doctors and Nick were fairly busy with what they were doing. I knew I would get in the way and I did a couple of times and sometimes the consequences were not pretty."

**Health Provider Discussion Questions:**

1. In your professional role, how do you deal with sharing patient information with siblings?
2. What factors influence how you proceed with this?
3. From your past experiences, what would you do differently?

**Parent Discussion Questions:**

1. How did your children gain information regarding their sibling's health care situation?
2. What ways did health care professionals share information or include your children in their sibling's care?
3. Was this a satisfactory process for you as a parent and your children?

### **Family Interview with Sandy**

Sandy is married to Greg who works in the oil industry. They have a 14 year old son Cory and an 11 year old son Nick. Sandy's parents and brother live in Strathmore. Greg's sister and mother are in Calgary and brother and sister in Edmonton. They have a good support system. Nick was a healthy and athletic boy who became gravely ill with toxic shock. Nick had a lengthy hospital stay along with numerous surgeries involving him losing both legs below the knees, his fingers and most of his thumbs. After considerable team effort from Nick, his family and staff, he has been discharged home. Sandy tells about Nick's story.

### **Salient Themes:**

#### **III Collaboration**

2. Family members as part of the collaborative team
  - a. parent involvement with multidisciplinary team

### **Learning Elements:**

- Respect family's knowledge of their child and situation
- Support families as partners

"In the beginning there were multi-disciplinary meetings that I was not involved in. On some occasions when I was there for a meeting, they soon realized that it would be helpful and be an asset to have me attend all the meetings. I often had the most current information. There were a lot of changes throughout the weekend. Infections developed or some condition got better. Sometimes you could clarify concerns. I would like to say that if you have a fairly intelligent and rational parent, then it would be helpful to include the parent earlier on because they are often the one consistent person there day after day. It depends on the person you are dealing with. I am not saying that all parents would be helpful and some individuals would not be helpful all the time. I think that someone who is there 24/7 and trying to learn everything and be an advocate for their child would be beneficial. It would not be a bad thing to consider having them attend the meetings."

### **Health Provider Discussion Questions:**

1. How would you feel if family members regularly took part in multidisciplinary meetings? What would the pros and cons be for both the health care professionals and the family?

### **Parent Discussion Questions:**

1. How would you feel if you were asked to take part in multi-disciplinary meetings regarding the care of your child? What would the benefits be for you? What would the benefits be for the multi-disciplinary team?

**Did you know?**

**Professionals practicing family centred care partner with parents in decision making.**

### **Family Interview with Kathy and Ray**

Ray and Kathy are married and have two daughters. Sandra is turning 11 years and Erin is 8 1/2 years. Ray's parents live near Edmonton. Kathy has a brother and sister in Grande Prairie. Her mother is in Lethbridge.

Kathy had no previous problems during her pregnancy. During delivery they noticed that Erin had isolated hydrocephalus. She was transported from the PLC to the NICU at ACH. Erin required surgery to deal with the hydrocephalus. Both Kathy and Ray provided information about Erin's health care experience.

### **Salient Themes:**

#### **III Collaboration**

2. Family members as part of the collaborative team
  - a. parental involvement with multidisciplinary team

### **Learning Elements:**

- Collaborative process
- Management of different opinions
- Respect for family information and requests

"We did have some problems with the early intervention team at the hospital. They were assessing her physical strengths and that made perfectly good sense. Some of the exercises they wanted us to do with her were questionable. She was not crawling. She had a big head to hold up. That was fine and we thought she would get there. Some of the strategies did not seem to make sense. No matter what we said about her condition and that we felt she needed to get bigger before she would be able to do these specific exercises, no changes were made. Finally we had enough. They did not listen to us."

"They had an agenda with a set of goals based on the assessment. Personally, I did not have too many concerns in that regard because we thought Erin just needed to get a little bigger and stronger and then it would come. Maybe that team needed to look at who the parent was. They need to be able a judge of character and say, "OK this mother is a nurse. She obviously is intelligent and educated. She has another child". Finally, Kathy said she was not coming back there anymore. This team was not adding any value for us."

### **Health Provider Discussion Questions:**

1. Can you identify any impediments to collaborative family centred care in this family story?
2. How might Kathy and Ray have a better experience of being heard?

### **Parent Discussion Questions:**

1. What suggestions do you have for Kathy and Ray to improve the working relationship with the early intervention team?

## Family Interview with Don

My family consists of my wife Vickie and my daughter Jacquie who is almost 4 years old. My wife has her parents, aunts and uncles here. She has 3 siblings of which one is in Calgary. My family is all out east outside of a brother in Red Deer. Don discusses the health care experience they had when Vickie needed to be induced and their daughter was born very prematurely and required lengthy hospitalization.

### Salient Themes:

#### III Collaboration

2. Family members as part of the collaborative team
  - a. parental involvement with multidisciplinary team

### Learning Elements:

- Sharing information between professionals and families
- Valuing parent contributions to the team

“To keep informed about Jacquie and what the doctors were doing, it was great that the chart was there. The first thing we did when we got to the unit was read what was happening. It was expected that the parents read the chart. We were allowed to be present at rounds and I do mean “allowed” because that was how it felt. It seemed that there was the expectation that you would not interfere during rounds. You were given a chance to ask questions, but only at the end. You really felt like you were a guest and it was a privilege to be a part of the rounds. Sometimes I felt we were listened to and what I said was valued and respected. It really depended on the doctor, some yes and some no.”

“The whole idea of collaboration and being part of a team really depended on the doctor. You are consulted, but you really don’t have the knowledge to make informed choices. You are presented with options of, “You can do this and it will have these benefits or you can do that and it will do all these bad things. Which one do you want to choose?” I did not really think you had a choice. It was more like they were informing you. Maybe that was fine in some cases.”

### Health Provider Discussion Questions:

1. What have been your experiences regarding parents involved in multidisciplinary team meetings or rounds?
2. Was this a successful endeavor? Why?

### Parent Discussion Questions:

1. Why is it important for you as a parent to attend multidisciplinary meetings or rounds regarding your child?
2. What benefits do you bring when you attend these meetings?

### Did you know?

Family centred care involves talking to patients and families, not around them.

## **Family Interview with Connor and Lise**

Connor and Lise have a daughter Alexandra. Lise's brother lives with them and he helps out. Connor's mother lives in Olds and sometimes comes to help. Connor has a sister but not from here. Lise has two sisters, one in Calgary and one in Strathmore. Her mother lives in High River but is sick and unable to help. Lise's father lives in France. They have a network of friends who help out in many ways but they are scared of Alexandra's fragile condition to help care of her. They have hired a student to help with her care.

Alexandra was born premature with genetic abnormalities. She is deaf, has a heart murmur along with feeding problems and seizures. Alexandra has had surgeries for her heart and stomach. Connor and Lise shared their thoughts regarding Alexandra's health care experience.

### **Salient Themes:**

#### **I. Communication**

1. Communication with patients and families
  - f. empowerment of families

#### **III Collaboration**

- 2.. Family members as part of the collaborative team
  - a. parental involvement with multidisciplinary team

### **Learning Elements:**

- Parents feeling confident caring for their child

"The palliative care doctors all know that our preferred place is at home and they make our preference a primary goal. They work to help our family get back home soon. Everyone knows us now and they treat us well. For example, in Emergency, they see us so often that as soon as we go in there and say," Baby seizure. Right this way." They get us in right away and into our own room so we don't have to expose Alexandra to other sick kids. She is so fragile!"

"Neurology allows us to make our own decisions about Alexandra's medication. They tell us all our options and trust us with the decisions. Neurology and Palliative Care Teams really make us feel like we are making good choices. I often hear that we are a pleasure to work with and that our choices are logical. They make us part of the team by including us in the decision making."

### **Health Provider Discussion Questions:**

1. This family felt empowered in confidently knowing they are doing a good job caring for their daughter. In your professional role, how do you empower your patients and families?

### **Parent Discussion Questions:**

1. What have your experiences been like working with a multidisciplinary team?
2. Did you feel as a parent you were involved as one of the team members?
3. Did you feel they supported and enabled you as parents to confidently care for your child?

**"Neurology and the Palliative Care Teams really make us feel like we are making good choices."**

## Family Interview with Cory

Cory is 14 years old. He lives with his parents Sandy and Greg and his 11 year old brother Nick. His extended family lives in Calgary, Edmonton and Strathmore. He and his family have a good support system. Nick was a healthy and athletic boy who became gravely ill with toxic shock. Nick had a lengthy hospital stay along with numerous surgeries involving him losing both legs below the knees, his fingers and most of his thumbs. After considerable effort from Nick, his family and staff, he has been discharged home. Cory tells about Nick's story and how this experience affected him and his family.

### Salient Themes:

#### III Collaboration

2. Family members as part of the collaborative team
  - b. patient's sibling involvement with multidisciplinary team

### Learning Elements:

- Determining sibling involvement with patient's care and discharge teaching

"The staff taught me some things about lifting Nick. Nick actually taught me the best way and the most comfortable way to move him from his bed to the chair. I was doing that at the hospital and at home. My mom's back was getting sore because she was helping him most of the time. My dad would often come instead. A physiotherapist never came to teach me how to transfer. It was OK to have Nick teach me that. It was fairly simple."

"I would've also liked to have been included in Nick's physiotherapy, seeing what he was doing and knowing how to help him out if he was doing those exercises at home. I knew one of his physiotherapists fairly well, and I would have felt comfortable asking her if I could come too but I think I was busy helping my mom doing other things around the hospital. That is one of the reasons I did not get involved more. It would have been nice if there was a bit of initiative from the physiotherapist to ask if I wanted to be involved."

"My mom taught me some emergency procedures regarding his central line and what to do if Nick started to bleed. We had an emergency kit and she taught me how to use everything in it. It didn't really matter to me if the staff or my mother taught me those emergency procedures."

### Did you know?

Family centred care includes persons who are important to the parents and family regarding the care of the child.

**Health Provider Discussion Questions:**

1. What are your beliefs regarding sibling involvement with your patients' care?
2. From your experience, what roles can siblings play regarding the patient's health care situation?
3. What do you think of this family story? What aspects would you change? Why?

**Parent Discussion Questions:**

1. How were your other children involved with their sibling's health care experience?
2. How was this arranged and by whom?
3. What comments did your children have regarding being involved in their sibling's health care experience?

## Family Interview with Lena and Bob

Lena and Bob are married and have four daughters. One daughter lives in Edmonton, one daughter lives in Calgary on her own and the other two daughters live with them. Bob's mother is in Calgary and he has a sister in Invermere. Lena's family is out east except for a brother in Red Deer. Their supports also include friends and the people they work with. Sharon, their 17 year old daughter has problems with her spine which has given her lots of pain. Sharon had back surgery and had many complications post-operatively. Lena and Bob spoke about Sharon's health care experience. They also provided input on Sharon's behalf, who shared her thoughts with them about her hospital experience.

### Salient Themes:

#### III Collaboration

2. Family members as part of the collaborative team
  - c. parent is the predominant caregiver

### Learning Elements:

- Family members discussing their roles involving patient care with staff
- Collaborative solutions between family and health care staff

"What really bugged me was the expectation from staff that parents will take care of the child at the hospital. When Sharon needed to go to the bathroom, we had to carefully roll her to the bedside, lift her up, unplug all the machines, help her shuffle to the bathroom which sometimes took up to 15 minutes to get to the washroom, hold her so she does not fall, record the output, and then get her back into bed and reconnect her to all the machines. Doing that frequently is exhausting."

"I think hospital staff needs to be aware this is happening and offer to help with her activities sometimes. After awhile, when Sharon needed to go to the bathroom, I'd tell her to ring for the nurse then leave for coffee. I was just too tired to do it again. I'll be doing this 24/7 when she goes home!"

"I'm willing to help as Sharon's father when hospital staff has more critical problems but when the staff have a down time, it is important for them to come back. Often nurses see parents doing basic care and they're happy to relinquish that task to them for the rest of the stay. It would be nice for them to offer to help sometimes. Often Lena did the majority of the work because of lack of staff. I wouldn't want to do this for Sharon and nor would Sharon want me to bathe her, so we're lucky to have Lena there. Some children do not have that flexibility. I do not think the child should have to wait because there are not the appropriate people around to help" replied Bob."

### Did you know?

In family centred care practice children, families and health professionals openly discuss their respective roles.

**Health Provider Discussion Questions:**

1. What would you do in your practice to prevent how Lena and Bob felt in this situation?
2. What might you say to Lena and Bob to build a better working relationship?

**Parent Discussion Questions:**

1. What would you do if you were in Lena and Bob's situation?
2. How do parents prevent this occurrence from happening when their child is in the hospital?

### **Family Interview with Connor and Lise**

Connor and Lise have a daughter Alexandra. Lise's brother lives with them and he helps out. Connor's mother lives in Olds and sometimes comes to help. Connor has a sister but not from here. Lise has two sisters, one in Calgary and one in Strathmore. Her mother lives in High River but is sick and unable to help. Lise's father lives in France. They have a network of friends who help out in many ways but they are scared of Alexandra's fragile condition to help care of her. They have hired a student to help with her care.

Alexandra was born premature with genetic abnormalities. She is deaf, has a heart murmur along with feeding problems and seizures. Alexandra has had surgeries for her heart and stomach. Connor and Lise shared their thoughts regarding Alexandra's health care experience.

#### **Salient Themes:**

##### **III Collaboration**

2. Family members as part of the collaborative team
  - c. parent is the predominant caregiver

#### **Learning Elements:**

- Parent confidence with patient safety

"I wrote a 20 pages long care plan. I can't and don't want to have to explain how to care for Alexandra twice a day, every time I am in the hospital. Connor and I found it easier to do all her care ourselves in the hospital. Every time we left it up to them there were major mix-ups. There were problems with wrong medications, not bringing the medication at the right time, forgetting to bring her feeds and leaving her feeds out for over 8 hours so it is going bad. These mistakes could cause Alexandra problems."

"I know everyone has Alexandra's best interest in mind, but at the same time it's hard because we want her care done a certain way. It's so tiring and overwhelming that you just want to break down and cry. We are always on our toes, and our confidence in the staff is low. We know that each and every one of the nurses would take care of our baby the way she needs if they had time but they don't have time to learn and care for Alexandra's very overwhelming needs. It's very tiring but it's better than not doing it."

"If we could have someone do it that we trusted, we wouldn't do it all the time – we would feel comfortable with taking a break. Sometimes I say to myself, maybe I should sit back and let them do it and see how it goes. When I did, problems happened, especially with medication and the G-tube. Fixing the mistakes that the nurses made is tiring and frustrating. Twice I had to change Alexandra's G-tube because a nurse plugged it with medication and did not know how to fix a plugged G-tube."

**Health Provider Discussion Questions:**

1. Describe the system impediments to family centred care in this family story?
2. What would you do to improve the working relationship between Connor, Lise and the health care professionals?

**Parent Discussion Questions:**

1. What experiences have you had in being the major caregiver in the hospital?
2. How did you deal with the situation?
3. What suggestions do you have to prevent this from happening?

### **Family Interview with Don**

My family consists of my wife Vickie and my daughter Jacquie who is almost 4 years old. My wife has her parents, aunts and uncles here. She has 3 siblings of which one is in Calgary. My family is all out east outside of a brother in Red Deer. Don discusses the health care experience they had when Vickie needed to be induced and their daughter was born very prematurely and required lengthy hospitalization.

### **Salient Themes:**

#### **III Collaboration**

2. Family members as part of the collaborative team
  - d. parent involvement with discharge planning

### **Learning Elements:**

- Parent involvement with discharge planning
- Hospital and community supports in place after discharge

“When our daughter was discharged home, we did feel comfortable and confident with the information we were given but we were scared as hell. I do not think there was anything that would not make us scared. I think the transition for home was handled well. We were involved with that decision as to when she would be transferred home. We stayed overnight one or two nights. There were also home visitations set up by community health. The nurse came to the home once a week to weigh and assess Jacquie. One thing that was very valuable was the Perinatal Follow-up Clinic. It has been extremely helpful to us. When we were discharged, they set us up with the clinic and we will take part in it till she is 5 years old. Since we have been home, we have had really tremendous support and resources for us.”

### **Health Provider Discussion Questions:**

1. Reflecting on past patient discharge experiences, what factors influenced the success of your patient's discharge home?
2. What suggestions do you have to make transitioning from a health care facility to home easier for patients and families?

### **Parent Discussion Questions:**

1. What were your experiences like when your child was discharged home?
2. Do you have suggestions for improvement?

## **Family Interview with Lena and Bob**

Lena and Bob are married and have four daughters. One daughter lives in Edmonton, one daughter lives in Calgary on her own and the other two daughters live with them. Bob's mother is in Calgary and sister is in Invermere. Lena's family is out east except for a brother in Red Deer. Their supports also include friends and the people they work with. Sharon, their 17 year old daughter has problems with her spine which has given her lots of pain. Sharon had back surgery and many postoperative complications. Lena and Bob spoke about Sharon's health care experience. They also provided input on Sharon's behalf, who shared her thoughts with them about her hospital experience.

### **Salient Themes:**

#### **I Communication**

2. Communication between multidisciplinary professionals
  - a. variety of settings

#### **III Collaboration**

3. Collaboration and coordination of health care professionals
  - a. medication regime

#### **VI Patient Safety**

2. Medication administration / medication experiences

### **Learning Elements:**

- Value family information and requests
- Collaborative process with health care professionals

"Sharon stated that not all of the information was shared with members of the team. There were many incidents of medication confusion which she found very frustrating. The morphine made her very itchy so one of the doctors proceeded to give her Benadryl. She started to get some asthma attacks which the staff thought was due to anxiety. As parents, we did not think that it was due to anxiety. She is not an overly anxious person. A different resident came in a couple of days later and said that Benadryl is often a drug that triggers asthma. When he took her off it, the asthma episodes stopped!"

"There was another incident with Pain Services in that they were going to take her off the morphine and put her on another pain medication. I said to them, "I heard this pain medication also works as an anticoagulant. Did you check with Sharon's hematologist?" Later, they set the pump up and started to give it to her. We assumed since we asked the question, they had followed up. A few hours later the hematologist walks in and says, "Why is she on that? She is already on Heparin. They need to find something else to give her. There are other solutions." We felt we were not listened to at all."

"Sharon was vomiting a lot so she was put on Gravol, which knocked her right out. At this time, they were monitoring her to make sure her blood clot did not travel to her brain. They did not want her to be knocked out like that but we could not wake her up. Pain Services came in the next day and just freaked out. "We have to get all the residents together and talk about what medications she can and can not be on." There seemed to be lots of confusion."

**Health Provider Discussion Questions:**

1. What would you do in this situation to promote effective communication and collaboration?
2. Are there any system impediments that influence your collaborative practice in family centred care?

**Parent Discussion Questions:**

1. What do you think about this family story?
2. What role can families play if they are involved in similar situations?

## Family Interview with Connor and Lise

Connor and Lise have a daughter Alexandra. Lise's brother lives with them and he helps out. Connor's mother lives in Olds and sometimes comes to help. Connor has a sister but not from here. Lise has two sisters, one in Calgary and one in Strathmore. Her mother lives in High River but is sick and unable to help. Lise's father lives in France. They have a network of friends who help out in many ways but they are scared of Alexandra's fragile condition to help care of her. They have hired a student to help with her care. Alexandra was born premature with genetic abnormalities. She is deaf, has a heart murmur along with feeding problems and seizures. Alexandra has had surgeries for her heart and stomach. Connor and Lise shared their thoughts regarding Alexandra's health care experience.

### Salient Themes:

#### III Collaboration

3. Collaboration and coordination of health care professionals
  - a. medication regime

#### IV Information Sharing

2. Value / respect patient and family information and requests
  - c. adapting patient care

#### VI Patient Safety

1. Communication between patient, family and health care professionals contributes to patient safety
  - a. staff communication

### Learning Elements:

- Parent confidence with patient safety

"Sometimes there is a breakdown in communication when notes from clinics don't make it to doctors/nurses in another clinic or when important patient information doesn't make it to the clusters when patients are admitted. Alexandra could have died because her neurological status with epilepsy was not a priority after her surgery. After her second surgery, Alexandra had a seizure for 20 minutes. I said, "Please get the medicine into her, she's to have it after 5 minutes." They said, "We need the doctor's order for that." "Please get him" I asked. They said they needed a signature. The doctor phoned in, but never showed up for another 20 minutes."

"She was having a seizure for about 2 hours. I pulled the medication from my bag and the nurses said, "No. You can't do that." I said, "That's too bad. I'm going to give it. I do it at home so why can't I do it here? If the doctor can get here before I give it to her, he can stop me. But I'm putting it in. She needs it." And I did. That was really hard and frustrating. She could've had brain damage and died. She has epilepsy and had an emergency protocol ordered but it was not followed through. I could not understand how that happened. That was the scariest time here. It was a severe breakdown in communication. Since then the neurologist has noted on the chart that we are allowed to give the seizure medications. At least we know that order is always in the chart. This problem has been fixed but we had to fight for it."

"That was the scariest time here. It was a severe break - down in communication."

**Health Provider Discussion Questions:**

1. What suggestions do you have to improve communication between health care professionals regarding patient information?
2. Do you see a role for parent involvement as part of the solution?

**Parent Discussion Questions:**

1. What suggestions do you have to improve communication between health care professionals regarding patient information?
2. Do you see parents playing a role as part of the solution?

## Family Interview with Catherine

The Crocker family is made up of Catherine and her three daughters, Karen 17 years, Ellen 15 years with Down Syndrome and Lily 12 years. Catherine is divorced and Tom, the girls' father sees them on Sundays. Catherine's family lives out east, with her mother in Windsor, her father in Quebec, her two sisters in Toronto and her brother in Quebec City. Tom's parents and seven siblings all live in Edmonton.

Lily has experienced medical and mental health issues for the last six years. She has said she wants to kill herself. She has been diagnosed with a nonverbal learning disability, a hand tremor, Tourettes, obsessive compulsive disorder and ADHD. Lily is being further assessed for narcolepsy and possible seizures.

### Salient Themes:

#### III Collaboration

3. Collaboration and coordination of health care professionals
  - a. medication regime

#### VI Patient Safety

2. Medication administration / medication experiences

### Learning Elements:

- Professional accountability and support

"The other thing that got confusing was when neurology put her on some medications for her tremors, while she was on her OCD medications. Apparently you can't take her OCD medications and one of her tremor medications together. Lily was hallucinating at school. I could not get in to see Dr. Frans so I just decided I did not care about the tremors and she could just use the laptop and I'd zip up her zippers on the days when her tremors are bad."

"Dr. Frans told me to take Lily off her SSRI so she could try her on Strattera for her ADHD. Unfortunately Strattera made her pass out. There were side effects when those medications are taken together. I ended up taking her off that medication too and putting her on something else because I couldn't get in to see Dr. Frans. Nobody seems to be coordinating anything. There was no coordination. I would go to Dr. Lister for the ADHD medications because Dr. Frans doesn't do that. He would say, "I don't know. What do you want her on? What do you think she should be on?" They always ask me that. If I was a doctor, I wouldn't be here."

"Things escalated with Lily and we tried so many medications. She must have been on at least 24 different medications to control her symptoms. Most of the medications had side effects and her self injury was getting to the point where it had to be dealt with. Dr. Frans had tried using a bunch of "out there" medications. That's when Dr. Lister, her pediatrician said to me, "I'm out of here. I don't even know what these medications are."

Did you know?

Family centred care is committed to providing safe practice.

**Health Provider Discussion Questions:**

1. What are the impediments to family centred care in this family story?
2. Describe how you would go about trying to alleviate them?

**Parent Discussion Questions:**

1. What experiences have you had regarding your child's medications regime when it involves prescriptions from different health care professionals?
2. What suggestions would you have for Catherine to help her?

## Family Interview with Connor and Lise

Connor and Lise have a daughter Alexandra. Lise's brother lives with them and he helps out. Connor's mother lives in Olds and sometimes comes to help. Connor has a sister but not from here. Lise has two sisters, one in Calgary and one in Strathmore. Her mother lives in High River but is sick and unable to help. Lise's father lives in France. They have a network of friends who help out in many ways but they are scared of Alexandra's fragile condition to help care of her. They have hired a student to help with her care.

Alexandra was born premature with genetic abnormalities. She is deaf, has a heart murmur along with feeding problems and seizures. Alexandra has had surgeries for her heart and stomach. Connor and Lise shared their thoughts regarding Alexandra's health care experience.

### Salient Themes:

#### III Collaboration

3. Collaboration and coordination of health care professionals
  - b. Palliative Care Team

### Learning Elements:

- Coordinator reduces parent stress and increases quality of patient care

"It would have been great to have someone in charge and coordinating Alexandra's care sooner. Up until recently we were doing a lot of that foot work by ourselves. It is tough to do this while trying to deal with a sick baby. A coordinator is needed, especially when you have more than one department or clinic involved. Each department does their own job exceptionally well but something is needed to help combine them together."

"Luckily, for the last 2 months, the Palliative Care Team has helped us. Palliative care doctors know Alexandra well and they also act as an intermediate between us and the other hospital doctors. They share her history with the other doctors rather than us having to go over her history 10 times a day."

"This team does a lot of the coordinating of care for us. It is an amazing benefit to be part of one general team who helps coordinate the chaotic hospital system for us. After explaining our desires to the Palliative Care Team, we have become a lot more comfortable and our life is more bearable. It would have been wonderful to have had help like this earlier when Alexandra's health concerns started becoming so complex."

### Health Provider Discussion Questions:

1. In your professional practice, do you see the need for a coordinator position to assist patients and families during their health care experience?
2. How do you envision a coordinator position be put into practice?

### Parent Discussion Questions:

1. Did you need someone to help coordinate and collaborate with other health care professionals regarding the needs of your child?
2. How do you envision a coordinator position be put into practice?

#### Did you know?

Practicing family centred care reduces health care costs.

## Family Interview with Carley

Carley and her husband Jim have three children; Julie 13 years, Robert 11 years and Dana 9 years. They had one son that died at three days old, 7 years ago and another son died at 6 years, one year ago. Rex was a medically fragile and globally delayed child. Carley has no family here. Jim's parents live in Manitoba and he has a sister here. They have developed a network of friends from church and their children's schools and activities. Carley discusses their experience with Rex's health situation involving palliative care.

### Salient Themes:

#### III Collaboration

3. Collaboration and coordination of health care professionals
  - b. palliative care experience

#### V Support

1. Multidisciplinary support for patient and family
  - g. palliative care

### Learning Elements:

- Assessing and meeting patient and family needs

"The best thing we did was to ask if our son qualifies for the Palliative Care Team. I somehow knew that with this team there would be better continuity of care with the doctors and a better understanding of what we needed as a family. The Palliative Care Team has three physicians, two nurses and a social worker who communicated with each other and knew Rex. They would come in, talk to you and assist you with any concerns. Also, we had access to the team 24 hours a day."

"With the Palliative Care Team, it was easier to get admitted and discharged because we did not have to go through Emergency and wait long hours. It made our lives so much easier. After talking to the Palliative Team, we'd go to the cluster and the orders would be called in. The palliative care doctor would come in every day and make and change the orders. We still were involved with a variety of clinics and the Palliative Team oversaw the coordination and care of all the specialty clinics. When we wanted Rex to go home on home oxygen, the palliative team facilitated this process."

"One time I asked that we not have students anymore. The Palliative Care Team further explained my request, smoothed things over and let people know we were not angry but this was just a quality of care choice. Often they could intervene and explain on our behalf. It would always go over better when it came from another professional."

"I always felt I was well informed and involved with the strategizing and decision making. They listened to our requests and we felt part of the collaborative team. We started with the Palliative Team in May and Rex died in November. In hindsight, I wish we were part of palliative care sooner because it would have made the admissions so much easier and our family life so much better."

"I somehow knew that with this team there would be better continuity of care.... and an understanding of what we needed as a family."

**Health Provider Discussion Questions:**

1. This family really appreciated collaboration, coordination and support from the Palliative Care Team. How have you participated in this type of team work in other health care situations?

**Parent Discussion Questions:**

1. This family really appreciated what the palliative team provided for them. From your health care experiences, what would you have appreciated to improve your situation?

### **Family interview with Marla**

Marla and her husband John have a son Adam, 10 years old. Marla has an 18 year old daughter and John has a 21 year old daughter from previous relationships. Marla's mother and four siblings all live in the Yukon. John's mother and sister are in Kamloops and three siblings in the Yukon. His mother is in the Siksika Nation. That is the reason why he moved to Calgary to work and to live on the reserve. Adam is being treated for a chronic and progressive condition affecting all his major organs. He has been treated since he was 1 ½ years old.

#### **Salient Themes:**

##### **III Collaboration**

3. Collaboration and coordination of health care professionals
  - c. appointment schedules with health care professionals

#### **Learning Elements:**

- Coordinator position needed for families

“The big problem at the hospital is that no one seems to be in charge to coordinate things. Cheryl is a nurse in charge of the cluster. I am tired of asking. I am tired of reaching out and keep asking for help. I would like a schedule and have people be there when we are there. Everyone seems to have stopped coming.”

“The psychologist worked with us because of Adam's weight. We saw the psychologist 4 or 5 times and after that he just didn't show up again. There were three times that me and John showed up at 1:00 and we waited till 1:30 and he still doesn't show up. We left because I am not going to wait. We would meet with him in Adam's room because he talked to Adam for a bit. I don't know what happened. He never showed up again. We do not know why. I never asked questions about it. I just let it go.”

“We have also seen a dietician. We have not seen her for a while too. The physiotherapist only came here once and Adam was acting up for her and I never saw her again. I don't know what happened with that.”

#### **Health Provider Discussion Questions:**

1. What are the impediments to family centred care in this family story?
2. How do you envision a coordinator of care for patients could be put into practice?

#### **Parent Discussion Questions:**

1. Would you appreciate someone to help coordinate the care your child receives? Why?

“The big problem at the hospital is that no one seems to be in charge to coordinate things.”

## Family Interview with Barb

Barb and Jim have two children, Tom 7, and Angelina 2. They live in Calgary. Barb's parents live in Calgary and her siblings live out of the country. Jim's mother lives in Grande Prairie and he has two siblings in Edmonton. Angelina is globally developmentally delayed and also has some kidney abnormalities since birth. Barb provides further details regarding their family story.

### Salient Themes:

#### III Collaboration

3. Collaboration and coordination of health care professionals
  - d. health care professionals from different settings

#### Learning Elements:

- Collaboration process amongst health care professionals
- Factors within the system influencing collaborative family centred care

"There were some good things that happened in that health care professionals were able to refer me to appropriate people right away. I would not have had a clue as to who to see. For example, the physiotherapist had recommended me to call Early Intervention to have someone come and help me with Angelina's developmental delays. She also arranged for me to see the Infant Team. I would never have known about these programs."

"The early intervention worker was very direct and helpful in letting me know what I should do now. She had noticed that Angelina did not respond when a loud noise occurred. She made a referral to audiology and that happened within 3 weeks. That seemed to have happened faster than if it was a doctor's referral. It turned out that she can hear fine. Once you are involved with the physiotherapy, occupational therapy professionals, you can see that they really work for the families and for what your child needs holistically as a whole person and not just a kidney, or brain or heart. I am finding there is greater help with this global referral."

"You can see that they really work for the families and for what your child needs holistically as a whole person and not just a kidney, or brain or heart."

#### Health care professional Discussion Questions:

1. Reflect on a situation you have had with a complex patient and family needing multidisciplinary help and coordination. Was this a successful collaborative experience for the health care professionals, patient and family? Why?
2. Can you identify any factors in the health care system that influences the success of collaborative family centred care?

#### Parent Discussion Questions:

1. What do you think about this family story? What experiences have you had where the health care professionals worked hard to meet your child's needs?
2. What are some factors that may influence the outcome of collaboration and coordination amongst health care professionals when dealing with patients and families?

## Family Interview with Catherine

The Crocker family is made up of Catherine and her three daughters, Karen 17 years, Ellen 15 years with Down Syndrome and Lily 12 years. Catherine is divorced and Tom, the girls' father sees them on Sundays. Catherine's family lives out east, with her mother in Windsor, her father in Quebec, her two sisters in Toronto and her brother in Quebec City. Tom's parents and 7 siblings all live in Edmonton. Lily has experienced medical and mental health issues for the last 6 years. She's been diagnosed with a nonverbal learning disability, a hand tremor, Tourettes, obsessive compulsive disorder and ADHD. Lily is being further assessed for narcolepsy and possible seizures.

### Salient Themes:

#### III Collaboration

3. Collaboration and coordination of health care professionals
  - d. health care professionals from different settings

#### V Support

1. Multidisciplinary support for patient and family
  - k. mental health experience

### Learning Elements:

- Coordination of patient care
- Professional accountability and family recourse

"We had a team meeting to discuss Lily's medical and mental health issues. It was decided Lily needed some classroom interventions. Dr. Frans, Lily's psychiatrist was to set up a school meeting but it never took place. Nothing was followed up. She said she got busy and couldn't do it. Grade 6 was a nightmare. I begged Dr. Frans to have a school meeting because they needed strategies for social scripting. There was to be a follow-up meeting with Dr. Frans, Dr. Lister, Lily's pediatrician and Lily's receiving school team for grade 7. Dr. Frans was to set up the meeting but it never happened."

"The school behavior psychologist said her job is only to implement the psychiatrist's strategies. When we started with Dr Frans, she was to do cognitive behavioral therapy with Lily to deal with her worries. Dr. Frans talks 5 minutes with Lily, asks her to leave, talks to me and then gives me a new prescription. There is no work being done with Lily. Dr. Frans told me to go get it done privately because she doesn't do that now. There's no communication with the school. I don't know what's going on."

"The school psychologist told me that Lily needs to be on the waiting list for Access Mental Health because I was not able to see Dr. Frans soon. Basically right now no one is talking to anybody or working together. Lily is receiving absolutely no service. Where do I go to tell someone about this? What do I do? We have an appointment with Dr. Frans in January, next year, that will be almost 10 months since we last seen her. The hospital has never heard of the Developmental Mental Health Clinic referred to me by Dr. Frans. Lily is lost in space. The Sleep Clinic has her on a 2 to 3 year waiting list for testing. Dr. Wilf, the neurologist doesn't want to do anything else about her seizures until we get the sleep assessment done. It has been so frustrating."

### Did you know?

Professionals practicing family centred care listen to patients and families.

**Health Provider Discussion Questions:**

1. Can you find the impediments to family centred care in this story and describe how you would go about trying to alleviate them?

**Parent Discussion Questions:**

1. How would you feel as a parent if health care professionals were not following through with their plan of care and not communicating amongst themselves in order to provide the best care for your child? What would your recourse be?

## Family Interview with Phillip

Phillip is 18 years old and lives with his parents and two brothers. Michael is 20 years and Andrew is 15 years with Down Syndrome. They have no immediate family in Edmonton but they do have great support from family members in B.C., Manitoba, and Alberta along with many friends in Edmonton. Andrew was diagnosed with leukemia four years ago and is currently in remission. Andrew recently had surgery on his feet due to complications from his chemotherapy and will be in casts for 10 weeks. Phillip's mother is a nurse and understands the medical aspects of Andrew's conditions.

### Salient Themes:

#### III Collaboration

3. Collaboration and coordination of health care professionals
  - d. health care professionals from different settings

### Learning Elements:

- Collaboration process amongst health care professionals
- Evaluation of patient and family care coordination involving different health care professionals in each area of practice

“Health care professionals should do discharge planning and teaching prior to two days before discharge. The occupational therapist from Home Care came to our home the day before discharge to determine what modifications were needed. We learned the proper angle for ramps to be constructed. The day he got home, my father and I made ramps inside and outside the house! She taught my mother how to transfer Andrew to and from the van using a transfer board and transfer belt.”

“The occupational therapist was also able to help my mother find more information about transportation for Andrew. When my mother called, they said she was too late to receive any transportation assistance and that the hospital was to complete all of those forms way in advance. The occupational therapist was a bit apologetic and said she normally comes to the home weeks prior to surgery but somehow Andrew's file slipped through the cracks. It would have helped if there was better coordination at the hospital and therefore make all of this less stressful on our family. We would have had a better idea how to cope with Andrew's new limitations. My mother had already rented equipment like the commode and wheelchair in advance. That was a good thing.”

### Health Provider Discussion Questions:

1. In your area of practice, how do you plan and coordinate effective patient and family care when different health care professionals are involved?
2. What suggestions do you have to improve collaboration and coordination of patient and family care?

### Parent Discussion Questions:

1. Reflecting on your child's health care experience, how effective was the coordination and planning of care at discharge?
2. What would you have wanted done differently?

“It would have helped if there was better coordination at the hospital and therefore make all of this less stressful on our family.”

### **Family Interview with Vicky**

The Smither family consists of Victoria, her husband Jon and their two children, Samantha, 12 years and Emma, 6 years. Emma has special needs due to encephalitis. Jon's parents live in a rural community and Victoria's parents are deceased. Victoria has one sister in Winnipeg and Jon has four siblings. They do not have a lot of family support in the city, but have a good network of friends. Victoria works part time at a hospital as a nurse. Emma has accessed a variety of health services and has had many hospital admissions. Her recent admission was for bladder surgery. Victoria explains more regarding Emma's health care experience.

### **Salient Themes:**

#### **IV Information Sharing**

1. Patient and family teaching
  - a. family member who is a health professional

#### **Learning Elements:**

- Influence of stress on learning
- Importance of timing, pacing, format and repetition when providing health care information
- Assumptions regarding learning style or parent by health care professional

"The nurse's explanation didn't really satisfy me. It would have been helpful if they said, "These are some possible things that might happen after her surgery. If you see them, don't panic". That would have made it more acceptable, easier to handle. Some teaching was done but staff needs to ensure that all questions have been answered. We were told that her pain needs would be high, but it would have been great to have more detailed information because I didn't realize the epidural would be in for four days and the morphine was to be given for a week."

"I would have appreciated if someone came back to me and said, "Did you hear and understand what I said" because I was stressed. Everybody knows when you are stressed you don't hear the same information and maybe you need to be reminded of the information discussed. Written information would have been beneficial. I could have looked at it when I was calm. If some of our needs were better anticipated, it would have been kinder."

"They did give us some suggestions and expectations. Again, being a nurse, you are expected to know certain things that maybe you don't. Maybe your information is out of date or there is new information. I think that is an important point for staff to consider. They need to talk to the family and to include the child so that the child can also anticipate what's happening. And if it is a special needs child, to even spend more time with them to ensure he or she knows what is going on."

**Health Provider Discussion Questions:**

1. Reflect back on your teaching experiences. Were they successful? What would you do differently?
2. If you were in a critical situation, reflect on how receptive and effective you would be as a learner. What would make it better for you?

**Parent Discussion Questions:**

1. If you were Victoria, what would you need to make this a better learning experience?
2. If you were in a critical situation, how effective would you be as a learner? What would make it better for you?

### **Family Interview with Lena and Bob**

Lena and Bob are married and have four daughters. One daughter lives in Edmonton, one daughter lives in Calgary on her own and the other two daughters live with them. Bob's mother is in Calgary and he has a sister in Invermere. Lena's family is out east except for a brother in Red Deer. Their supports also include friends and the people they work with. Sharon, their 17 year old daughter has problems with her spine which has given her lots of pain. Sharon had back surgery and had many complications post-operatively. Lena and Bob spoke about Sharon's health care experience. They also provided input on Sharon's behalf, who shared her thoughts with them about her hospital experience.

#### **Salient Themes:**

#### **IV Information Sharing**

1. Patient and family teaching
  - b. family discharge experiences

#### **Learning Elements:**

- Teaching and learning process
- Supporting the family at discharge

"Prior to discharge, the nurses showed us how to do the injection and gave me the opportunity to give an injection. They said Home Care was going to come to the house for a couple of times to make sure we were doing it right. That was how it was set up. By the time we were ready to go home, I was able to give the injection once and Bob did not give the needle at all yet. It felt like they were eager to get us out the door."

"The nurse said I did a great job giving the injection and that we did not need Home Care to come in. We said that we wanted Home Care to come. We were leaving at 5:00 in the evening and they said that Home Care could not come tonight but they could come in the morning. We still had to give the evening injection, so what good was that! We felt like we were doing things by the seat of our pants, not feeling totally confident and prepared to give the injection after discharge. We did fine. The back up was not there. The staff should know how long it takes to get these resources in place and should not discharge you until they are in place. I am not a medical person. I am sure there are a lot of other people who perhaps are less knowledgeable and would have lots of problems which could lead to huge safety issues."

#### **Health Provider Discussion Questions:**

1. Can you identify the impediments to family centred care in this family story?
2. Describe how you would go about alleviating them.

#### **Parent Discussion Questions:**

1. What will assist you in learning and remembering a skill which you will be doing for your child after discharge?
2. What would you do in this situation if you were not confident with the skills you were taught at the time of your child's discharge?

"We felt like we were doing things by the seat of our pants, not feeling totally confident and prepared to give the injection after discharge."

### **Family Interview with Cara**

Cara and her husband have three children; a daughter 20 years, a son 16 years, and another daughter 4 years. They moved from New Delhi in 2000. Her husband's family lives in Canada; a brother in Toronto, a sister in Winnipeg, a brother in Calgary, a sister in India, and his father lives with them for 6 months of the year. Cara's parents and siblings are in India. We don't have many friends. I meet with some people but they are not friends. Their youngest daughter Suneet was diagnosed with leukemia and soon relapsed after her treatment was completed. She had a bone marrow transplant. Suneet has recovered well though still has some feeding problems. Cara describes her daughter's health care experiences.

### **Salient Themes:**

#### **IV Information Sharing**

1. Patient and family teaching
  - b. family discharge experiences

### **Learning Elements:**

- Teaching and learning process
- Planning community support after discharge

“At the beginning when Suneet was to go home, I was scared and worried. I felt that I couldn't do it. I said, “I want her home, but I do not want to take care of her tubes.” They said, “If you want to go home, you need to learn to do this.” I am so scared to touch her tubes. “

“When I first went home, they started me with someone coming every week to do this. Home Care came to do the dressing change while I held her. My husband, he can't help because he can't see Suneet so upset. When she sees the dressing stuff, she gets so upset. At the beginning it was very hard to do the dressing changes and the tube feedings. I had some problems and I had to come to the clinic every week for help. They showed me what to do so I could do everything myself. Finally, I started to do it myself, when I got more comfortable. It is better now and Suneet now even helps.”

### **Health Provider Discussion Questions:**

1. Reflect on a past teaching experience you had with a patient or family. Was it successful? What would you do differently the next time?

### **Parent Discussion Questions:**

1. Reflect on past teaching experiences you have had with health care professionals. Was it a positive experience? How could it have been better?

### **Family Interview with Jack**

Jack and his wife Doreen have two daughters, Michelle, 14 years and Allison, 11 years. Jack has his mother and sister in the city but his mother has dementia and is not able to help. His sister is a tremendous support. Doreen's family is all out east. They have support also from Jack's employers and their network of friends. Michelle was diagnosed with leukemia and received a stem cell transplant from her donor sister. Jack reflected on their health care experiences involving their daughter Michelle.

#### **Salient Themes:**

#### **IV Information Sharing**

1. Patient and family teaching
  - b. family discharge experiences

#### **Learning Elements:**

- Elements for successful teaching

"We had great support and education from the staff, especially from the nurses. We had to give Michelle injections of GCSF and had to give Allison injections as well. One of the nurses offered herself so we could give her injections. This way we would know what it would feel like on a person. I said, "No, I'm not going to do that." She had us practice on oranges but told us that it would not feel like that when we did the actual injection. It did give us some practice. She gave us some excellent coaching. We got excellent training on how to clean the broviac catheter."

"We got great help from the dietician regarding Michelle's compromised immune system. We got tons of information about how to properly prepare food, how to wash the food and how to keep our kitchen clean. We were taught about hand washing."

"They provided us with supplies for dressing changes and an emergency broviac kit incase the catheter came out. Staff told us to not travel more than 20 minutes away from the hospital. They gave us good explanations of what we needed to know."

#### **Health Provider Discussion Questions:**

1. What specific strategies or approaches do you use to make patient and family teaching a success?

#### **Parent Discussion Questions:**

1. Think back when you were taught by a health professional. Was the teaching successful?
2. What would you suggest for improvement?

**Did you know?**

**Family centred care practices often decrease the length of hospitalization.**

### **Family Interview with Marla and Valerie**

Valerie and Marla's family consists of their parents and two sisters. Their older sister Carmen lives in Edmonton. Valerie lives by herself in Calgary. Marla and her youngest sister Sharon live at home with their parents Lena and Bob. Their 17 year old sister has had problems with her spine resulting in lots of pain. Sharon had back surgery and many complications postoperatively. Valerie and Marla spoke about Sharon's health care experience.

#### **Salient Themes:**

#### **IV Information Sharing**

1. Patient and family teaching
  - c. sibling experience with patient discharge

#### **Learning Elements:**

- Assessing the patient's caregivers and supporters
- Supporting siblings as partners

"The teaching that occurred was with mostly with our parents. It would have been helpful to also include Valerie and myself in learning how to give the injection in case my parents were not there to do it. I have sometimes given Sharon's shots. Between Sharon and my parents, they have taught me how to do it. The health care professionals never asked if we, the sibling were going to be involved in Sharon's care. They seemed to have this understanding that our parents would be there all the time. They never asked for us to be involved?"

"That would have interested us because we could be a backup. This would relieve the pressure on our parents to have to be home at a specific time to give Sharon her injection. I thought it was interesting that the nurses never taught Sharon how to give her own injections. Now Sharon may not have been receptive to do her injection but she may have in the future, but they did not include her with the initial teaching. They did not ask if she was interested or say that if she does change her mind to let them know. For me, I would think teens Sharon's age would possibly want that control."

"We needed to be more assertive asking questions and making our needs known. We needed to have a comfort level so the staff wouldn't look down on us and say, "Why do you want to know about that when you are not the parent and just the sibling?" I think that's part of the attitude that comes through sometimes. It is the parent's responsibility. Health care professionals do not want to teach other people to do it if they do think it is a necessity. I think even younger siblings would like to partake in their sibling's care. They would like a role and a purpose."

"The health care professionals never asked if we, the siblings were going to be involved in Sharon's care."

**Health Provider Discussion Questions:**

1. As a health professional, what experiences have you had in sibling involvement with your patient's care?
2. What would the pros and cons be for both the health care professionals and the family?

**Parent Discussion Questions:**

1. How would you feel if your children more actively participated in the care of their sibling? What do you see as the advantages and disadvantages?

## Family Interview with Phillip

Phillip is 18 years old and lives with his parents and two brothers, Michael is 20 years and Andrew is 15 years with Down Syndrome. They have no immediate family in Edmonton but they do have great support from family members in B.C., Manitoba, and Alberta along with many friends in Edmonton. Andrew was diagnosed with leukemia four years ago and is currently in remission. Andrew recently had surgery on his feet due to complications from his chemotherapy and will be in casts for 10 weeks. Phillip's mother is a nurse and understands the medical aspects of Andrew's conditions.

### Salient Themes:

#### IV Information Sharing

1. Patient and family teaching
  - c. sibling experience with patient discharge

### Learning Elements:

- Determining family members to be included in family discharge teaching
- Considering the role patient's siblings play regarding their care

"When Andrew got home after his foot surgery, the main area of concern was learning how to safely use the wheelchair and commode. I wanted to know how to safely transfer him to the wheelchair, the commode, the bed, the couch and the van without him weight bearing on his casts. My mother taught me how to do this safely without hurting me or Andrew. That would have been helpful to learn from the physiotherapist because she does this for a living and sometimes it is helpful to get information directly from the health professional. My mother is a nurse so it was helpful too."

"I would have appreciated health care staff asking who would be involved in Andrew's care. My older brother Michael is in Halifax, so that just left me and my parents to care for Andrew. Learning how to transfer Andrew safely was important to all of us. The physiotherapist taught my mom at the hospital but that should have been offered to all of us before he was discharged."

"While Andrew was in the hospital, I really did not feel like I was included or that staff even considered me to be an important person on Andrew's team. This feeling of inclusion happened more when Andrew was back at home. I think people forget about the patient's siblings. They have an important role to play in helping care for their brother or sister."

### Health Provider Discussion Questions:

1. How do you determine who to include when you do patient discharge teaching?
2. What opportunities have you had to include patient's siblings in the discharge planning and teaching? Was this effective?

### Parent Discussion Questions:

1. When your child was being discharged, who was involved in the discharge teaching?
2. Would your children have appreciated being a part of this teaching? Why or why not?

"I would have appreciated health care staff asking who would be involved in Andrew's care.... I think people forget about the patient's siblings. They have an important role to play in helping the family care for their brother or sister."

## Family Interview with Catherine

The Crocker family is made up of Catherine and her three daughters, Karen 17 years, Ellen 15 years with Down Syndrome and Lily 12 years. Catherine is divorced and Tom, the girls' father sees them on Sundays. Catherine's family lives out east, with her mother in Windsor, her father in Quebec, her two sisters in Toronto and her brother in Quebec City. Tom's parents and seven siblings all live in Edmonton. Lily has experienced medical and mental health issues for the last six years. She has said she wants to kill herself. She has been diagnosed with a nonverbal learning disability, a hand tremor, Tourettes, obsessive compulsive disorder and ADHD. Lily is being further assessed for narcolepsy and possible seizures.

### Salient Themes:

#### IV Information Sharing

1. Patient and family teaching
  - d. information regarding patient diagnosis

### Learning Elements:

- Appropriate teaching for patient and family

"I do not feel as a parent that I am an active member of the team caring for Lily. For example, Lily had an MRI. We finally got an appointment to go over the results 3 to 4 months later because they couldn't tell me the results over the phone. They discussed the MRI results and as I am walking out of the room, they hand me a pamphlet and tell me I may want to go to this support group. Not thinking, I put it into my bag and went into the parkade. I then pull it out and read, "Your child has been diagnosed with Tourettes." No one ever said that to me in the room. I went charging back up there and said to the intern, "You are lucky that I already have a child with Down syndrome and I have a thick skin. You don't hand parents a pamphlet that tells them that your child has Tourettes without explaining it to me. What is that based on?" He replied, "The MRI and her tics." I said, "OK, fine, but you know what, that is something you tell me to my face." He didn't look a bit contrite. They don't care."

### Health Provider Discussion Questions:

1. As a professional, what are some of the impediments you face when doing patient and family teaching?
2. What changes are needed so that patients and families are taught effectively?

### Parent Discussion Questions:

1. As a parent, what are your expectations when learning about your child's diagnosis from a health professional?
2. Describe some of your learning experiences with health care professionals.
3. What made the experience successful and what made the experience lacking?

Did you know?

Family centred care practice helps parents understand their child's health concerns.

### **Family Interview with Moira**

Moira's family is made up of her father, mother and brother. Her parents are divorced and her mother has remarried. Moira lives with her mother, stepfather, brother and stepsister. Her brother and stepsister are both four years older than her. Moira was 12 years old and in grade 7 when diagnosed with leukemia. During the course of her chemotherapy treatment, her mother and stepfather separated. Moira is now 18 years old and is providing information about her health care experience.

#### **Salient Themes:**

#### **IV Information Sharing**

1. Patient and family teaching
  - e. teenage patients learning experience

#### **Learning Elements:**

- Teaching and learning process at an appropriate level
- Supporting and empowering teenage patients

"Teaching at the hospital was good. I had a Broviac catheter early in my treatment. My mom and I both learned how to do the dressing change and manage it. That is one thing that the health care professionals were great because they taught me how to do the dressing change. I felt like I had some control. My mom assisted me when I did the dressing changes. When I was at the hospital, the nurses would provide us with all of the supplies and let me do it with my mom."

"I would have loved more written and understandable information about leukemia. A lot of it was given verbally or the written information involved big thick books. I did not have the concentration or the ability to read them."

#### **Health Provider Discussion Questions:**

1. As a health professional, how do you approach patient teaching with a teen to make it meaningful and helpful? What process do you use?
2. What experiences have you had in supporting and empowering teenage patients with their health care situation?

#### **Parent Discussion Questions:**

1. Describe any experiences your child had in which they were given an opportunity to actively participate in their care?
2. How did your child feel regarding the opportunity to participate or not being able to participate in their care?

#### **Did you know?**

**Family centred care helps patients and families to build on their strengths by participating in experiences that enhance control and independence.**

## Family Interview with Ann

Ann and Robert are married and have two children, Lisa 2 1/2 years and Laura 6 months. Robert works fulltime and Ann is on a maternity leave. Robert's parents are in Calgary. Ann's sister is in Calgary and her parents live about 5 hours from Calgary. She has good family support. Laura has been in the hospital since she was 2 1/2 weeks old. Laura has had surgery to remove her ovary and some of her bowel. She has an ostomy and is receiving total parenteral nutrition. Ann provided information regarding Laura's health care experience.

### Salient Themes:

#### I Communication

2. Communication between multidisciplinary professionals
  - a. variety of settings

#### IV Information Sharing

2. Value/respect patient and family information and requests
  - a. listening to family concerns

### Learning Elements:

- Communication process
- Professionals valuing and respecting family's knowledge of their child

"I had a late ultrasound because they thought the baby was measuring smaller and they also found some abnormalities in her abdomen. They suggested I be induced. After she was born, I thought they were to do an in depth abdominal assessment and investigation. I thought it was done, as I requested. I was misled. It was not done. People did not know that she had abnormalities in her abdomen. They gave her a few palpations and said her belly was fine. I kept asking my family doctor for Laura to have an ultrasound, but she got sick before she had the ultrasound."

"We had huge communication problems. Communication wise, I wouldn't have accepted the doctor's answer that there was no problem. The head of Neonatology implied that they did not have the faxed ultrasound results but my obstetrician disagreed. I'll never know. I specifically informed the pediatrician why I was induced and could he do what was required for Laura. He brushed me off."

"I wish I would have been more persistent with that doctor, subsequent doctors and nurses. I kept asking if they checked everything out and I kept hearing that everything was fine. I should have worded my questions better and ask what they did to determine she was OK. How did they come to that conclusion is what I should have asked. Asking the right question is certainly one suggestion I have for parents who are in this position. Ask very specific questions."

"I should have worded my questions better and ask what they did to determine she was OK."

**Health Provider Discussion Questions:**

1. Can you identify reasons why these communication problems occurred and what is needed to prevent this happening again?
2. How would you as a health care professional communicate more effectively with Ann and other health care professionals?
3. Discuss the benefits of collaboration for both Ann and the health care professionals in this situation.

**Parent Discussion Questions:**

1. Can you identify reasons why these communication problems occurred and what is needed to prevent this happening again?
2. How would you as a parent communicate differently in this situation? What might you say to the health care professional?

### **Family Interview with Lena and Bob**

Lena and Bob are married and have four daughters. One daughter lives in Edmonton, one daughter lives in Calgary on her own and the other two daughters live with them. Bob's mother is in Calgary and he has a sister in Invermere. Lena's family is out east except for a brother in Red Deer. Their supports also include friends and the people they work with. Sharon, their 17 year old daughter has problems with her spine which has given her lots of pain. Sharon had back surgery and had many complications post-operatively. Lena and Bob spoke about Sharon's health care experience. They also provided input on Sharon's behalf, who shared her thoughts with them about her hospital experience.

### **Salient Themes:**

#### **IV Information Sharing**

2. Value / respect patient and family information and requests
  - a. listening to family concerns

### **Learning Elements:**

- Listening and responding to family concerns

"Sharon was admitted the second time because she had a blood clot. I mentioned to the staff that a close family friend had died of a blood clot which had gone to his lungs just when he was being discharged. The first thing Sharon said when she heard she had a blood clot was if she was going to die. It was obvious that she remembered this friend and had put the scenario together. The staff knew this was an issue and Sharon was scared."

"I asked if someone from psychology would come down and assess if she was as OK on the inside as she was presenting on the outside. They did. They assessed she was fine and dealing with all of this appropriately. Sharon was concerned about it, but not excessively or irrationally. The psychologist gave us her card and told us we could call her if we had any questions. There were support systems available. They did send people down if you showed any interest or concern" commented Lena.

### **Health Provider Discussion Questions:**

1. Reflect back on a situation where a patient or family voiced their concerns and requests regarding their care. How did you handle the situation? Would you do anything differently in the future?

### **Parent Discussion Questions:**

1. What experiences have you had with professionals when you have voiced concerns and made requests regarding your child's care? How was the situation handled? Would you do anything differently the next time you were in this situation?

### **Family Interview with Don**

My family consists of my wife Vickie and my daughter Jacquie who is almost 4 years old. My wife has her parents, aunts and uncles here. She has 3 siblings of which one is in Calgary. My family is all out east outside of a brother in Red Deer. Don discusses the health care experience they had when Vickie needed to be induced and their daughter was born very prematurely and required lengthy hospitalization.

#### **Salient Themes:**

#### **IV Information Sharing**

2. Value / respect patient and family information and requests
  - a. listening to family concerns

#### **Learning Elements:**

- Information sharing process between professionals and families

“My wife was pregnant and due in mid April. Around Christmas time she was not feeling well and went to her obstetrician. Jacquie was checked out and said to be fine and was told to not worry. She continued to not feel well and a few weeks later went to labor and delivery at FHH and they checked her out and said everything is fine. Jacquie was still not feeling well. A week later she was checked out again and they said her BP was a bit high but nothing to worry about. This all happened over 3 weeks around Christmas time. The first week of January, she went back, and they told her everything was fine. They asked if this was her first child and told her to go home but if she has these symptoms, then she needs to worry.”

“The next day, she started to have those symptoms. Jacquie came back to the hospital. All of a sudden they diagnosed her with toxemia and she was showing signs of kidney failure. She was also at risk for other problems which I can't remember. They said they would have to deliver the baby early. She was 25 weeks along. They didn't listen or validate her feelings that something was wrong. If they had listened to her, they probably could have done something a lot earlier. As it turned out, they kept her in the hospital for a week and delivered our daughter at 26 weeks being 11/2 pounds at birth.”

“It was frustrating for her and for me too. You go to the doctor and he says she is fine and you believe him. If it was not for my wife, who insisted that something was wrong, we probably would have lost the child. Also my wife could have been sick. God only knows what could have happened to her too.”

#### **Health Provider Discussion Questions:**

1. What are your thoughts about this family story?
2. How would you have approached this family situation?

#### **Parent Discussion Questions:**

1. What are your thoughts about this family story?
2. If this happened to you, how would you want health care professionals to help you deal with your concerns?

#### **Did you know?**

**Family centred care decreases the number of admissions and emergency visits.**

### **Family Interview with Don**

My family consists of my wife Vickie and my daughter Jacquie who is almost 4 years old. My wife has her parents, aunts and uncles here. She has 3 siblings of which one is in Calgary. My family is all out east outside of a brother in Red Deer. Don discusses the health care experience they had when Vickie needed to be induced and their daughter was born very prematurely and required lengthy hospitalization.

### **Salient Themes:**

#### **IV Information Sharing**

2. Value / respect patient and family information and requests
  - a. listening to family concerns

### **Learning Elements:**

- Information sharing between families and professionals
- Parents advocating for their child

“The other thing that would have made it easier is if we felt that we were listened to. Our daughter had a lot of difficulties keeping food down and was regurgitating on gastrointestinal stuff. My wife became convinced she was lactose intolerant. She was being tube fed formula and she would soon regurgitate the food. No one would listen to my wife when she expressed her thoughts about lactose intolerance to the doctors and nurses. No body would believe her or do anything about it. They kept feeding her milk. My daughter was discharged home and after a week, she developed bloody diarrhea. We took her to Children’s Hospital and guess what, she is lactose intolerant!”

“It was so frustrating. My wife fought a lot to get care for her during that whole time. Just getting people to listen to her was a problem. It would make it easier if they would understand that we know our child and our situation. We may not know the words, but we know. It is important to listen to us. That leaves you feeling like you are always fighting.”

“I’m not sure what I would have done differently regarding not being listened to. Perhaps my wife would be better to answer that. For me, I would trust my instincts and trust my wife a lot more. At the time, I felt I do not know and I will listen to the doctors and take their advice. Retrospectively, I wouldn’t do that. As parents, we do know something.”

### **Health Provider Discussion Questions:**

1. From listening to this story, what are the impediments to family centred care? From your experience, are there any factors that contribute to this situation?
2. What suggestions do you have to promote a less confrontational relationship between this family and health care professionals?

### **Parent Discussion Questions:**

1. What is it like for parents when they don’t feel health care professionals are listening to them?
2. Think back to a time when you were advocating for your child. Was it a successful experience for both you and the health team? Would you do anything differently the next time?

Did you know?

Family centred care acknowledges parents as the “experts” regarding their children.

### **Family Interview with Carley**

Carley and her husband Jim have three children; Julie 13 years, Robert 11 years and Dana 9 years. They had one son that died at three days old, 7 years ago and another son died at 6 years, one year ago. Rex was a medically fragile and globally delayed child. Carley has no family here. Jim's parents live in Manitoba and he has a sister here. They have developed a network of friends from church and their children's schools and activities. Carley discusses their experience with Rex's health situation involving palliative care.

### **Salient Themes:**

#### **IV Information Sharing**

2. Value / respect patient and family information and requests
  - a. listening to family concerns

### **Learning Elements:**

- Finding ways to support family's concerns and requests

"When Rex got his port, they knew I could learn how to access him but I told them that I did not want to learn. The surgeon said that it would be easy for me to do this because of my medical background. I just did not want to do it. I wanted to set up the support here in the hospital and in the community so that if I was not available, someone else could do it. They had arranged to have a nurse flush his port at home and the Palliative Care Team would flush the port in the hospital. I was going to step in soon and learn how to do the procedure but I wanted to make sure all of the supports were in place. This way if I did not want to do the procedure, someone else would be prepared to do it."

### **Health Provider Discussion Questions:**

1. What core concepts of family centred care are addressed in this family story?
2. Can you relate any of these family centred care concepts to your own practice?

### **Parent Discussion Questions:**

1. What did you appreciate in this family story?
2. Describe a situation you encountered where health care professionals listened to your concerns and supported your requests during your child's health care experience?
3. How did the outcome make you feel?

### **Family Interview with Moira**

Moira's family is made up of her father, mother and brother. Her parents are divorced and her mother has remarried. Moira lives with her mother, stepfather, brother and stepsister. Her brother and stepsister are both four years older than her. Moira was 12 years old and in grade 7 when diagnosed with leukemia. During the course of her chemotherapy treatment, her mother and stepfather separated. Moira is now 18 years old and is providing information about her health care experience.

### **Salient Themes:**

#### **IV Information Sharing**

2. Value / respect patient and family information and requests
  - b. listening to patient concerns

### **Learning Elements:**

- Information sharing between patient, family and health care professionals
- Parents advocating for their teenager

“One of the medications I was receiving was causing me huge joint issues so I came by ambulance one night and they gave me morphine. I went to emergency and they moved me to the cluster. One of the doctors told my parents my pain was all in my head and I have been depressed. He wanted me to have a psych consultation. He did not bother to get someone in to check if my concerns were real. My mom got loud and got an orthopedic doctor. He found out that my bones were completely depleted. I did have arthritic osteoporosis in my joints. My concerns were real. They never told us to take calcium or growth hormones while I was on treatment. My growth has been seriously stunted. I now have to build up my calcium level when I could have been doing it all along. After that incident, that doctor was not the family favorite. I did not trust him. If he thought I was making everything up, why would I want to tell him any of my concerns? I did tell him my concerns with him and he just kind of shrugged it off. We actually switched doctors after that.”

### **Health Provider Discussion Questions:**

1. What family centred care concepts do you feel need to be addressed in this family story?
2. What experiences have you had regarding respecting the information and concerns from your teen patients.

### **Parent Discussion Questions:**

1. What experiences has your teen had regarding health care professionals respecting the information and concerns they voiced?
2. What made it a positive experience? What could have made it better?

### **Family Interview with Ann**

Ann and Robert are married and have two children, Lisa, 2 1/2 years old and Laura, 6 months old. Robert works fulltime and Ann's on a maternity leave. Robert's parents are in Calgary. Ann's sister's in Calgary and her parents live outside of Calgary. She has good family support. Laura has been in the hospital since she was 2 1/2 weeks old. Laura has had surgery to remove her ovary and some of her bowel. She has an ostomy and is receiving total parenteral nutrition. Ann provided information regarding Laura's health care experience.

#### **Salient Themes:**

#### **IV Information Sharing**

2. Value / respect patient and family information and requests
  - c. adapting patient care
3. Sharing information with family at multidisciplinary meetings
  - a. invite child, youth and parent participation at multidisciplinary meetings

#### **VII System Policies and Procedures**

1. Program changes and flexibility
  - a. inclusion of family during multidisciplinary meetings

#### **Learning Elements:**

- Open and honest dialogue between family and professionals
- Respect for family choices and requests
- Program and policy changes for greater family involvement at team meetings

“Communication and information sharing could have gone better for both me and the health care staff. The health care professionals really tried to make me feel part of the team, but I still get the feeling they are placating me. They listen and reflect back accurately or sometimes inaccurately. But often they can't do anything with that information any way.”

“On the other hand, I know they have gone slower with the feeds because of my feelings and what I have said. I know there were times they followed through on things I was requesting. But on the other hand, I know there were a lot of times that they haven't.”

“At the beginning, the main doctor said, “It's important to us that you have all the information.” At that point, I really believed that, but now I do not believe that to be true. I know for a fact that we are not given all the information. Sometimes it was as if they said, “OK, Tell mom this now”. Soon every doctor, nurse and housekeeper tells you that bit of information. You then go for another week without any information. It was frustrating to always be in the dark.”

“There were meetings involving all the “short gut” babies. It was comforting to know everyone worked together using a multidisciplinary approach. That was wonderful. Everyone was contributing information to help make decisions about my baby. I would have liked to have been there, hearing what everyone had to say. These people met every week to discuss Laura's case, but I never asked if I could attend. I felt like I could not be around when they did rounds.”

“You then go for another week without any information. It was frustrating to always be in the dark.”

**Health Provider Discussion Questions:**

1. Can you identify system impediments to family centred care in this family story? How would you provide a greater information sharing approach with the family? What are the pros and cons in including patients and families during rounds and multidisciplinary meetings?
2. From your experience, what are the overall risks and benefits of acknowledging and acting upon family decisions and requests when providing family centred care?

**Parent Discussion Questions:**

1. As a parent, what changes would you like to see to improve collaboration and information sharing between parents and health care team?
2. How do you feel when your family decisions and requests have been acknowledged and acted upon by the health care team?

## Family Interview with Connor and Lise

Connor and Lise have a daughter Alexandra. Lise's brother lives with them and he helps out. Connor's mother lives in Olds and sometimes comes to help. Connor has a sister but not from here. Lise has two sisters, one in Calgary and one in Strathmore. Her mother lives in High River but is sick and unable to help. Lise's father lives in France. They have a network of friends who help out in many ways but they are scared of Alexandra's fragile condition to help care of her. They have hired a student to help with her care. Alexandra was born premature with genetic abnormalities. She is deaf, has a heart murmur along with feeding problems and seizures. Alexandra has had surgeries for her heart and stomach. Connor and Lise shared their thoughts regarding Alexandra's health care experience.

### Salient Themes:

#### III Collaboration

3. Collaboration and coordination of health care professionals
  - a. medication regime

#### IV Information Sharing

2. Value / respect patient and family information and requests
  - c. adapting patient care

#### VI Patient Safety

1. Communication between patient, family and health care professionals contributes to patient safety
  - a. staff communication

### Learning Elements:

- Parent confidence with patient safety

"Sometimes there is a breakdown in communication when notes from clinics don't make it to doctors/nurses in another clinic or when important patient information doesn't make it to the clusters when patients are admitted. Alexandra could have died because her neurological status with epilepsy was not a priority after her surgery. After her second surgery, Alexandra had a seizure for 20 minutes. I said, "Please get the medicine into her, she's to have it after 5 minutes." They said, "We need the doctor's order for that." "Please get him" I asked. They said they needed a signature. The doctor phoned in, but never showed up for another 20 minutes."

"She was having a seizure for about 2 hours. I pulled the medication from my bag and the nurses said, "No. You can't do that." I said, "That's too bad. I'm going to give it. I do it at home so why can't I do it here? If the doctor can get here before I give it to her, he can stop me. But I'm putting it in. She needs it." And I did. That was really hard and frustrating. She could've had brain damage and died. She has epilepsy and had an emergency protocol ordered but it was not followed through. I could not understand how that happened. That was the scariest time here. It was a severe breakdown in communication. Since then the neurologist has noted on the chart that we are allowed to give the seizure medications. At least we know that order is always in the chart. This problem has been fixed but we had to fight for it."

"That was the scariest time here. It was a severe breakdown in communication."

**Health Provider Discussion Questions:**

1. What suggestions do you have to improve communication between health care professionals regarding patient information?
2. Why do you think this breakdown in communication occurred?
3. Do you see a role for parent involvement as part of the solution?
4. Can you think of things that might help prevent this from happening again?

**Parent Discussion Questions:**

1. What suggestions do you have to improve communication between health care professionals regarding patient information?
2. Do you see parents playing a role as part of the solution?

### **Family Interview with Lena and Bob**

Lena and Bob are married and have four daughters. One daughter lives in Edmonton, one daughter lives in Calgary on her own and the other two daughters live with them. Bob's mother is in Calgary and he has a sister in Invermere. Lena's family is out east except for a brother in Red Deer. Their supports also include friends and the people they work with. Sharon, their 17 year old daughter has problems with her spine which has given her lots of pain. Sharon had back surgery and had many complications post-operatively. Lena and Bob spoke about Sharon's health care experience. They also provided input on Sharon's behalf, who shared her thoughts with them about her hospital experience.

#### **Salient Themes:**

#### **IV Information Sharing**

2. Value / respect patient and family information and requests
  - d. respecting teenage patient

#### **Learning Elements:**

- Rights of children and youth.

"Sharon's other comment was that professionals really need to listen to patients, especially if they are a teenager and can clearly communicate. Sharon had lots of blood taken and the nurse said she was going to put the anesthetic patch on so the needle wouldn't be painful. Sharon asked that the patch not be put on because she found it more painful than the needle when she took it off later. The nurse replied, "The resident ordered it." Sharon replied, "But do I have to have it on? There are lots of things I have to have. Do I have to have this?" The nurse said, "But the resident ordered it. He's thinking of you. He does not want this to hurt you."

"Sharon reiterated, "But I told you, it hurts me more than the needle. I do not want it." The nurse refused her request and absolutely insisted that she had to have it. Sharon was getting quite tense. The nurse proceeded to do it on the right hand. I said to her that they will not take her blood from the right hand because her IV is there. The nurse said, "The sign says no BP on her left arm."

"English was not her first language. I tried to explain that they were taking blood, not doing a blood pressure. They told me that in ICU, but this nurse would not listen, and proceeded to put the patch on the right arm. Blood Services came in and they also talked to the nurse who insisted they take the blood from the right arm. The nurse finally walked out of the room. She felt she was not listened to."

#### **Health Provider Discussion Questions:**

1. In your professional role, how do you deal with underage patients who refuse specific treatments? What factors influence your response to this problem?
2. What could you have done differently?

#### **Parent Discussion Questions:**

1. How would you deal with your underage child refusing some type of treatment?
2. What factors would influence your response to this problem?

#### **Did you know?**

**Family centred care respects the voices of children and youth.**

### **Family Interview with Moira**

Moira's family is made up of her father, mother and brother. Her parents are divorced and her mother has remarried. Moira lives with her mother, stepfather, brother and stepsister. Her brother and stepsister are both four years older than her. Moira was 12 years old and in grade 7 when diagnosed with leukemia. During the course of her chemotherapy treatment, her mother and stepfather separated. Moira is now 18 years old and is providing information about her health care experience.

### **Salient Themes:**

#### **IV Information Sharing**

2. Value / respect patient and family information and requests
  - d. respecting children and youth (patient)

### **Learning Elements:**

- Teenage independence
- Collaborative relationship

“Having a voice and a place to voice my concerns was important even if they were just little concerns that arose. My mother felt comfortable talking to one of the head nurses and I was comfortable talking to any of the nurses. There was always a nurse on the unit that I trusted and could talk to because there were always little bumps and problems along the way.”

“Sometimes I felt health care professionals listened to me and sometimes my mom had to go to reinforce my wishes. We had a big incident and my mom had to talk to management. They started to take me more seriously and I was not just coming up to them to complain because I felt like it. This incident was regarding when I went to the bathroom and had the door closed. A nurse opened the door and stood watching me while I went to the bathroom. I understood if I was a younger kid or unsteady on my feet and they had to make sure I was alright but I was completely capable to use the bathroom myself. I requested to be left alone in the bathroom. When I said to please leave, it was not followed through. My mom went to complain and said that this was horrible and not appropriate. Something was said to all the staff on the cluster about teenage independence.”

### **Health Provider Discussion Questions:**

1. When working with teenage patients, what ways do you change your practice in order to have a good working relationship with them?
2. What rights do teenage patients have in your area of practice?

### **Parent Discussion Questions:**

1. What experiences has your teen had with health care professionals regarding teen independence?
2. Which process worked best in order to develop a good working relationship between them?

“Having a voice and a place to voice my concerns was important even if they were just little concerns that arose.”

## Family Interview with Marla and Valerie

Valerie and Marla's family consists of their parents and two sisters. Their older sister Carmen lives in Edmonton. Valerie lives by herself in Calgary. Marla and her youngest sister Sharon live at home with their parents Lena and Bob. Their 17 year old sister has had problems with her spine resulting in lots of pain. Sharon had back surgery and many complications postoperatively. Valerie and Marla spoke about Sharon's health care experience.

### Salient Themes:

#### IV Information Sharing

2. Value / respect patient and family information and requests
  - e. respecting patient's siblings

### Learning Elements:

- Communication process
- Rights of children & youth

"As Sharon's sisters we did not feel like we were part of the team. Even if you would call staff for something, sometimes things would never happen until my parents arrived. My parents would talk to staff and say that this was still an issue or that this is still going on. The health care professionals would say, "Oh really, we did not know that", like they just heard this for the first time. As siblings, we told them the problem, but they did not take it to heart as though you did not pull a lot of weight."

"An example regarding this was with one of Sharon's pain medication. They wanted to start her on a particular pain medication and I said I was pretty sure that medication made her sick and Sharon also concurred that it was true. I asked if there was someone they could call to find out before they put her on it. No one listened. It was only when my mother came in, asked what she was on, that they started to listen. She told them that medication makes Sharon sick and they immediately took her off it. It was more like Sharon and her sisters did not know what we were talking about. That was frustrating for both Sharon and for us."

### Health Provider Discussion Questions:

1. From your experience, what do you think is going on for this family?
2. What factors would influence your response to this problem?
3. How would you do things differently and why?

### Parent Discussion Questions:

1. How would you deal with this particular family experience?
2. What factors would influence your response to this problem?

"As siblings, we told them the problem, but they did not take it to heart as though you did not pull a lot of weight."

## Family Interview with Carley

Carley and her husband Jim have three children; Julie 13 years, Robert 11 years and Dana 9 years. They had one son that died when he was three days old, 7 years ago and another son, Rex died when he was 6 years, one year ago. Rex was a medically fragile and globally delayed child. Carley has no family here. Jim's parents live in Manitoba and he has a sister here. They have developed a network of friends from church and from their children's schools and activities. Carley discusses their experience with Rex's health situation involving palliative care.

### Salient Themes:

#### IV Information Sharing

2. Value / respect patient and family information and requests
  - f. acknowledging family values and beliefs

### Learning Elements:

- Determining and understanding family beliefs
- Respecting family values and beliefs

"People often think that palliative care means that the child is dying soon but really it is about making them live well while they are here. I believe that the definition of palliative care at least in the Children's Hospital is any child with a life limiting or threatening illness that they are not expected live over the age of 18."

"The biggest time and challenge with that was when we were inpatient. I think that a lot of the inpatient staff felt that with palliative care patients, you do not treat acute illnesses anymore and you really just keep the kids comfortable until they die. They found it a conflict that your child is still in there being treated and if they get sick, or need antibiotics or fluid therapy, that you still want to have that done. Parents want their child treated acutely and at the same time keeping them comfortable. Parents do not want to worry about their child's quality of care. I was concerned that signing the DNR would somehow lower his quality of care. "

"I think the staff did not know how to take care of Rex. We thought about it several times. We did not sign the DNR paper until a couple of hours before he died because we thought it was not relevant at the time. A lot of the time the staff felt that if there was a palliative care child in the hospital than there should be a signed DNR done. Sometimes, they were actually irritated that one was not signed. They thought we were in denial and did not understand how serious our son's condition was. Really, it is an individual decision and we knew when the time was right and necessary, we would be there to make that decision. Most times, up until the end, he was ill but not in a life threatening way that we needed to sign the DNR."

### Did you know?

Family centred care practices lead to a wiser allocation of resources.

**Health Provider Discussion Questions:**

1. In your professional role, have you experienced families stating their beliefs and values that will influence the care the patient receives?
2. Were those values and beliefs a concern for you and other health care professionals caring for the patient and family?

**Parent Discussion Questions:**

1. What do you think about this family story?
2. Describe an experience you may have had where your beliefs and values regarding your child's care were different than the health care professionals you were working with?
3. How did you deal with it?

## Family Interview with Ann

Ann and Robert are married and have two children, Lisa, 2 1/2 years old and Laura, 6 months old. Robert works fulltime and Ann's on a maternity leave. Robert's parents are in Calgary. Ann's sister's in Calgary and her parents live outside of Calgary. She has good family support. Laura has been in the hospital since she was 2 1/2 weeks old. Laura has had surgery to remove her ovary and some of her bowel. She has an ostomy and is receiving total parenteral nutrition. Ann provided information regarding Laura's health care experience.

### Salient Themes:

#### IV Information Sharing

2. Value / respect patient and family information and requests
  - c. adapting patient care
3. Sharing information with family at multidisciplinary meetings
  - a. parent inclusion at multidisciplinary meetings

#### VII System Policies and Procedures

1. Program changes and flexibility
  - a. inclusion of family during multidisciplinary meetings

### Learning Elements:

- Open and honest dialogue between family and professionals
- Respect for family choices and requests
- Program and policy changes for greater family involvement at team meetings

"Communication and information sharing could have gone better for both me and the health care staff. The health care professionals really tried to make me feel part of the team, but I still get the feeling they are placating me. They listen and reflect back accurately or sometimes inaccurately. But often they can't do anything with that information any way."

"On the other hand, I know they have gone slower with the feeds because of my feelings and what I have said. I know there were times they followed through on things I was requesting. But on the other hand, I know there were a lot of times that they haven't."

"At the beginning, the main doctor said, "It's important to us that you have all the information." At that point, I really believed that, but now I do not believe that to be true. I know for a fact that we are not given all the information. Sometimes it was as if they said, "OK, Tell mom this now". Soon every doctor, nurse and housekeeper tells you that bit of information. You then go for another week without any information. It was frustrating to always be in the dark."

"There were meetings involving all the "short gut" babies. It was comforting to know everyone worked together using a multidisciplinary approach. That was wonderful. Everyone was contributing information to help make decisions about my baby. I would have liked to have been there, hearing what everyone had to say. These people met every week to discuss Laura's case, but I never asked if I could attend. I felt like I could not be around when they did rounds."

**"You then go for another week without any information. It was frustrating to always be in the dark."**

**Health Provider Discussion Questions:**

1. Can you identify system impediments to family centred care in this family story? How would you provide a greater information sharing approach with the family? What are the pros and cons in including patients and families during rounds and multidisciplinary meetings?
2. From your experience, what are the overall risks and benefits of acknowledging and acting upon family decisions and requests when providing family centred care?

**Parent Discussion Questions:**

1. As a parent, what changes would you like to see to improve collaboration and information sharing between parents and health care team?
2. How do you feel when your family decisions and requests have been acknowledged and acted upon by the health care team?

## Family Interview with Brigitta

Brigitta is Finnish and Carl is Canadian. They are married and have three children; Jennifer 21 years, Robert 16 years and Meg 14 years. They moved from Finland in 1997 to Pincher Creek. Carl is a farmer. Carl's siblings are in Pincher Creek, Calgary, Maine, Peru, and San Francisco. Brigitta's family is in Finland. Robert had a motorcycle accident resulting in him having a severely broken arm along with significant complications. Brigitta described Robert's health care experience.

### Salient Themes:

#### I Communication

1. Communication with patients and families
  - c. language barrier

#### IV Information Sharing

3. Sharing information with patient and family
  - b. informed choices – consent forms

### Learning Elements:

- Communication process
- Language barrier

“Dr. Carson said Robert needed more manual setting and some surgery. You thought you were just taking your kid for a check up and now he is going to surgery.”

“Written information would have been helpful to know what is going on. I understand that doctors do not have time to do that. There are a lot of things I could have looked up on the computer if they wrote key words. There were even computers at the hospital I could have used while waiting. It was hard when I phoned home and I couldn't tell my husband much except what Robert had started with the letter C! I don't know what it is. I am very confused. I know they are very busy and doing their best. It is not about taking care of me but it would help to get some information or to have it explained.”

“I signed the papers. There were lots of papers with very good explanation but when you are in a state of mind that your kid is going to surgery, you can't think and you forget. It would be nice to later sit down and read a copy of all the papers you signed. What did I read and what did I really sign? They said there were three or four options and I signed those papers. When I walked away from the room, I wondered which one I had chosen. You were told what was to happen but you remember only two and not the rest. If I could only read and understand it better. You are alone and your husband is somewhere else.”

“It would be nice to later sit down and read a copy of all the papers you signed. What did I read and what did I really sign?”

**Health care professional Discussion Questions:**

1. As a health care professional, what concerns come to mind when you read this family story?
2. What would you do in this situation to promote better communication? What would you say to Brigitta?
3. Are there any system impediments to family centred care in this story? Do you have any suggestions to alleviate them?

**Parent Discussion Questions:**

1. As a parent, what is it like to feel overwhelmed by the paperwork?
2. What would you do to improve the communication between you and the health care professional?

### **Family Interview with Margaret**

Margaret and Dave are married with three children. Thomas is 8 years old and their twin daughters, Ciara and Maeve are 11 months old. They had another daughter Aileen who died at 24 months of an unknown cause over a year ago. Margaret has parents and a sister in the city and two sisters out on the west coast. Dave's parents and 3 siblings also live in the city.

#### **Salient Themes:**

#### **IV Information Sharing**

3. Sharing information with patient and family
  - b. informed choices – consent forms

#### **Learning Elements:**

- Honest, clear and accurate information required for decision making

“The doctors left the decision of taking her off life support to us. They did ask us to think about organ donation. I always said, if anything happens, I want to donate my organs. It was clear cut. Donating Aileen's organs was a major decision to make and I think we were confused at the beginning. We thought it would be like on TV. Someone donates an organ and there is someone waiting for the heart. We found out it may not be that way. It may and it may not. If we were donating her organs, we had to have a time to let her go. If not, it would be on our schedule, when we were ready to let her go, when we were ready to turn off the machine.”

“It wasn't until the second meeting when the doctor explained that because Aileen died of something unknown, there wasn't a 100% guarantee that her organs would be used. Doctors can either take them or say no to them because they do not know what happened to her and why she died. That was a hard pill to swallow. We wanted to know that if you take her heart, you will use her heart. Don't cut her up, take her heart and then say no. We couldn't imagine her being a reject. It was too painful. We just couldn't do it.”

#### **Health Provider Discussion Questions:**

1. What experiences have you had working with patients and families who are faced with making major decisions?
2. Would you do anything differently to assist in this decision making process?

#### **Parent Discussion Questions:**

1. How did health providers support you when you were faced with making a major decision?
2. What information did you need in order to make a more informed decision?

### **Family Interview with Brigitta**

Brigitta is Finnish and Carl is Canadian. They are married and have three children; Jennifer 21, Robert 16 and Meg 14. They moved from Finland in 1997 to Pincher Creek to farm. Carl's siblings are in Pincher Creek, Calgary, Maine, Peru, and San Francisco. Brigitta's family is in Finland.

Robert had a motorcycle accident resulting in him having a severely broken arm along with significant complications. He required surgery and is now recuperating postoperatively. Brigitta described Robert's health care experience.

### **Salient Themes:**

#### **IV Information sharing**

3. Sharing information with patient and family
  - c. orientation to facility structure and process

### **Learning Elements:**

- Strategies regarding facility orientation for patient and family

"Robert was already on his way to U Cluster. I did not know what a cluster was. I had a map and I finally found U cluster and Robert. His clothes were still in day surgery. I didn't know I was to take them up to the room. They had the bag there for a couple of days. I'm sure they were wondering whose clothes they were. There were lots of things I didn't understand about the system here."

"People come to the hospital for situations where they are not prepared. We were not prepared. There was a little booklet by his bedside about the hospital. It didn't tell you how the food system works. Are you to feed the kids? I did not know the trays were on the table. I did not know I could take one. Nobody explained how it works. I knew about the bathrooms. I read the booklet but a lot was missing."

### **Health care professional Discussion Questions:**

1. What do you see as the impediments to family centred care in this story?
2. What suggestions do you have to improve this situation for patients and families?

### **Parent Discussion Questions:**

1. Have you shared a similar situation like Brigitta's? How did you feel? What did you do?
2. As a parent, what hospital or procedural information would have been helpful to know during your child's health care experience?
3. Who in the facility would be the best person to provide that information to patients and families?
4. What are some other ways patients and families could be orientated to the health care facility?

"I did not know what a cluster was ..... There were lots of things I didn't understand about the system here."

### **Family Interview with Barb**

Barb and Jim have two children, Tom 7, and Angelina 2. They live in Calgary. Barb's parents live in Calgary and her siblings live out of the country. Jim's mother lives in Grande Prairie and he has two siblings in Edmonton. Angelina is globally developmentally delayed and also has some kidney abnormalities since birth. Barb provides further details regarding their family story.

### **Salient Themes:**

#### **IV Information Sharing**

3. Sharing information with patient and family
  - c. orientation to facility structure and process

### **Learning Elements:**

- Methods of informing patients and families about the facility

"I think at the beginning, we felt lost because you didn't understand the system. How do things work? All you know is that you are going to see a specialist about something and you still don't know what is wrong with your child. It is confusing."

"We didn't really feel knowledgeable about the hospital, cluster or clinic. I learned by asking. Parents need a handout to know about resources available so they can read it when they don't feel so stressed. When you are admitted, there is a booklet that tells you information. I didn't realize there was a room with beds, available for parents. I slept in a chair in her room. Many people do not speak English and they need help to understand what is in the booklet. What is needed is a person such as a volunteer or staff member, probably someone paid would do a better job. This person would come and talk to each family. Having someone on stand by and be available will not work either. I know there are resource people available but families need the personality to talk to them. Some families are scared and will not do this. This staff member must make a point to visit all parents and go over what is available and that includes the clinics too."

"When you are starting to go to a clinic, you don't know things such as the referral process. My confusion was in regard to being passed around from clinic to clinic and really not understanding how things worked."

### **Health Provider Discussion Questions:**

1. In your professional role, how do you contribute towards patients and families being orientated to the facility or clinical program?
2. From your perspective, what suggestions do you have to improve this situation?

### **Parent Discussion Questions:**

1. Describe what it was like when you came to a health care facility or clinical program for the first time?
2. What would you have appreciated to know and understand better in order to have improved your health care experience?
3. What suggestions do you have to improve this situation?

### **Family Interview with Lena and Bob**

Lena and Bob are married and have four daughters. One daughter lives in Edmonton, one daughter lives in Calgary on her own and the other two daughters live with them. Bob's mother is in Calgary and he has a sister in Invermere. Lena's family is out east except for a brother in Red Deer. Their supports also include friends and the people they work with. Sharon, their 17 year old daughter has problems with her spine which has given her lots of pain. Sharon had back surgery and had many complications post-operatively. Lena and Bob spoke about Sharon's health care experience. They also provided input on Sharon's behalf, who shared her thoughts with them about her hospital experience.

#### **Salient Themes:**

#### **IV Information Sharing**

3. Sharing information with patient and family
  - c. orientation to facility structure and process

#### **Learning Elements:**

- Pertinent patient and family information
- Ways to disseminate facility orientation information

"We were not orientated to the hospital or to some of the clusters. We may have had someone tell us information about the teen room, but a lot of it was from walking around and finding it ourselves. We didn't know if we could use the microwaves to heat up food. Some clusters did explain the process for the food trays and what is available in the fridge."

"We usually stayed till after midnight and were back at the hospital, 7:30 in the morning. We thought we needed to get away for a break and maybe get some sleep. We couldn't sleep well at the hospital. We did not know about the separate room available to parents. No one told us about that. I think there is a lot of assumption that parents know what is available. I know there is the booklet on the cluster but sometimes you do not even have time to read it. Sometimes it doesn't give you a complete understanding of what is available."

"One thing that may be helpful is for there to be an information channel on the TV so that pertinent hospital information can be provided, like what cafeteria is open during the evenings or nights and how do you get to use the teen room."

#### **Health Provider Discussion Questions:**

1. What ideas do you have to better orientate patients and families to the facility?

#### **Parent Discussion Questions:**

1. What did you need to know about the facility when your child was receiving care?
2. How should that information be best provided to you?

### **Family Interview with Kathy and Ray**

Ray and Kathy are married and have two daughters. Sandra is turning 11 years and Erin is 8 ½ years. Ray's parents live near Edmonton. Kathy has a brother and sister in Grande Prairie. Her mother is in Lethbridge. Kathy had no previous problems during her pregnancy. She had a cesarean section and the staff noticed that Erin had isolated hydrocephalus. She was transported from the PLC to the NICU at ACH. Erin required surgery to deal with the hydrocephalus. Both Kathy and Ray provided information about Erin's health care experience.

#### **Salient Themes:**

#### **IV Information Sharing**

3. Sharing information with patient and family
  - d. current and reputable health information

#### **Learning Elements:**

- Family resources to access reliable information (books, articles, internet sites)

"I made the mistake of researching hydrocephalus condition by myself because I was not getting any information and I did not know what to else to do. I went to the Children's Hospital Library and researched. Unfortunately I got the wrong books that discussed outdated mortality statistics. I am reading these horrible statistics from the 70's and 80's when the results were not that good. I was getting bad information and was very overwhelmed. I asked the doctors questions and they can do only so much because they are busy too."

"It would have been great to have someone sit down with me and go over what is happening. That would have been helpful. I am a visual guy and I would have benefited from that. There was so much going on the first couple of hours. I am not sure I would have left her for a long period of time to listen to someone. It would have been helpful to have someone write down some basic details of my daughter's condition so I could have looked up more information later on the internet, though you have to be careful with the sites you choose. You need some basic schematics of what is going on with your child's condition. This would help to explain what is happening."

#### **Health Provider Discussion Questions:**

1. In your professional role, how do you provide your patients and families with current and reliable information?

#### **Parent Discussion Questions:**

1. What have been your experiences in obtaining current and reliable information in order to better understand your child's health care needs?
2. Do you have any suggestions for improving this situation?

"I made the mistake of researching hydrocephalus condition by myself because I was not getting any information and I did not know what else to do."

## Family Interview with Margaret

Margaret and Dave are married with three children. Thomas is 8 years old and their twin daughters, Ciara and Maeve are 11 months old. They had another daughter Aileen who died at 24 months of seizures from an unknown cause over a year ago. Margaret has parents and a sister in the city and two sisters out on the west coast. Dave's parents and three siblings also live in the city.

### Salient Themes:

#### IV Information Sharing

3. Sharing information with patient and family
  - d. current and reputable information
  - f. parent experience in emergency / ICU

### Learning Elements:

- Keeping family informed during critical situations

"They asked us to leave the room when they were intubating Aileen. Looking back, I would not do that. I just followed what they wanted. I would have stayed in the room. I could hear what I thought was her crying. I knew that she was not crying. I wanted her to know I was there, even if it was to just to hold her hand. I did not know how much she felt. We left. It took them a long time. No one came out to tell us what was happening or to give us updates. I don't know if she was having a seizure again. They told us they were taking her to ICU. I was shocked. It took awhile for them to get everything set up in the ICU. We sat in the waiting room and an intern asked us a battery of questions. Our big concern was to see her. We only saw her for about 10 seconds when they were wheeling her in to ICU. Eventually, a nurse came in to say we could see her."

"I would have appreciated someone coming in to give us updates. I would have liked them to say, "It took a bit of time to intubate Aileen, Mr. and Mrs. Bresh." This was our second child, a healthy child, who never had to go through the ins and outs of the hospital. It was the first time I was in an ICU."

"We now know Aileen was so drugged, she did not know what was going on. I think that is hard for parents. We are not dealing with adults, we are dealing with children. Parents can't explain what purpose they play to be there but maybe for the parent it just puts them in control. It makes them a part of caring for their child. I can understand why they don't want parents around the child, but they have to accommodate the parents, even if it is only to give them updates."

### Health Provider Discussion Questions:

1. How can we involve parents in critical care situations?
2. What barriers exist that prevent parents from being present during procedures?  
Are there ways to tackle those barriers?

### Parents Discussion Questions:

1. What are your experiences regarding being kept informed about your child's condition?
2. What suggestions do you have for improvement?

"I would have appreciated someone coming in to give us updates."

### **Family Interview with Margaret**

Margaret and Dave are married with three children. Thomas is 8 years old and their twin daughters, Ciara and Maeve are 11 months old. They had another daughter Aileen who died at 24 months of an unknown cause over a year ago. Margaret has parents and a sister in the city and two sisters out on the west coast. Dave's parents and 3 siblings also live in the city.

#### **Salient Themes:**

#### **IV Information Sharing**

3. Sharing information with patient and family
  - d. current and reputable health information

#### **Learning Elements:**

- Sharing useful information
- Obtaining current and reputable information sources

“It was hard to remember all the information given to us. It would have been nice to have that information written down. When in ER, it would have been nice to have the basic spelling of the problems and the medication given.”

“A lot of the information given to us was way above us. We didn't understand it. I think we were so overwhelmed and shell shocked. We did not want to feel stupid. We would nod at the doctors. My sister would then get on the computer and look it up. With her son's cerebral palsy, she had seen it all, heard it all and was able to dissect it better. She gave me, Dave and our parents the information.”

“I found we were going on the internet for information. The infectious disease doctor said to not read the internet. We felt that was our only life line. I think it was because the internet is scary and there would be death involved. Aileen's situation would be slightly different. They did not want us to read things that were not applicable.”

#### **Health Provider Discussion Questions:**

1. Reflect on a past teaching experience you had with a patient or family. Have you had experiences with this kind of issue being described by the family?
2. What might have been done differently?
3. How do you deal with the concern of patients and families accessing current and reputable information from the internet?

#### **Parent Discussion Questions:**

1. Do you have problems accessing current and reputable health care information?
2. Would you have appreciated some assistance from health care staff to obtain this information?

“A lot of the information given to us was way above us. We didn't understand it.”

## Family Interview with Connor and Lise

Connor and Lise have a daughter Alexandra. Lise's brother lives with them and helps out. Connor's mother lives in Olds and comes to help. Connor's sister is not from here. Lise has sisters in Calgary and Strathmore. Her mother lives in High River but is sick and unable to help. Lise's father lives in France. They have a network of friends who help out in many ways but they are scared of Alexandra's fragile condition to help care for her. They have hired a student to help with her care.

Alexandra was born premature with genetic abnormalities. She is deaf, has a heart murmur along with feeding problems and seizures. Alexandra has had surgeries for her heart and stomach. Connor and Lise shared their thoughts regarding Alexandra's health care experience.

### Salient Themes:

#### IV Information Sharing

3. Sharing information with patient and family
  - e. family accessing patient information

#### VII System Policies and Procedures

2. Policy Changes
  - b. family access to patient information

### Learning Elements:

- Parents making informed choices
- System policy changes for family access to patient information

"When there is a complicated case like my baby, the file is huge so the doctors rely on us to inform them. If it's up to us to tell the doctors about her history and what's happening, we should be allowed to look at the chart. I requested a copy of her file from staff almost every day. Doctors would say I could have a copy of their notes. I would get my hopes up thinking FINALLY I FOUND THE RIGHT PERSON TO HELP ME! I would believe them but it never happened. No one would actually give me the file. "A doctor needs to go over it with you" I was told. What doctor has time to do this?"

"To be honest I resorted to trickery to get information about Alexandra. I'd read her file when she went for tests because most lab techs did not know about FOIP or they were too embarrassed to take the file away when I started reading it. I'd also offer to carry Alexandra down to the tests myself. I'd take a small detour to peek at a few pages."

"We did request her health records, but it took time and there was a fee. It would have been better to review as we went. We needed the chart to help us make decisions regarding the need for Alexandra's stomach surgery that has long past. We wanted to make an informed choice. I am glad to have the file now. I still am not able to see the more recent records. I have to order them again for a charge. Luckily, I now try to keep myself informed and up to date by keeping records. It is easier due to what I have learned and not due to help from the medical staff."

"We needed the chart to help us make decisions regarding the need for Alexandra's surgery. We wanted to make an informed choice."

**Health Provider Discussion Questions:**

1. Have you had experience with the issue being described by this family?
2. How did you deal with the situation?
3. What are your thoughts regarding patients and families having access to the patient's chart?

**Parent Discussion Questions:**

1. Have you ever requested access to you child's chart? What happened?
2. What are your thoughts regarding parents' rights in accessing their child's chart?

## Family Interview with Margaret

Margaret and Dave are married with three children. Thomas is 8 years old and their twin daughters, Ciara and Maeve are 11 months old. They had another daughter Aileen who died at 24 months of seizures from an unknown cause over a year ago. Margaret has parents and a sister in the city and two sisters out on the west coast. Dave's parents and three siblings also live in the city.

### Salient Themes:

#### IV Information Sharing

3. Sharing information with patient and family
  - d. current and reputable information
  - f. parent experience in emergency / ICU

### Learning Elements:

- Keeping family informed during critical situations

"They asked us to leave the room when they were intubating Aileen. Looking back, I would not do that. I just followed what they wanted. I would have stayed in the room. I could hear what I thought was her crying. I knew that she was not crying. I wanted her to know I was there, even if it was to just to hold her hand. I did not know how much she felt. We left. It took them a long time. No one came out to tell us what was happening or to give us updates. I don't know if she was having a seizure again. They told us they were taking her to ICU. I was shocked. It took awhile for them to get everything set up in the ICU. We sat in the waiting room and an intern asked us a battery of questions. Our big concern was to see her. We only saw her for about 10 seconds when they were wheeling her in to ICU. Eventually, a nurse came in to say we could see her."

"I would have appreciated someone coming in to give us updates. I would have liked them to say, "It took a bit of time to intubate Aileen, Mr. and Mrs. Bresh." This was our second child, a healthy child, who never had to go through the ins and outs of the hospital. It was the first time I was in an ICU."

"We now know Aileen was so drugged, she did not know what was going on. I think that is hard for parents. We are not dealing with adults, we are dealing with children. Parents can't explain what purpose they play to be there but maybe for the parent it just puts them in control. It makes them a part of caring for their child. I can understand why they don't want parents around the child, but they have to accommodate the parents, even if it is only to give them updates."

### Health Provider Discussion Questions:

1. In your professional role, how do you share information with families?
2. What problems do you face when keeping families informed?

### Parents Discussion Questions:

1. What are your experiences regarding being kept informed about your child's condition?
2. What suggestions do you have for improvement?

"I would have appreciated someone coming in to give us updates."

## Family Interview with Margaret

Margaret and Dave are married with three children. Thomas is 8 years old and their twin daughters, Ciara and Maeve are 11 months old. They had another daughter Aileen who died at 24 months of an unknown cause over a year ago. Margaret has parents and a sister in the city and two sisters out on the west coast. Dave's parents and 3 siblings also live in the city.

### Salient Themes:

#### IV Information Sharing

3. Sharing information with patient and family
  - g. termination of life support

### Learning Elements:

- The need for families to have honest information
- Professionals supporting families
- Compassion and humanity

“One of the doctors was particularly wonderful. I guess knowing she was human and she had demands but still had time for us was comforting. I think she did go home for a while, but she seemed to check in with us. Not in a way that she was in a hurry and wanted to get it done. I remember asking her, “How is she doing? Are we hanging on too long? The doctor was there to answer all our questions. What is going to happen when they take her off life support? Will it be long? Will she be in pain? She assured us that she was going to keep her pain free. She told us that there will be stuff coming out of her mouth and nose. So we were ready for it. She prepared us for things that you would never think of.”

“The social worker gave us suggestions too. She asked, “What was her favorite music?” It was the Lion King. They went and found the music and we played the music. The social worker told us to get into bed with her and we did. We lied down with her. They pushed the beds together, Dave, Thomas, Aileen and I. She told us to hold her, dance with her. Dave danced with her when she died. It was sort of like the social worker realized Dave was not going to get the chance to dance with Aileen on her wedding day. It is one of the memories that we've got. It was one of the most precious moments he will take to his grave.”

“The nurses gave us a beautiful box with a locket of her hair. They took her foot prints and hand prints. They think ahead of what you wish you had. They even asked if we wanted to wash and dress her. I just wanted to remember lying in bed holding Aileen.”

### Health Provider Discussion Questions:

1. What have your experiences been in telling patients and families difficult and sensitive information?
2. What suggestions do you to help new health care professionals?

### Parent Discussion Questions:

1. What is it like to lose a child?
2. What supports did you appreciate?
3. What other supports did you need?

“The doctor was there to answer all our questions.”

### **Family Interview with Marla and Valerie**

Valerie and Marla's family consists of their parents and two sisters. Their older sister Carmen lives in Edmonton. Valerie lives by herself in Calgary. Marla and her youngest sister Sharon live at home with their parents Lena and Bob. Their 17 year old sister has had problems with her spine resulting in lots of pain. Sharon had back surgery and many complications postoperatively. Valerie and Marla spoke about Sharon's health care experience.

#### **Salient Themes:**

#### **IV Information Sharing**

3. Sharing information with patient and family
  - h. sibling experience

#### **Learning Elements:**

- Communication process

"Many times health care professionals asked us to relay information to our parents but I didn't have a clue as to who they were. They never said their name, so I didn't know if they were the nurse, intern or doctor. Not knowing who they were and not introducing themselves added to this misconception. The information was usually given verbally and I sometimes did not understand the information because I was not familiar with the terminology, it was hard to understand the meaning. They could have taken more time to make sure you understood the message before they left the room. It really depended upon the person on whether I was comfortable to ask for clarification. Some of them were more willing to stick around and talk to you. Others just wanted to leave the room. If it was someone that knew Sharon really well, it was better."

"If health care professionals provided written information it would have been helpful to remember especially if there were more than one message from two different people. Sharon was better at relaying the messages because she knew who all these people were. Sometimes if we knew this was important information, we would ask if they could come back in 10 minutes because our parents would be arriving then. There were some professionals that would do that for sure."

#### **Health Provider Discussion Questions:**

1. As a health care professional, what concerns come to mind when you read this family story?
2. What would you do in this situation to promote better communication?

#### **Parent Discussion Questions:**

1. What experiences have you and other family members had regarding communication and information sharing with health care professionals?
2. Reflecting upon these experiences, what worked well and what suggestions do you have for improvement?

## Family Interview with Sandy

Sandy is married to Greg who works in the oil industry. They have a 14 year old son Cory and an 11 year old son Nick. Sandy's parents and brother live in Strathmore. Greg's sister and mother are in Calgary and brother and sister in Edmonton. They have a good support system. Nick was a healthy and athletic boy who became gravely ill with toxic shock. Nick had a lengthy hospital stay along with numerous surgeries involving him losing both legs below the knees, his fingers and most of his thumbs. After considerable team effort from Nick, his family and staff, he has been discharged home. Sandy tells about Nick's story.

### Salient Themes:

#### V Support

1. Multidisciplinary support for patient and family
  - a. scheduling poster

#### VII System policies and procedures

1. Program changes and flexibility
  - b. Assignment and scheduling of multidisciplinary patient

### Learning Elements:

- How to meet the patient's physical and emotional needs
- Flexibility of caregiver's schedule

"Nick's case was so complicated along with his care. Here I had this sick boy, who had so many teams in the hospital wanting to see him every day, but he was really not getting enough sleep. He would be woken early for blood tests and then his day would continue from there. He was tired every day, but there was never an opportunity for him to have a nap. He was on dialysis. He had this busy, busy schedule. There were x-rays and always things going on."

"One of the brilliant child life workers came up with the idea of posting a large poster on the back of the door that had grids with the days of the week and hours of the day. The poster was laminated and there were stickers so people could use them to book times on the schedule. There were times scheduled for sleep, family visits, so Cory could visit with his brother, OT, PT and other doctor visits. We had some very valuable doctors lined up at the door wanting to see Nick and they would be waiting for their turn. Sometimes there would be a dry spell."

"Before this schedule was made, you did not know who would be at the door and you did not know if it was a good time to say, "Close you eyes and have a sleep." It is helpful not only for the children and families but also for the staff. The doctors are not waiting and the nurses have time to do all the things they have scheduled. I thought the poster was absolutely brilliant and extremely helpful."

#### Did you know?

Family centred care involves individualized, flexible and responsive practices.

**Health Provider Discussion Questions:**

1. How does this poster schedule initiative exemplify the principles of family centred care?
2. What makes this experience a wonderful example of providing family centred care?

**Parent Discussion Questions:**

1. Susan was thrilled with the solution to her son needing more rest. What have been your experiences when you needed to work with team members to deal with a concern? What steps were needed to resolve this concern?

## **Family Interview with Barb**

Barb and Jim have two children, Tom 7, and Angelina 2. They live in Calgary. Barb's parents live in Calgary and her siblings live out of the country. Jim's mother lives in Grande Prairie and he has two siblings in Edmonton. Angelina is globally developmentally delayed and also has some kidney abnormalities since birth. Barb provides further details regarding their family story.

### **Salient Themes:**

#### **V Support**

1. Multidisciplinary support for patient and family
- b. early intervention specialist

### **Learning Elements:**

- Determining needs of patient and family
- Determining alternative ways to provide support to patient and family

"I would have to say the person that made the most difference in support was the early intervention worker, Marg. She thinks it is because she was coming to the house. I don't think that was the case. I think it is because of who she is. Marg provides suggestions in an honest, down to earth, and forward manner. She tells you what she thinks. I think that was what has helped me."

"Marg was the one that told me about Family Support for Children with Disabilities. When I had mentioned I had been to the hospital 168 times since Angelina was born she asked if I was receiving any help with mileage and parking. I said. "No. What do you mean?" She told me to call this number and they would be able to provide help for us. They put us on a financial assistance program that is not income based but needs based. I thought that was great because we would not have qualified because of our incomes but we are still feeling the crunch because of all the medical things that are happening. We had to hire a nanny in our home for three months in the summer because of Angelina's surgery. She couldn't be in the day care. We couldn't afford that even though we make enough money. We couldn't spend it on that. We had other things that we had to spend it on. I felt funny calling them. I didn't know about FSCD till Angelina was one year old, but knowing about that service earlier would have been helpful."

### **Health care professional Discussion Questions:**

1. When trying to support your patients and families, how do you determine their needs?
2. There are a number of suggestions this parent made regarding how the early intervention worker had supported her. From your past experiences, look back at a situation in which a family needed support. What did you do? How did you do it? Did it work? Would you do it differently?

### **Parent Discussion Questions:**

1. Who has provided you the best support during your child's health care experience? Why?
2. What message would you tell health care professionals regarding your experiences and needs involving family support?

### **Family Interview with Connor and Lise**

Connor and Lise have a daughter Alexandra. Lise's brother lives with them and he helps out. Connor's mother lives in Olds and sometimes comes to help. Connor has a sister but not from here. Lise has two sisters, one in Calgary and one in Strathmore. Her mother lives in High River but is sick and unable to help. Lise's father lives in France. They have a network of friends who help out in many ways but they are scared of Alexandra's fragile condition to help care of her. They have hired a student to help with her care.

Alexandra was born premature with genetic abnormalities. She is deaf, has a heart murmur along with feeding problems and seizures. Alexandra has had surgeries for her heart and stomach. Connor and Lise shared their thoughts regarding Alexandra's health care experience.

### **Salient Themes:**

#### **V Support**

1. Multidisciplinary support for patient and family
  - c. multidisciplinary experience

### **Learning Elements:**

- Factors influencing successful multidisciplinary family support

"There has been a lot of support given by the social workers, home care and hospital staff. They helped us get in touch with Family Services for Children with Disabilities which has helped us pay for someone to come into the home to care for Alexandra. We also have a nurse that has come once a week since she has been born. She has put in the orders to have someone come to the house at night in combination with palliative care as well. So together, we do feel like we are supported. We do feel like they are trying to help us. They are very, very good helping us to have a life and providing the help so we do not have to go back to the hospital. They do all they can. The palliative team is great. With all the help we have received we have been able to put a little bit of consistency into our chaotic lives."

### **Health Provider Discussion Questions:**

1. From your experience providing multidisciplinary family support, what factors influence its success for the family?
2. What is needed to improve family centred care support?
3. What makes this a good example of family centred care?

### **Parent Discussion Questions:**

1. What have your experiences been with multidisciplinary family support?
2. What did you need that was not provided to you?

### **Family interview with Marla**

Marla and her husband John have a son Adam, 10 years old. Marla has an 18 year old daughter and John has a 21 year old daughter from previous relationships. Marla's mother and four siblings all live in the Yukon. John's mother and sister are in Kamloops and three siblings in the Yukon. His mother is in the Siksika Nation. That is the reason why he moved to Calgary to work and to live on the reserve. Adam is being treated for a chronic and progressive condition affecting all his major organs. He has been treated since he was 1 ½ years old.

### **Salient Themes:**

#### **V Support**

1. Multidisciplinary support of patient and family
  - d. aboriginal coordinator

### **Learning Elements:**

- Meeting cultural needs

"We deal with Martha, the Aboriginal Coordinator. She provides us with the most support especially since Lora, the social worker left. She helps us with things like the food vouchers and parking. Martha talks to us and understands what we are going through with the move and living way out on the reserve. She meets our cultural needs. Everything has been fine."

### **Health Provider Discussion Questions:**

1. What experiences have you had with culturally diverse patients and families?
2. Were there resources to help you develop a collaborative relationship with the patient and family?

### **Parent Discussion Questions:**

1. How do your specific cultural needs influence your health care experience?

Did you know?

Respecting family diversity is important in family centred care.

### **Family Interview with Margaret**

Margaret and Dave are married with three children. Thomas is 8 years old and their twin daughters, Ciara and Maeve are 11 months old. They had another daughter Aileen who died at 24 months of an unknown cause over a year ago. Margaret has parents and a sister in the city and two sisters out on the west coast. Dave's parents and 3 siblings also live in the city.

### **Salient Themes:**

#### **V Support**

1. Multidisciplinary support for patient and family
- e. ICU experience

### **Learning Elements:**

- Helping families deal with death

“The social worker was so supportive. She told us that she had lost a teenage daughter suddenly, so immediately we felt we could embrace her. She knew what we were going through. This was not someone off the street giving us lip service.”

“Our problem was that everyone wanted to come to the ICU to see Aileen and we had to say no and send people away. The staff ended up putting us in a big room and then everyone could come and sit with her. The nurses were fantastic. When we wanted to hold her, they still helped us even though it was quite a job to sort the tubes and get her out of bed. They would do anything for us.”

“The two nurses we had could almost read us better than we could read ourselves. We often needed to be alone with Aileen. We needed Thomas to be in the room with us and only us. The nurse would take charge and say, “It is time all of you left because I think they need to have time by themselves.” She would drop the hint because at the time you know all the people are here to say good bye but at the same time you do not give a damn about them. Just leave us alone to be with our family. I think they knew I wanted to scream, “You do not have the right.” Sometimes the social worker also took matters in her own hands and became the middle person. The nurses and social worker made that easier for us because they could be the bad people.”

### **Health Provider Discussion Questions:**

1. What ways have you supported families dealing with an imminent death in their family?
2. Is there a need for greater family centred care resources to help in this area?

### **Parent Discussion Questions:**

1. Is this a good example of family centred care support in the loss of a child?
2. What type of support is needed or not needed at end of life and through a grieving process?

## Family Interview with Sandy

Sandy is married to Greg who works in the oil industry. They have a 14 year old son Cory and an 11 year old son Nick. Sandy's parents and brother live in Strathmore. Greg's sister and mother are in Calgary and brother and sister in Edmonton. They have a good support system. Nick was a healthy and athletic boy who became gravely ill with toxic shock. Nick had a lengthy hospital stay along with numerous surgeries involving him losing both legs below the knees, his fingers and most of his thumbs. After considerable effort from Nick, his family and staff, he has been discharged home. Sandy tells about Nick's story.

### Salient Themes:

#### V Support

1. Multidisciplinary support for patient and family
  - f. long term patient experience

### Learning Elements:

- Diversity of people within the health care system who successfully provided family centred care.
- Positive outcomes of family centred care

"This might be helpful to people who are looking at jobs in the health care industry. I always wanted to thank everyone who has been so kind to us while we were here."

- ❖ "To the doctors who saved my son's life and managed to keep him alive and as comfortable as possible through all this.
- ❖ To the nurses who did most of the work and became more than friends and were more like family. They always knew the right thing to say or do to help our entire family through the tough times.
- ❖ To the social workers, psychologists and others who did so much more than just keep us sane.
- ❖ To the pastors who without their connections, this story would have had a much different outcome.
- ❖ To the photographer, who with the pastors, made us laugh until it hurt.
- ❖ To the child life people who tried to help keep him entertained and kept me company.
- ❖ To the physical therapists and occupational therapists who helped Nick heal and become strong.
- ❖ To the x-ray and ultrasound technicians who were so gentle with him.
- ❖ To all the support staff, maintenance people and porters who moved him carefully and gently, cleaned our room, washed our floors and did the tango with their mops to cheer me up if I had tears in my eyes. No one ever passed without a cheery hello or a concerned inquiry as to how Nick was doing.
- ❖ And to all the staff at the school who make school such an enjoyable place to be."

"I have been told by many wise people that in a different place this story would have had a very different ending. When we entered the doors of the hospital two weeks ago for his last surgery, Nick said, "We're home." After all he has been through here, it says so much about this hospital that he could feel that way. I

think that is why people go into health care because they want to make a difference and help people. That is what we have really seen.”

**Health Provider Discussion Questions:**

1. Reflecting on Sandy’s tribute, describe what makes this a good example of family centred care?
2. How do you feel about the quality of care this family received?

**Parent Discussion Questions:**

1. This family was involved with numerous team members during Nick’s health care experience. Reflecting on Sandy’s tribute, have you experienced such a successful partnership with health care personnel?
2. What is the impact for a family in receiving this level of quality health care?

## Family Interview with Carley

Carley and her husband Jim have three children; Julie 13 years, Robert 11 years and Dana 9 years. They had one son that died at three days old, 7 years ago and another son died at 6 years, one year ago. Rex was a medically fragile and globally delayed child. Carley has no family here. Jim's parents live in Manitoba and he has a sister here. They have developed a network of friends from church and their children's schools and activities. Carley discusses their experience with Rex's health situation involving palliative care.

### Salient Themes:

#### III Collaboration

3. Collaboration and coordination of health care professionals
  - b. palliative care experience

#### V Support

1. Multidisciplinary support for patient and family
  - g. palliative care

### Learning Elements:

- Assessing and meeting patient and family needs

"The best thing we did was to ask if our son qualifies for the Palliative Care Team. I somehow knew that with this team there would be better continuity of care with the doctors and a better understanding of what we needed as a family. The Palliative Care Team has three physicians, two nurses and a social worker who communicated with each other and knew Rex. They would come in, talk to you and assist you with any concerns. Also, we had access to the team 24 hours a day."

"With the Palliative Care Team, it was easier to get admitted and discharged because we did not have to go through Emergency and wait long hours. It made our lives so much easier. After talking to the Palliative Team, we'd go to the cluster and the orders would be called in. The palliative care doctor would come in every day and make and change the orders. We still were involved with a variety of clinics and the Palliative Team oversaw the coordination and care of all the specialty clinics. When we wanted Rex to go home on home oxygen, the palliative team facilitated this process."

"One time I asked that we not have students anymore. The Palliative Care Team further explained my request, smoothed things over and let people know we were not angry but this was just a quality of care choice. Often they could intervene and explain on our behalf. It would always go over better when it came from another professional."

"I always felt I was well informed and involved with the strategizing and decision making. They listened to our requests and we felt part of the collaborative team. We started with the Palliative Team in May and Rex died in November. In hindsight, I wish we were part of palliative care sooner because it would have made the admissions so much easier and our family life so much better."

"I somehow knew that with this team there would be better continuity of care... and an understanding of what we needed as a family."

**Health Provider Discussion Questions:**

1. This family really appreciated collaboration, coordination and support from the Palliative Care Team. How have you participated in this type of team work in other health care situations?
2. What makes this such a good experience for the family and the staff?
3. Is this approach to care described here only applicable for palliative care patients and families?

**Parent Discussion Questions:**

1. This family really appreciated what the palliative team provided for them. From your health care experiences, what would you have appreciated to improve your situation?

### **Family Interview with Moira**

Moira's family is made up of her father, mother and brother. Her parents are divorced and her mother has remarried. Moira lives with her mother, stepfather, brother and stepsister. Her brother and stepsister are both four years older than her. Moira was 12 years old and in grade 7 when diagnosed with leukemia. During the course of her chemotherapy treatment, her mother and stepfather separated. Moira is now 18 years old and is providing information about her health care experience.

### **Salient Themes:**

#### **V Support**

1. Multidisciplinary support for patient and family
  - h. social worker

### **Learning Elements:**

- Teaching to meet the needs and level of the audience
- Aiding patient transition back to school

“Something I believe a social worker did do was to come and talk to my class at school. I am very grateful for that. When kids hear about cancer there will be a lot of rumors. Even after the social worker came in to talk, there was the rumor that if you hugged me, you would get cancer. It was good that she could answer other people's questions. That way when I went back to school it was not as bad.”

### **Health Provider Discussion Questions:**

1. What family centred care concepts were put into play in this family story?
2. As a professional, what experiences have you had in providing support to your patient in their school, work or community setting?

### **Parent Discussion Questions:**

1. What type of support did your teen receive from health care professionals in their school, work or community setting? How was it beneficial?
2. What other places would your teen have benefited a health professional's support?

### **Family Interview with Cory**

Cory is 14 years old. He lives with his parents, Sandy and Greg and his 11 year old brother Nick. His extended family lives in Calgary, Edmonton and Strathmore. He and his family have a good support system. Nick was a healthy and athletic boy who became gravely ill with toxic shock. Nick had a lengthy hospital stay along with numerous surgeries involving him losing both legs below the knees, his fingers and most of his thumbs. After considerable effort from Nick, his family and staff, he has been discharged home. Cory tells about Nick's story and how this experience affected him and his family.

#### **Salient Themes:**

##### **V Support**

1. multidisciplinary support for patient and family
  - i. child life worker

#### **Learning Elements:**

- Ways to meet sibling and family's emotional needs
- Development of sibling support programs
- Better utilization of resources for patients and siblings
- Being responsive to the needs of families

"The child life workers would include me a lot. There was one child life worker who noticed that I was bored sometimes. I would just sit in a corner while the doctors and nurses would care for Nick. She said she could get a key to the teen room for me and she let me have it for a couple of months. The teen room had a computer. It was usually empty. Sometimes there were other kids there. It wasn't important for me to be with other siblings in similar situations as me. I was more independent at the hospital so it didn't really matter to me. I enjoyed doing things on my own."

"We really appreciated what the child life workers did for us. They closed off the playroom for awhile when they knew our relatives were coming into town. On New Year's Day, they closed the room up so we could have a party with Nick, family and friends. That was fun. During Christmas they closed off the teen room. We could decorate the room and put our gifts in there. They would lock it so nothing would be missing. That was great."

#### **Health Provider Discussion Questions:**

1. In your area of practice, what resources and support are provided for patients and their siblings?
2. In your area of practice, what resources are needed to better support patients and their siblings?

#### **Parent Discussion Questions:**

1. During your child's health care situation, what resources and support did your children experience?
2. What specific resources or support did your child and his or her siblings appreciate during that time? Why?
3. What suggestions do they have for improvement?

#### **Did you know?**

**Family centred care advocates for health care facilities and services to be welcoming for families.**

### **Family Interview with Brigitta**

Brigitta is Finnish and Carl is Canadian. They are married and have three children; Jennifer 21, Robert 16 and Meg 14. They moved from Finland in 1997 to Pincher Creek to farm. Carl's siblings are in Pincher Creek, Calgary, Maine, Peru, and San Francisco. Brigitta's family is in Finland. Robert had a motorcycle accident resulting in a severely broken arm along with significant complications. He required surgery immediately. Brigitta described Robert's health care experience.

### **Salient Themes:**

#### **V Support**

1. Multidisciplinary support for patient and family
  - j. operating room experience

### **Learning Elements:**

- Discussing OR process with family
- Determining ways to support the family

"When Robert went to surgery, they gave me a pager but it never beeped. Here I am sitting and the surgery waiting room is empty and everyone has gone home. I think they close at 4:00. I went in and I asked about Robert and how he was doing. They said he was still in the operating room. No one paged me and no one talked to me. It would have been helpful if someone could have told me what was happening and how he was doing? I don't want to keep bothering them. They have important jobs to do but you feel like you are not sure if you can ask the staff questions."

"I thought if they gave me the pager, they were going to let me know how he was doing. There was no communication."

### **Health care professional Discussion Questions:**

1. Reflecting on this experience, what could have been done differently?
2. What would you do in this situation to support Brigitta?

### **Parent Discussion Questions:**

1. What do you think of this family story?
2. Would you prefer staff paging you using a beeper or the public overhead page? Why?
3. How could the staff have made this a more supportive experience?

## **Family Interview with Catherine**

The Crocker family is made up of Catherine and her three daughters, Karen 17 years, Ellen 15 years with Down Syndrome and Lily 12 years. Catherine is divorced and Tom, the girls' father sees them on Sundays. Catherine's family lives out east, with her mother in Windsor, her father in Quebec, her two sisters in Toronto and her brother in Quebec City. Tom's parents and 7 siblings all live in Edmonton. Lily has experienced medical and mental health issues for the last 6 years. She's been diagnosed with a nonverbal learning disability, a hand tremor, Tourettes, obsessive compulsive disorder and ADHD. Lily is being further assessed for narcolepsy and possible seizures.

### **Salient Themes:**

#### **III Collaboration**

3. Collaboration and coordination of health care professionals
  - d. health care professionals from different settings

#### **V Support**

1. Multidisciplinary support for patient and family
  - k. mental health experience

### **Learning Elements:**

- Coordination of patient care
- Professional accountability and family recourse

"We had a team meeting to discuss Lily's medical and mental health issues. It was decided Lily needed some classroom interventions. Dr. Frans, Lily's psychiatrist was to set up a school meeting but it never took place. Nothing was followed up. She said she got busy and couldn't do it. Grade 6 was a nightmare. I begged Dr. Frans to have a school meeting because they needed strategies for social scripting. There was to be a follow-up meeting with Dr. Frans, Dr. Lister, Lily's pediatrician and Lily's receiving school team for grade 7. Dr. Frans was to set up the meeting but it never happened."

"The school behavior psychologist said her job is only to implement the psychiatrist's strategies. When we started with Dr. Frans, she was to do cognitive behavioral therapy with Lily to deal with her worries. Dr. Frans talks 5 minutes with Lily, asks her to leave, talks to me and then gives me a new prescription. There is no work being done with Lily. Dr. Frans told me to go get it done privately because she doesn't do that now. There's no communication with the school. I don't know what's going on."

"The school psychologist told me that Lily needs to be on the waiting list for Access Mental Health because I was not able to see Dr. Frans soon. Basically right now no one is talking to anybody or working together. Lily is receiving absolutely no service. Where do I go to tell someone about this? What do I do? We have an appointment with Dr. Frans in January, next year, that will be almost 10 months since we last seen her. The hospital has never heard of the Developmental Mental Health Clinic referred to me by Dr. Frans. Lily is lost in space. The Sleep Clinic has her on a 2 to 3 year waiting list for testing. Dr. Wilf, the neurologist doesn't want to do anything else about her seizures until we get the sleep assessment done. It has been so frustrating."

**Health Provider Discussion Questions:**

1. Have you been involved in a similar situation? What did it feel like?
2. What could have been done to make this experience more family centred?

**Parent Discussion Questions:**

1. How would you feel as a parent if health care professionals were not following through with their plan of care and not communicating amongst themselves in order to provide the best care for your child? What would your recourse be?

## Family Interview with Cory

Cory is 14 years old. He lives with his parents Sandy and Greg and his 11 year old brother Nick. His extended family lives in Calgary, Edmonton and Strathmore. He and his family have a good support system. Nick was a healthy and athletic boy who became gravely ill with toxic shock. Nick had a lengthy hospital stay along with numerous surgeries involving him losing both legs below the knees, his fingers and most of his thumbs. After considerable effort from Nick, his family and staff, he has been discharged home. Cory tells about Nick's story and how this experience affected him and his family.

### Salient Themes:

#### V Support

1. Multidisciplinary support for patient and family
  - I. family support experience

### Learning Elements:

- Assessing the needs of all family members
- Determining ways to support and meet the needs of family members

"I would like to tell health care professionals and new staff that when taking care of patients it is important to get to know the whole family – patient, parents, and siblings. It is really supportive to us knowing that they care. The social workers really tried to get to know Nick and my mom. They tried to look after them as well as they could and know how they were feeling."

"In the hospital my dad got really angry and was stressed. He took out some of his anger on me. To improve this situation I think if the social worker got more involved with him, maybe that would have changed the experience. They did not support him as much as the rest of the family."

"My dad tried to distance himself from most people in the hospital too. He did not try to learn what was happening to Nick. He just wanted to know how he was doing but not all the details. I think the main source of stress was my dad's anger. The big thing was to find some way for him to relieve it. That is an area that could have been improved."

### Health Provider Discussion Questions:

1. When working with patients and their families, how do you assess the needs of the family members?
2. What multidisciplinary team approach do you use when working with families dealing with a critical health care experience?
3. What would you like to change in order to better support these families?

### Parent Discussion Questions:

1. What do you think of this story? In what ways can you relate to Cory's comments?
2. Reflecting on this story, what might have been done differently?

"I would like to tell health care professionals and new staff that when taking care of patients it is important to get to know the whole family – patient, parents, and siblings."

### Family Interview with Ann

Ann and Robert are married and have two children. Lisa is 2 1/2 years old and Laura is 6 months old. Robert is working fulltime and Ann is on a maternity leave. Robert's parents are in Calgary. Ann's sister has just moved back to Calgary and her parents live about 5 hours from Calgary. She has good family support. Laura has been in the hospital since she was 2 1/2 weeks old. Laura has had surgery to remove her ovary and some of her bowel. She has an ostomy and is receiving total parenteral nutrition. Ann provided information regarding Laura's health care experience.

### Salient Themes:

#### V Support

2. Diverse employee support for patient and family
  - a. housekeeping and cafeteria employees

### Learning Elements:

- Health care employee's work practice impacting on patient and family
- Health care employee's role in family centred care

"When we first came, I was so pleased that the housekeeping staff was so friendly and treated your child as normal. If the child was crying in the hallway, that was OK and you soon knew that that is the norm here. Every person tries to create that atmosphere here. Normal is comforting and that was one of the initial positive feelings I had here. Everybody is here to help. I did not know where I was in the hallway so housekeeping showed me the way. They smiled at you and once they get to know you, it is always "Hi" or "See you". They know why you are here and they are so friendly."

"I was in the cafeteria waiting for Laura to get out of surgery and ordered something to eat. Then of course after I ordered it, my name came over the loud speaker. My food was not ready and I tried to explain my problem to the cafeteria worker. They said I should just come back later when it was convenient and that they knew me. "Don't worry about it. Just get your baby." Just that comment made me feel better. It is interesting that it's those small things that make such a difference and are so important."

### Health Provider Discussion Questions:

1. Reflect on the health care employees that may impact your patient and family's health care experience. What approach is most effective?

### Parent Discussion Questions:

1. Care and support is not just limited to health care professionals but to other employees within the health care facility. Reflect your experiences with the health care system. What are some of the small things that made a big difference to you?

#### Did you know?

Providing family centred care makes you feel good about the work you do.

## Family Interview with Lena and Bob

Lena and Bob are married and have four daughters. One daughter lives in Edmonton, one daughter lives in Calgary on her own and the other two daughters live with them. Bob's mother is in Calgary and he has a sister in Invermere. Lena's family is out east except for a brother in Red Deer. Their supports also include friends and the people they work with. Sharon, their 17 year old daughter has problems with her spine which has given her lots of pain. Sharon had back surgery and had many complications post-operatively. Lena and Bob spoke about Sharon's health care experience. They also provided input on Sharon's behalf, who shared her thoughts with them about her hospital experience.

### Salient Themes:

#### V Support

2. Diverse employee support for patient and family
  - a. housekeeping and cafeteria employee

### Learning Elements:

- What is support?
- What are some ways employees support patients and families?

"We received support from many people in the hospital. Sharon found the housekeeping staff really great and they joked a lot with her. "They even gave me a balloon that another patient left behind", stated Sharon. Sometimes it does not take much to make someone's day when things are tough. Even Bonnie, the unit clerk was amazing. Sharon said that clerk made her day. Bonnie took the time for Sharon and made something like a bath a really special time. It felt more like a spa with a bubble bath, music, and warm towels. This person made the effort to keep meals warm for her and to keep her company."

"The people in the cafeteria were great too. They realized we have been here for awhile and said we should take a coffee card and get it stamped for a free coffee, then proceeded to punch the card for coffees we had purchased in the past. Little things like that are appreciated and make you feel a bit better."

### Health Provider Discussion Questions:

1. What does support mean and look like?
2. Looking at your personal work experience, what supportive ways have you impacted patients and families?

### Parent Discussion Questions:

1. What supportive ways have health care employees impacted you?

"Little things like that are appreciated and make you feel a bit better."

### **Family Interview with Moira**

Moira's family is made up of her father, mother and brother. Her parents are divorced and her mother has remarried. Moira lives with her mother, stepfather, brother and stepsister. Her brother and stepsister are both four years older than her. Moira was 12 years old and in grade 7 when diagnosed with leukemia. During the course of her chemotherapy treatment, her mother and stepfather separated. Moira is now 18 years old and is providing information about her health care experience.

### **Salient Themes:**

#### **V Support**

2. Diverse employee support for patient and family
  - b. parking attendant / cafeteria employees

### **Learning Elements:**

- Volunteers and health care employees role in family centred care
- Volunteer and health care employee's work practice impacting on patient and family support

"Health care employees and volunteers were wonderful because they took the time to know our names, including my brother and my best friend. One volunteer would always get a green popsicle for my brother when she saw him come in. It's the little things that really matter and improve the day to day life around the hospital. My mom became friends even with the parking attendant. When coming in or out, she would ask how my mom was doing. Saying hello, asking how the siblings and parents are doing. That is huge. It is again the little things that make a difference."

"The cafeteria staff was also incredible. When I would come out from surgery later at night, I would always want some French fries. My mom would ask for this the day of my surgery and they would have it sent up ready for me. It is kind of silly but it meant so much and I remember them for their kindness."

### **Health Provider Discussion Questions:**

1. Think back to your work / volunteer experiences. What were some ways you supported patients and families? Which approach was most effective?
2. Think about your experiences as a patient or family member. What made the difference for you?

### **Parent Discussion Questions**

1. Describe your experiences with health care employees and volunteers that impacted you, your child who was ill and his or her siblings during your family's health care experience.
2. What experiences meant most to you and your family? Why?

## Family Interview with Victoria

The Smither family consists of Victoria, her husband Jon and their two children, Samantha, 12 years and Emma, 6 years. Emma has special needs due to encephalitis. Jon's parents live in a rural community and Victoria's parents are deceased. Victoria has one sister in Winnipeg and Jon has four siblings. They do not have lots of family support, but have a network of friends. Victoria works part time at a hospital as a nurse. Emma has accessed a variety of health services and has had many hospital admissions. Her recent admission was for bladder surgery. Victoria explains more regarding Emma's health care experience.

### Salient Themes:

#### V Support

3. Volunteer support

### Learning Elements:

- Assessing patient and family needs
- Managing patient and family needs

"The child life workers suggested a volunteer because she saw how stressed I was. No one else had looked at that fabric of my needs or my family needs outside of Emma's. Holistically, I think if they looked at our family's needs, it would have helped a lot."

"The volunteer recognized the position I was in. He said to me. "Go. I'm here". He made me comfortable enough to go for a break or lie down for awhile. He really impressed us. No one else had ever said to me, "You're stressed. Go out for awhile. I'll be here". They would say "Are you OK?" very quickly. It's very easy to give the pat question. No one would investigate any further beyond the superficial. "Are you OK? Bye." No one came in from social services. We did get a follow up from the child life worker. She did periodically come in but of course on weekends we didn't have those services so that was kind of tough. There were a couple of nurses that were very kind too."

### Health Provider Discussion Questions:

1. How do you determine the needs of patients and families? How do we invite patients and families to share what they have to say?
2. Why was the volunteer such a successful support for Victoria?

### Parent Discussion Questions:

1. Victoria felt staff did not account for her family's unique needs. Have you experienced a similar situation?
2. What did you need in order to feel more supported?
3. Why was the experience with a volunteer such a good example of family centred care?

"Holistically, I think if they looked at our family's needs, it would have helped a lot."

### **Family Interview with Connor and Lise**

Connor and Lise have a daughter Alexandra. Lise's brother lives with them and he helps out. Connor's mother lives in Olds and sometimes comes to help. Connor has a sister but not from here. Lise has two sisters, one in Calgary and one in Strathmore. Her mother lives in High River but is sick and unable to help. Lise's father lives in France. They have a network of friends who help out in many ways but they are scared of Alexandra's fragile condition to help care of her. They have hired a student to help with her care.

Alexandra was born premature with genetic abnormalities. She is deaf, has a heart murmur along with feeding problems and seizures. Alexandra has had surgeries for her heart and stomach. Connor and Lise shared their thoughts regarding Alexandra's health care experience.

#### **Salient Themes:**

##### **V Support**

3. Volunteer support

#### **Learning Elements:**

- Benefits of volunteer support to families

"Volunteers have been good. They gave us the opportunity to have some food and to go to the bathroom. Sometimes I know I will have to leave the hospital, and if I am unable to find someone to cover for me, I will request a volunteer. They will write it on the board. They have been really good. I know they are not allowed to do certain things, but they will call the nurse. I'll explain to the volunteer what I want them to look for and what to expect. All of them have been good. One even taught me sign language to talk to Alexandra. They have been very respectful and willing to call the nurse and tell the nurse what I wanted to have done in specific situations. The volunteers have been very helpful."

#### **Health Provider Discussion Questions:**

1. How have volunteers been utilized in your area of practice?
2. Why is this a good example of family centred care?

#### **Parent Discussion Questions:**

1. What have your experiences been with volunteers during your child's health care experience?

## Family Interview with Barb

Barb and Jim have two children, Tom 7, and Angelina 2. They live in Calgary. Barb's parents live in Calgary and her siblings live out of the country. Jim's mother lives in Grande Prairie and he has two siblings in Edmonton. Angelina is globally developmentally delayed and also has some kidney abnormalities since birth. Barb provides further details regarding their family story.

### Salient Themes:

#### V Support

4. Parent to parent support
  - a. Infant Team bringing parents together

### Learning Elements:

- Specific support needs identified
- Opportunities to fulfill these needs

"I did go the Resource Center to see if there were any parent groups who had children with kidney problems. They told me I should call the Kidney Foundation. That was really not what I was looking for. What I really wanted was somebody else to talk to a parent, not a professional but a parent who was going through what we were going through and to see how they were handling things. I actually met a parent whose child was having the same type of surgery. She had to do the same types of things we had to do. It was great to have someone who could relate to what you were going through. Sometimes it is helpful to talk to parents who have already gone through what you may be dealing with and to share how they managed everything."

"The Infant Team actually is trying to do that. They set up group sessions with children in the same developmental age group and part of the idea was for other parents to meet each other. It's nice that they are making that effort for us. I thought that would be nice in the clinics as well. I am finding them on my own. I am not finding them through the hospital."

"You say, 'I have a special needs child and suddenly someone else says they know someone who also has a special needs child and you meet them. In genetics, for example, the hardest part of dealing with Angelina's medical issues is the unknown. We have no idea why she is like this. If she does or does not have a Syndrome, it really doesn't matter, but it would be nice to talk to other parents. Perhaps every couple months we could get together and discuss how everyone's feeling not knowing what is wrong with their child. That would be helpful. I think all the clinics could benefit from something like that."

### Health care professional Discussion Questions:

1. From your experience as a health care professional, where do your patients and families receive the most beneficial support?
2. How do you in your health care role contribute towards facilitating greater parent to parent support?

### Parent Discussion Questions:

1. Where do you receive your most beneficial support?
2. How do you think the health care system could facilitate greater parent to parent support for both groups?

"What I really wanted was to talk to a parent, not a professional but a parent who was going through what we were going through....."

## Family Interview with Kathy and Ray

Ray and Kathy are married and have two daughters. Sandra is turning 11 years and Erin is 8 1/2 years. Ray's parents live near Edmonton. Kathy has a brother and sister in Grande Prairie. Her mother is in Lethbridge.

Kathy had no previous problems during her pregnancy. During delivery they noticed that Erin had isolated hydrocephalus. She was transported from the PLC to the NICU at ACH. Erin required surgery to deal with the hydrocephalus. Both Kathy and Ray provided information about Erin's health care experience.

### Salient Themes:

#### V Support

4. Parent to parent support
  - b. internet chat line

### Learning Elements:

- Accessing parent support groups
- Benefiting from parent support groups

"Social work was not offered back then to support families. In fact, there was no support group for Erin's condition. There was a spina bifida group that was similar but our case was so different. When we were at the clinic, I said that one thing I would have loved to have had were parents like us, come in and talk to other parents and show them there are cases in which there is a happy outcome. There was nothing there for us. We were overwhelmed because it was just doom and gloom. They kept saying that you will not know her development until she is 31/2 to 5 years old, a wait and see, day by day progression. It all depends how her brain recovers. She can be everything from a totally comatose vegetable, to a 100% completely normal and healthy child to everything in between. I went on the internet and found a hydrocephalus.org and there was a chat line. It was also doom and gloom. I started to type in Erin's story to show other parents how positive it was. More people started to do that too. We really could have used a parent support group at that time. It would really be nice to have someone that has gone through this too."

### Health Provider Discussion Questions:

1. Do the patients and families you work with want support from other patients and families who have had similar experiences?
2. How do you encourage parent to parent support within your discipline?

### Parent Discussion Questions:

1. Did you want the support from other parents during your child's health care experience?
2. How did you access other parents who had similar experiences?

#### Did you know?

Family centred care encourages and facilitates parent to parent support.

### **Family Interview with Don**

My family consists of my wife Vickie and my daughter Jacquie who is almost 4 years old. My wife has her parents, aunts and uncles here. She has 3 siblings of which one is in Calgary. My family is all out east outside of a brother in Red Deer. Don discusses the health care experience they had when Vickie needed to be induced and their daughter was born very prematurely and required lengthy hospitalization.

#### **Salient Themes:**

##### **V Support**

4. Parent to parent support
  - c. skilled parent volunteer (mentor)

#### **Learning Elements:**

- Assessing parent's support needs
- Determining person to best support them

"I can only talk about my experience as the dad in the equation of support. I am sure my wife felt she could have had more support. During the days there were things organized for moms there like a pumping room and they would sit down and talk. For dads in the evenings, there was nothing and nobody. So I don't think I got any support really."

"At the time, there was some support from the Parents in Partnership Committee which we are a part of now. They organized educational topics for parents. I think all of the talks were during the day and there was nothing in the evenings. I think they are doing something in the evenings now. That would have been a great thing to have had when I was there. I didn't necessarily need another dad but just an opportunity to talk to another parent. I would come in and sit down. Everybody else is beside the bed of their child. You can't really talk, so you just sit down and stay there for 3 or 4 hours and then go home."

"I think a social worker did come during that time. The thing with social workers is that you always think that you are being assessed and you do not know what the implications are from not getting a good assessment, so you do not tell the social worker what is going on. You are not sure of what the agenda is and what is going to happen if they determine that you are not a fit parent! Maybe call them something else. I think a social worker follows a clinical model and just reinforces the doctor, patient, social worker, and client relationships. It's all the power involved between you and the medical team and the social worker is just part of the medical team."

"Somebody that would be really valuable needs to be at your level and not at the other levels. They need to be on your side and not on the side of the medical team. For me, I would have benefited from another parent for support or perhaps someone with some training that has the social worker skills but is not a social worker. Someone who is not part of that system and you felt was there working with you."

**Health Provider Discussion Questions:**

1. From your experience, what is your opinion about parents feeling a power struggle between themselves and the system?
2. Can you envision designated skilled parents playing a more formal but independent role, working with parents and professionals employed within the system?

**Parent Discussion Questions:**

1. Reflect on your experiences with the health care system. Have you had experiences where you felt that the system was not on your side? Did it feel like a power differential?
2. Who were the people that best supported you; other parents or health care professionals?

### **Family Interview with Jack**

Jack and his wife Doreen have two daughters, Michelle, 14 years and Allison, 11 years. Jack has his mother and sister in the city but his mother has dementia and is not able to help. His sister is a tremendous support. Doreen's family is all out east. They have support also from Jack's employers and their network of friends. Michelle was diagnosed with leukemia and received a stem cell transplant from her donor sister. Jack reflected on their health care experiences involving their daughter Michelle.

#### **Salient Themes:**

##### **V Support**

4. Parent to parent support
  - c. skilled parent volunteer (mentor)

##### **VII System Policies and Procedures**

1. Program changes and flexibility
  - c. initiation of new programs

#### **Learning Elements:**

- Needs assessment from parents regarding parent mentorship program
- Collaboration with health care professionals and parent mentors

"I think there really needs to be a mentoring program where people are given the opportunity to meet with experienced families. Select families, because you don't want somebody that is a bit of a banana, telling people "Oh my God, this is going to be so awful for you." You want people who have had good experiences. I think there should be a mentoring program. We are doing this already, but it would be easier if there was a facilitated process where there was some type of administrative process to hook up parents together as contacts."

#### **Health Provider Discussion Questions:**

1. What do you think about this idea of a parent mentorship program? How might it be helpful for families? What are the possible problems?
2. How do you envision a parent mentorship program working?

#### **Parent Discussion Questions:**

1. Would you have preferred to receive support from another parent who has had similar experiences as you?
2. How does a parent mentorship program appeal to your needs? Why?

**"I think there really needs to be a mentoring program where people are given the opportunity to meet with experienced families."**

### **Family Interview with Margaret**

Margaret and Dave are married with three children. Thomas is 8 years old and their twin daughters, Ciara and Maeve are 11 months old. They had another daughter Aileen who died at 24 months of an unknown cause over a year ago. Margaret has parents and a sister in the city and two sisters out on the west coast. Dave's parents and 3 siblings also live in the city.

### **Salient Themes:**

#### **V Support**

4. Parent to parent support
  - d. grief support group

### **Learning Elements:**

- Resources available for grieving families

"The grief coordinator recommended The Compassionate Friends support group to us. I need support. I am not the type that can sit in a corner and lock the door. I need to talk to others and see what is out there. She said, "This is what you can do. Try it. If you don't like it then leave." I think that was good for Dave and me."

"My network with Compassionate Friends was a wonderful support system that we had. Compassionate Friends is a group of grieving parents and is put on by the CHR. You know that you are not alone. Misery loves company. Compassionate Friends say we belong to a club that no one wants to belong to."

"We would meet once a month. There were 2 groups, a group who are grieving the loss of a young child and the other group was the loss of someone 15 years and older. We would meet in one room and then do our mission. We did not feel we could relate to parents that had lost their child at the age of 40. It is hard to hear about the child they had lost who was married and had children when many of the parents like us did not even get that opportunity. The issues are so different. The needs are so different."

"I wish there was more support for grandparents because they grieved Aileen and my loss. It was like a double loss. There needs to be some sort of support system for grandparents. I know the grief counselor has a network but it means you are picking up the phone to ask for help. I guess they could have gotten support through Compassionate Friends even though the program is for parents only. Perhaps another grandparent could have talked to them."

### **Health Provider Discussion Questions:**

1. What experiences have you had in helping families grieve and cope with death or even a life altering situation?
2. Are there any specific situations you have noted that do not have support groups to assist families?

### **Parent Discussion Questions:**

1. Describe any experiences you had with support groups to help you grieve?
2. What were the benefits of this support group to you?
3. What could have been improved?

### **Family Interview with Marla and Valerie**

Valerie and Marla's family consists of their parents and two sisters. Their older sister Carmen lives in Edmonton. Valerie lives by herself in Calgary. Marla and her youngest sister Sharon live at home with their parents Lena and Bob. Their 17 year old sister has had problems with her spine resulting in lots of pain. Sharon had back surgery and many complications postoperatively. Valerie and Marla spoke about Sharon's health care experience.

### **Salient Themes:**

#### **V Support**

5. Recreational support
  - a. age appropriate activities

### **Learning Elements:**

- Determining ways to better provide recreational support for teenage patients

"I believe the child life worker came twice in all the time Sharon was in the hospital. Once they told us that bingo was starting and the other time she brought in some videos. I know they do more for younger kids. They do not seem to be that focused on teenagers. I think her mood would have been happier if she had someone to do things with. It would have given her less time to dwell on the fact that her arm and back hurt."

"Part of the problem was that many of the activities were not age appropriate. We did attend bingo but the prizes were geared to 10 years and under. It would be great to have prizes and activities appropriate for teenagers. Sharon would have enjoyed doing activities with a volunteer. When we would visit her, we tried to get her to play games with us. We would bring those types of activities when we visited."

"The teen room is there but if you go, there is no one in there. They need someone to encourage the teens to go to that room. They say you can use it but the room is always locked. You then need to find someone with the key to unlock it. That is an added step and if you have taken the effort to get there in the first place, you don't want to have to go searching for that person. You just sort of give up and go back to the room."

### **Health Provider Discussion Questions:**

1. In your health care role, what do you need to know in order to provide support to your teenage patient?
2. What suggestions do you have to enhance recreational support for the teenage patients in your health care facility?

### **Parent Discussion Questions:**

1. Describe the support your teenager received during his or her health care experience.
2. What can be done to improve the hospital experience for teens?

### **Family Interview with Lena and Bob**

Lena and Bob are married and have four daughters. One daughter lives in Edmonton, one daughter lives in Calgary on her own and the other two daughters live with them. Bob's mother is in Calgary and he has a sister in Invermere. Lena's family is out east except for a brother in Red Deer. Their supports include friends and fellow employees. Sharon, their 17 year old daughter has problems with her spine which has given her lots of pain. Sharon had back surgery and had many complications post-operatively. Lena and Bob spoke about Sharon's health care experience. They also provided input on Sharon's behalf, who shared her thoughts with them about her hospital experience.

### **Salient Themes:**

#### **VI Patient Safety**

1. Communication between patient, family and health professional contributes to patient safety
  - a. staff communication

### **Learning Elements:**

- Effective staff communication
- Strategies to disseminate information

"It was common for new doctors to come in and not know a lot Sharon's history. They would ask us many questions and you answer them the best you can, but you hope they are not relying just on your own memory for the basic information you provide. That was a bit uncomfortable because it seemed no one was reading her file. If they read the chart, they would know that she had back surgery and they should not be getting her to sit straight up but rather to log roll her. We were lucky enough that Sharon is very verbal and old enough to tell them what she is suppose to do after the surgery. It was frustrating that it was not documented that she was not able to eat her meals or take her medications due to her left arm with the blood clot being so swollen and her right arm with an IV and not being able to bend it. Could that not be documented?"

"Due to medications, Sharon was quite out of it and her call button and pain medication button was often not within her reach. They changed her bed and forgot to put them closer to her. She was throwing up and calling for help but no one could hear her. Her roommate was able to get her help. When we got there, there was still dried green bile on her face. She was covered with vomit in her hair, on her back where she had surgery, and on her nightgown, sheets, and pillow case. When things go wrong, you worry about safety. It really shakes your confidence as a parent. You really wonder if you should be going home tonight."

"We would wait till the night nurse was on shift and explain to her that Sharon needs her call button and pain medication button near here because she can't reach it due to her surgery. Finally, someone came up with the idea of pinning it to her gown. Still, many forgot to do this. They started to use signs to inform people. We were told they tape pertinent patient information at the change of shift. We want to know what they are doing with this information! It needs to be documented more clearly for safety reasons."

**Health Provider Discussion Questions:**

1. What are your ideas about how communication could be improved in this situation?

**Parent Discussion Questions:**

1. Have you experienced concerns about lack of staff communication regarding your child's care?
2. How did you deal with it and what suggestions do you have for effective communication between patient, family and health care professionals?

## Family Interview with Connor and Lise

Connor and Lise have a daughter Alexandra. Lise's brother lives with them and he helps out. Connor's mother lives in Olds and sometimes comes to help. Connor has a sister but not from here. Lise has two sisters, one in Calgary and one in Strathmore. Her mother lives in High River but is sick and unable to help. Lise's father lives in France. They have a network of friends who help out in many ways but they are scared of Alexandra's fragile condition to help care of her. They have hired a student to help with her care. Alexandra was born premature with genetic abnormalities. She is deaf, has a heart murmur along with feeding problems and seizures. Alexandra has had surgeries for her heart and stomach. Connor and Lise shared their thoughts regarding Alexandra's health care experience.

### Salient Themes:

#### III Collaboration

3. Collaboration and coordination of health care professionals
  - a. medication regime

#### IV Information Sharing

2. Value / respect patient and family information and requests
  - c. adapting patient care

#### VI Patient Safety

1. Communication between patient, family and health care professionals contributes to patient safety
  - a. staff communication

### Learning Elements:

- Parent confidence with patient safety

"Sometimes there is a breakdown in communication when notes from clinics don't make it to doctors/nurses in another clinic or when important patient information doesn't make it to the clusters when patients are admitted. Alexandra could have died because her neurological status with epilepsy was not a priority after her surgery. After her second surgery, Alexandra had a seizure for 20 minutes. I said, "Please get the medicine into her, she's to have it after 5 minutes." They said, "We need the doctor's order for that." "Please get him" I asked. They said they needed a signature. The doctor phoned in, but never showed up for another 20 minutes."

"She was having a seizure for about 2 hours. I pulled the medication from my bag and the nurses said, "No. You can't do that." I said, "That's too bad. I'm going to give it. I do it at home so why can't I do it here? If the doctor can get here before I give it to her, he can stop me. But I'm putting it in. She needs it." And I did. That was really hard and frustrating. She could've had brain damage and died. She has epilepsy and had an emergency protocol ordered but it was not followed through. I could not understand how that happened. That was the scariest time here. It was a severe breakdown in communication. Since then the neurologist has noted on the chart that we are allowed to give the seizure medications. At least we know that order is always in the chart. This problem has been fixed but we had to fight for it."

"That was the scariest time here. It was a severe breakdown in communication."

**Health Provider Discussion Questions:**

1. What suggestions do you have to improve communication between health care professionals regarding patient information?
2. Do you see a role for parent involvement as part of the solution?

**Parent Discussion Questions:**

1. What suggestions do you have to improve communication between health care professionals regarding patient information?
2. Do you see parents playing a role as part of the solution?

### **Family Interview with Catherine**

The Crocker family is made up of Catherine and her three daughters, Karen 17 years, Ellen 15 years with Down Syndrome and Lily 12 years. Catherine is divorced and Tom, the girls' father sees them on Sundays. Catherine's family lives out east, with her mother in Windsor, her father in Quebec, her two sisters in Toronto and her brother in Quebec City. Tom's parents and seven siblings all live in Edmonton. Lily has experienced medical and mental health issues for the last six years. She has said she wants to kill herself. She has been diagnosed with a nonverbal learning disability, a hand tremor, Tourettes, obsessive compulsive disorder and ADHD. Lily is being further assessed for narcolepsy and possible seizures.

### **Salient Themes:**

#### **VI Patient Safety**

1. Communication between patient, family and health care professionals contributes to patient safety
  - b. coordinator for patient safety

### **Learning Elements:**

- Need and selection of coordinator position

"There are coordination problems with all of Lily's needs resulting in a negative health care experience for me and my family. No one will commit to a plan of action. Parents need to be more assertive with their pediatrician and make them take charge because if you don't have someone coordinating this, it does get confusing and it often becomes unsafe. I probably do get information confused because I have had so many diagnoses made, taken away and given back."

"Your pediatrician needs to be at all team meetings. They can not happen without them. The pediatrician needs to be up to date and be able to dispense medications when you experience service disruptions from other health team members. They are the ones who can stand back and look at the whole kid such as medical issues, puberty, school situation, and mental health. There is no one else on your team that can do that. Each professional is only going to look at what he or she needs to see. If you don't have someone to step up to the plate for you to help coordinate and follow up on treatments and meetings, then you need to find someone. I would never do this alone again, ever. It is exhausting. I have watched my kid just totally sink."

### **Health Provider Discussion Questions:**

1. What experiences have you had with families voicing their concerns regarding the lack of coordination with patient care?
2. What are your suggestions to deal with this problem?

### **Parent Discussion Questions:**

1. Have you had any experiences similar to the one described here?
2. What are your thoughts about the coordination of care for children with complex needs could be improved?

## **Family Interview with Lena and Bob**

Lena and Bob are married and have four daughters. One daughter lives in Edmonton, one daughter lives in Calgary on her own and the other two daughters live with them. Bob's mother is in Calgary and sister is in Invermere. Lena's family is out east except for a brother in Red Deer. Their supports also include friends and the people they work with. Sharon, their 17 year old daughter has problems with her spine which has given her lots of pain. Sharon had back surgery and many postoperative complications. Lena and Bob spoke about Sharon's health care experience. They also provided input on Sharon's behalf, who shared her thoughts with them about her hospital experience.

### **Salient Themes:**

#### **I Communication**

2. Communication between multidisciplinary professionals
  - a. variety of settings

#### **III Collaboration**

3. Collaboration and coordination of health care professionals
  - a. medication regime

#### **VI Patient Safety**

2. Medication administration / medication experiences

### **Learning Elements:**

- Value family information and requests
- Collaborative process with health care professionals

"Sharon stated that not all of the information was shared with members of the team. There were many incidents of medication confusion which she found very frustrating. The morphine made her very itchy so one of the doctors proceeded to give her Benadryl. She started to get some asthma attacks which the staff thought was due to anxiety. As parents, we did not think that it was due to anxiety. She is not an overly anxious person. A different resident came in a couple of days later and said that Benadryl is often a drug that triggers asthma. When he took her off it, the asthma episodes stopped!"

"There was another incident with Pain Services in that they were going to take her off the morphine and put her on another pain medication. I said to them, "I heard this pain medication also works as an anticoagulant. Did you check with Sharon's hematologist?" Later, they set the pump up and started to give it to her. We assumed since we asked the question, they had followed up. A few hours later the hematologist walks in and says, "Why is she on that? She is already on Heparin. They need to find something else to give her. There are other solutions." We felt we were not listened to at all."

"Sharon was vomiting a lot so she was put on Gravol, which knocked her right out. At this time, they were monitoring her to make sure her blood clot did not travel to her brain. They did not want her to be knocked out like that but we could not wake her up. Pain Services came in the next day and just freaked out. "We have to get all the residents together and talk about what medications she can and can not be on." There seemed to be lots of confusion."

**Health Provider Discussion Questions:**

1. What would you do in this situation to promote effective communication and collaboration?
2. Are there any system impediments that influence your collaborative practice in family centred care?

**Parent Discussion Questions:**

1. What do you think about this family story?
2. What role can families play if they are involved in similar situations?

## Family Interview with Jack

Jack and his wife Doreen have two daughters, Michelle, 14 years and Allison, 11 years. Jack has his mother and sister in the city but his mother has dementia and is not able to help. His sister is a tremendous support. Doreen's family is all out east. They have support also from Jack's employers and their network of friends. Michelle was diagnosed with leukemia and received a stem cell transplant from her donor sister. Jack reflected on their health care experiences involving their daughter Michelle.

### Salient Themes:

#### III Collaboration

1. Development of trusting and working relationship between health care professionals, patient and family
  - b. honesty of health care professional

#### VI Patient Safety

2. Medication administration / medication experiences

### Learning Elements:

- Using patients and families as safety checks
- Dealing with errors and near miss incidents

"We were more experienced with Michelle's medications. The nurse came in to give her the meds. I asked what she was doing. "I'm giving her meds." I replied, "No, you are too early." She said, "No it is the right time." I asked her what the dose was and she told me and I said the dose and the time of the medication was changed. "No, no, this is the right dose and time." I was insistent and asked her to please check. She didn't argue and she came back to assure me that it was the correct dose and time. Well I assured her it was not correct. I asked her to call the doctor because there was a mistake and to please not give it to her until the orders were clarified."

"She came back and said, "I am glad you pushed it because I would have given the wrong dose. Thanks for pointing that out." She was very open and honest. I appreciated that she respected and valued my opinion. It was not regarded as a mistake or an error but as a near miss. I had less angst over that incident than the "Oops and oh no" episode we previously experienced and not being given any explanation as to what had gone wrong."

"This is something that all parents appreciate, open and honest communication and professionals listening to parents. We know we are not scientists, we are not nurses but we certainly know our kids. We know our meds and we know when they are given. Parents learn that pretty quickly. Give parents credit when credit is due and respect their concerns. If parents say something is wrong, than you need to respect it. We still do not know what happened for the first incident. We did not have a trusting relationship after that episode with the "Oops" nurse. "

Did you know?

Family centred care increases parent confidence.

**Health Provider Discussion Questions:**

1. What are some changes needed to prevent errors and near misses in your area of practice?
2. Do you see a role for patient and family members in being part of a medication checking system prior to the medications being administered?

**Parent Discussion Questions:**

1. Have you experienced similar situations where an error or an error had almost happened to your child?
2. What suggestions do you have to prevent this from happening again?

## Family Interview with Catherine

The Crocker family is made up of Catherine and her three daughters, Karen 17 years, Ellen 15 years with Down Syndrome and Lily 12 years. Catherine is divorced and Tom, the girls' father sees them on Sundays. Catherine's family lives out east, with her mother in Windsor, her father in Quebec, her two sisters in Toronto and her brother in Quebec City. Tom's parents and seven siblings all live in Edmonton.

Lily has experienced medical and mental health issues for the last six years. She has said she wants to kill herself. She has been diagnosed with a nonverbal learning disability, a hand tremor, Tourettes, obsessive compulsive disorder and ADHD. Lily is being further assessed for narcolepsy and possible seizures.

### Salient Themes:

#### III Collaboration

3. Collaboration and coordination of health care professionals
  - a. medication regime

#### VI Patient Safety

2. Medication administration / medication experiences

### Learning Elements:

- Professional accountability and support

"The other thing that got confusing was when neurology put her on some medications for her tremors, while she was on her OCD medications. Apparently you can't take her OCD medications and one of her tremor medications together. Lily was hallucinating at school. I could not get in to see Dr. Frans so I just decided I did not care about the tremors and she could just use the laptop and I'd zip up her zippers on the days when her tremors are bad."

"Dr. Frans told me to take Lily off her SSRI so she could try her on Strattera for her ADHD. Unfortunately Strattera made her pass out. There were side effects when those medications are taken together. I ended up taking her off that medication too and putting her on something else because I couldn't get in to see Dr. Frans. Nobody seems to be coordinating anything. There was no coordination. I would go to Dr. Lister for the ADHD medications because Dr. Frans doesn't do that. He would say, "I don't know. What do you want her on? What do you think she should be on?" They always ask me that. If I was a doctor, I wouldn't be here."

"Things escalated with Lily and we tried so many medications. She must have been on at least 24 different medications to control her symptoms. Most of the medications had side effects and her self injury was getting to the point where it had to be dealt with. Dr. Frans had tried using a bunch of "out there" medications. That's when Dr. Lister, her pediatrician said to me, "I'm out of here. I don't even know what these medications are."

### Did you know?

Family centred care practice increases your child's safety by having conversations about their care.

**Health Provider Discussion Questions:**

1. Why is this family story not a good example of family centred care?
2. What could you do differently?

**Parent Discussion Questions:**

1. What experiences have you had regarding your child's medications regime when it involves prescriptions from different health care professionals?
2. What suggestions would you have for Catherine to help her?

## Family Interview with Ann

Ann and Robert are married and have two children, Lisa, 2 1/2 years old and Laura, 6 months old. Robert works fulltime and Ann's on a maternity leave. Robert's parents are in Calgary. Ann's sister's in Calgary and her parents live outside of Calgary. She has good family support. Laura has been in the hospital since she was 2 1/2 weeks old. Laura has had surgery to remove her ovary and some of her bowel. She has an ostomy and is receiving total parenteral nutrition. Ann provided information regarding Laura's health care experience.

### Salient Themes:

#### IV Information Sharing

2. Value / respect patient and family information and requests
  - c. adapting patient care
3. Sharing information with family at multidisciplinary meetings
  - a. parent inclusion at multidisciplinary meetings

#### VII System Policies and Procedures

1. Program changes and flexibility
  - a. inclusion of family during multidisciplinary meetings

### Learning Elements:

- Open and honest dialogue between family and professionals
- Respect for family choices and requests
- Program and policy changes for greater family involvement at team meetings

"Communication and information sharing could have gone better for both me and the health care staff. The health care professionals really tried to make me feel part of the team, but I still get the feeling they are placating me. They listen and reflect back accurately or sometimes inaccurately. But often they can't do anything with that information any way."

"On the other hand, I know they have gone slower with the feeds because of my feelings and what I have said. I know there were times they followed through on things I was requesting. But on the other hand, I know there were a lot of times that they haven't."

"At the beginning, the main doctor said, "It's important to us that you have all the information." At that point, I really believed that, but now I do not believe that to be true. I know for a fact that we are not given all the information. Sometimes it was as if they said, "OK, Tell mom this now". Soon every doctor, nurse and housekeeper tells you that bit of information. You then go for another week without any information. It was frustrating to always be in the dark."

"There were meetings involving all the "short gut" babies. It was comforting to know everyone worked together using a multidisciplinary approach. That was wonderful. Everyone was contributing information to help make decisions about my baby. I would have liked to have been there, hearing what everyone had to say. These people met every week to discuss Laura's case, but I never asked if I could attend. I felt like I could not be around when they did rounds."

"You then go for another week without any information. It was frustrating to always be in the dark."

**Health Provider Discussion Questions:**

1. Can you identify system impediments to family centred care in this family story? How would you provide a greater information sharing approach with the family? What are the pros and cons in including patients and families during rounds and multidisciplinary meetings?
2. From your experience, what are the overall risks and benefits of acknowledging and acting upon family decisions and requests when providing family centred care?

**Parent Discussion Questions:**

1. As a parent, what changes would you like to see to improve collaboration and information sharing between parents and health care team?
2. How do you feel when your family decisions and requests have been acknowledged and acted upon by the health care team?

## Family Interview with Sandy

Sandy is married to Greg who works in the oil industry. They have a 14 year old son Cory and an 11 year old son Nick. Sandy's parents and brother live in Strathmore. Greg's sister and mother are in Calgary and brother and sister in Edmonton. They have a good support system. Nick was a healthy and athletic boy who became gravely ill with toxic shock. Nick had a lengthy hospital stay along with numerous surgeries involving him losing both legs below the knees, his fingers and most of his thumbs. After considerable team effort from Nick, his family and staff, he has been discharged home. Sandy tells about Nick's story.

### Salient Themes:

#### V Support

1. Multidisciplinary support for patient and family
  - a. scheduling poster

#### VII System policies and procedures

1. Program changes and flexibility
  - b. assignment and scheduling of multidisciplinary patient

### Learning Elements:

- How to meet the patient's physical and emotional needs
- Flexibility of caregiver's schedule

"Nick's case was so complicated along with his care. Here I had this sick boy, who had so many teams in the hospital wanting to see him every day, but he was really not getting enough sleep. He would be woken early for blood tests and then his day would continue from there. He was tired every day, but there was never an opportunity for him to have a nap. He was on dialysis. He had this busy, busy schedule. There were x-rays and always things going on. "

"One of the brilliant child life workers came up with the idea of posting a large poster on the back of the door that had grids with the days of the week and hours of the day. The poster was laminated and there were stickers so people could use them to book times on the schedule. There were times scheduled for sleep, family visits, so Cory could visit with his brother, OT, PT and other doctor visits. We had some very valuable doctors lined up at the door wanting to see Nick and they would be waiting for their turn. Sometimes there would be a dry spell."

"Before this schedule was made, you did not know who would be at the door and you did not know if it was a good time to say, "Close you eyes and have a sleep." It is helpful not only for the children and families but also for the staff. The doctors are not waiting and the nurses have time to do all the things they have scheduled. I thought the poster was absolutely brilliant and extremely helpful."

#### Did you know?

Family centred care involves individualized, flexible and responsive practices.

**Health Provider Discussion Questions:**

1. How does this poster schedule initiative exemplify the principles of family centred care?

**Parent Discussion Questions:**

1. Susan was thrilled with the solution to her son needing more rest. What have been your experiences when you needed to work with team members to deal with a concern? What steps were needed to resolve this concern?

### **Family Interview with Sandy**

Sandy is married to Greg who works in the oil industry. They have a 14 year old son Cory and an 11 year old son Nick. Sandy's parents and brother live in Strathmore. Greg's sister and mother are in Calgary and brother and sister in Edmonton. They have a good support system. Nick was a healthy and athletic boy who became gravely ill with toxic shock. Nick had a lengthy hospital stay along with numerous surgeries involving him losing both legs below the knees, his fingers and most of his thumbs. After considerable team effort from Nick, his family and staff, he has been discharged home. Sandy tells about Nick's story.

### **Salient Themes:**

#### **VII System policies and procedures**

1. Program changes and flexibility
  - b. assignment and scheduling of multidisciplinary patient

### **Learning Elements:**

- Flexibility of policies and procedures within the system
- Family involvement with policy changes

“Upon reflection, there was one area that could have improved. The problem we had at the hospital involved staff inconsistency primarily on weekends, evenings and sometimes on Mondays when the doctors changed. If you are not a complicated patient, it is not a big deal.”

“When dealing with Nick's complicated care, it was always stressful with staff changes at the end of 1 week, 2 week or even over the weekend, particularly with doctors. The nurses continued to be the same but the doctors would come in with this huge chart that they could not possibly read completely. Sometimes when they switched him to different teams, we would face new doctors every two weeks because of a new rotation. They would not know all the details about Nick. It was tiring having to go over all the details. Sometimes on Mondays when something went wrong, the doctors were swamped with new patients to learn. That was always an issue the entire time we were here.”

“Dr Flint and Dr. Stone listened to our concerns and tried to help us. We thought if something was missed, we could lose him because he was still quite fragile. A couple of weeks before we were to leave, Dr Colt came up with a brilliant solution. Instead of taking the patient and having the doctors rotate and have this complicated patient get lost in all the ways this system works, he decided to have the patient and the family pick 6 designated doctors and when ever possible they would just take Nick and move him between Team 3 and 4. Sometimes the physician might not be on the same team but he might be able to take him that week due to his work schedule. We had 5 or 6 doctors on a regular basis that saw Nick so there was consistency.”

“The initial system was not working and if I could make a difference for someone else, well that was important. People here were very supportive of that and wanted to make some changes.”

**Health Provider Discussion Questions:**

1. Reflect on your experiences of this family story. How do you feel when you have to deal with frequent patient rotation changes? Does that impact your ability to practice from a family centred care perspective? If it does, are there some strategies that you could use to lessen the impact of rotational changes on patients and families?

**Parent Discussion Questions:**

1. What are the benefits to both the family and the health care system when families are included as partners when making changes to the policies and practice of the system?
2. How can parents and families be involved in making any changes to policies and practice to the health system?

## **Family Interview with Connor and Lise**

Connor and Lise have a daughter Alexandra. Lise's brother lives with them and he helps out. Connor's mother lives in Olds and sometimes comes to help. Connor has a sister but not from here. Lise has two sisters, one in Calgary and one in Strathmore. Her mother lives in High River but is sick and unable to help. Lise's father lives in France. They have a network of friends who help out in many ways but they are scared of Alexandra's fragile condition to help care of her. They have hired a student to help with her care.

Alexandra was born premature with genetic abnormalities. She is deaf, has a heart murmur along with feeding problems and seizures. Alexandra has had surgeries for her heart and stomach. Connor and Lise shared their thoughts regarding Alexandra's health care experience.

### **Salient Themes:**

#### **III Collaboration**

1. Development of trusting and working relationship between health care professionals, patient and family
  - c. continuity of staff

#### **VII System policies and procedures**

1. Program changes and flexibility
  - b. assignment and scheduling of multidisciplinary patient

### **Learning Elements:**

- Parent confidence with safe nursing care
- Policy revision regarding nurse-patient continuity

"We find shift changes to be a very big problem at the ACH. It is rare to get the same nurse twice, it is almost like they try to give you a different one every time. It is hard for us to explain Alexandra's care. She is very complicated and her care is very specific. She is not your normal baby."

"I asked if it was possible to get the same nurse because we wanted to get someone that we have already explained how we wanted her care done, in order to have some consistency in our lives. Most of them are willing to do that and learn her special care, but it takes more than one night to learn. When I ask if that nurse could have her the next time, they said that would not be possible because of the schedule. "It is not in our capabilities." It depends on who you talk to. Some do not want the nurses to get attached to the children. Some of them say it is because the schedule is so crazy. It is not really a part of their policy to have the same nurse over again. You never really get the same story from anyone. I thought that was a dumb policy. That is one of our bigger complaints."

### **Health Provider Discussion Questions:**

1. What do you see as the advantages and disadvantages for staff-patient continuity in your area of practice?
2. How do you provide continuity of care to your patients?

### **Parent Discussion Questions:**

1. Why do you think continuity of care is an important component of family centred care?

## Family Interview with Jack

Jack and his wife Doreen have two daughters, Michelle, 14 years and Allison, 11 years. Jack has his mother and sister in the city but his mother has dementia and is not able to help. His sister is a tremendous support. Doreen's family is all out east. They have support also from Jack's employers and their network of friends. Michelle was diagnosed with leukemia and received a stem cell transplant from her donor sister. Jack reflected on their health care experiences involving Michelle.

### Salient Themes:

#### VII System Policies and Procedures

1. Program changes and flexibility
  - c. initiation of new programs

### Learning Elements:

- Program evolution meeting patient and family needs
- Patient and family involvement in program planning
- Transitional care

"Michelle is 18 and they are starting to talk about transitioning her to the adult program at the Tom Baker Center. Transitioning, transitioning, what the heck does that mean? Nobody told us. It just angered me. We are experienced and not stupid people. Don't keep it as a big mystery. Does it mean they give us a box of her files and we wander into the Tom Baker and start looking around? Is there any contact information? Does she have a primary oncologist? Do we have a person to speak to? Do we set up an appointment? These were some of our issues."

"We had a meeting with our primary nurse, a psychosocial person, and Michelle's primary transplant doctor. There's not an automatic process. In fact, oncology has no formal process in place. Perhaps 6 months before you leave there is some co-treating where you have some procedures done at the ACH but you are starting to move over to the Tom Baker for other things and this sets up a process map."

"There are a lot of people who have transitioned to the Tom Baker Center and said it was not a good experience. I think that for all the good that is done in the rest of the Southern Alberta Oncology Program, this is something that has never been properly addressed in my experience. I think it is detrimental to the program. Up until we met with them to express our concerns, Michelle would come home from clinic saying, "They don't care about me anymore. They just want me out of there. They don't care about treating me. They talk about having to transition and they don't tell us what that is." It is terrible. I don't even think they realized they were doing it. Perhaps the doctors assumed something was going on. There was nothing on the administration end to facilitate this. It is a process that needs to be addressed."

Did you know?

Programs and services are better when we work together.

**Health Provider Discussion Questions:**

1. Look back to new programs you have helped to develop, what were the reasons for this new change?
2. Did you have a parent's perspective to help develop the new program?
3. How might you as health care professionals and experienced families work together to make this needed system change?

**Parent Discussion Questions:**

1. What involvement have you had with planning new health care programs?
2. How beneficial is it to have parents as part of a new program planning team?
3. How might you as health care professionals and experienced families work together to make this needed system change?

### **Family Interview with Jack**

Jack and his wife Doreen have two daughters, Michelle, 14 years and Allison, 11 years. Jack has his mother and sister in the city but his mother has dementia and is not able to help. His sister is a tremendous support. Doreen's family is all out east. They have support also from Jack's employers and their network of friends. Michelle was diagnosed with leukemia and received a stem cell transplant from her donor sister. Jack reflected on their health care experiences involving their daughter Michelle.

#### **Salient Themes:**

##### **V Support**

4. Parent to parent support
  - c. skilled parent volunteer (mentor)

##### **VII System Policies and Procedures**

1. Program changes and flexibility
  - c. initiation of new programs

#### **Learning Elements:**

- Needs assessment from parents regarding parent mentorship program
- Collaboration with health care professionals and parent mentors

"I think there really needs to be a mentoring program where people are given the opportunity to meet with experienced families. Select families, because you don't want somebody that is a bit of a banana, telling people "Oh my God, this is going to be so awful for you." You want people who have had good experiences. I think there should be a mentoring program. We are doing this already, but it would be easier if there was a facilitated process where there was some type of administrative process to hook up parents together as contacts."

#### **Health Provider Discussion Questions:**

1. In your area of practice, do you see the benefits of a parent mentorship program?
2. How do you envision a parent mentorship program working?

#### **Parent Discussion Questions:**

1. Would you have preferred to receive support from another parent who has had similar experiences as you?
2. How does a parent mentorship program appeal to your needs? Why?

**"I think there really needs to be a mentoring program where people are given the opportunity to meet with experienced families."**

### **Family Interview with Don**

My family consists of my wife Vickie and my daughter Jacquie who is almost 4 years old. My wife has her parents, aunts and uncles here. She has 3 siblings of which one is in Calgary. My family is all out east outside of a brother in Red Deer. Don discusses the health care experience they had when Vickie needed to be induced and their daughter was born very prematurely and required lengthy hospitalization.

### **Salient Themes:**

#### **VII System policies and procedures**

2. Policy changes
  - a. problem solving process for parents

### **Learning Elements:**

- Process for problem resolution between parents and professionals

“One of the things you struggle as a parent is that if you go over someone’s head, if you make too much of a fuss about something, than how does that affect the care of your child. That was always in the back of our minds. You do not want to tick those people off. They are the ones taking care of our daughter. We want her to have the best care.”

“I am not sure how I would have advocated more regarding our situation of no one listening to our concerns and beliefs that our daughter is lactose intolerant. That is what I would challenge the Health Region. How do you deal with such concerns? My wife and I have one idea. When you are having your child admitted, there needs to be a contract, with someone to sit down with you and discuss it. The contract outlines that these are your rights and your responsibilities as a parent and this is who is responsible for what. If you have a problem, this is the process. If you disagree, this is the process you go through. The contract would be signed. We really didn’t know how to proceed. Perhaps someone like an ombudsman would be helpful.”

“I can’t say that there was anything the Health Region did that was so threatening to make us feel that way. It is just that a parent is unsure in that situation.”

### **Health Provider Discussion Questions:**

1. What are your thoughts regarding a contract for parents stating their rights, responsibilities and a process they can use if they have a major concern while their child is in the hospital?
2. Are there any other system policy changes needed that might help parents deal with their concerns more effectively?

### **Parent Discussion Questions:**

1. Think back to your experiences at the hospital. Can you identify with this parent’s experience?
2. What other ideas do you have that would give parents direction when they are faced with problems with the health care system?

## Family Interview with Connor and Lise

Connor and Lise have a daughter Alexandra. Lise's brother lives with them and helps out. Connor's mother lives in Olds and comes to help. Connor's sister is not from here. Lise has sisters in Calgary and Strathmore. Her mother lives in High River but is sick and unable to help. Lise's father lives in France. They have a network of friends who help out in many ways but they are scared of Alexandra's fragile condition to help care for her. They have hired a student to help with her care.

Alexandra was born premature with genetic abnormalities. She is deaf, has a heart murmur along with feeding problems and seizures. Alexandra has had surgeries for her heart and stomach. Connor and Lise shared their thoughts regarding Alexandra's health care experience.

### Salient Themes:

#### IV Information Sharing

3. Sharing information with patient and family
  - e. family accessing patient information

#### VII System Policies and Procedures

2. Policy Changes
  - b. family access to patient information

### Learning Elements:

- Parents making informed choices
- System policy changes for family access to patient information

"When there is a complicated case like my baby, the file is huge so the doctors rely on us to inform them. If it's up to us to tell the doctors about her history and what's happening, we should be allowed to look at the chart. I requested a copy of her file from staff almost every day. Doctors would say I could have a copy of their notes. I would get my hopes up thinking FINALLY I FOUND THE RIGHT PERSON TO HELP ME! I would believe them but it never happened. No one would actually give me the file. "A doctor needs to go over it with you" I was told. What doctor has time to do this?"

"To be honest I resorted to trickery to get information about Alexandra. I'd read her file when she went for tests because most lab techs did not know about FOIP or they were too embarrassed to take the file away when I started reading it. I'd also offer to carry Alexandra down to the tests myself. I'd take a small detour to peek at a few pages."

"We did request her health records, but it took time and there was a fee. It would have been better to review as we went. We needed the chart to help us make decisions regarding the need for Alexandra's stomach surgery that has long past. We wanted to make an informed choice. I am glad to have the file now. I still am not able to see the more recent records. I have to order them again for a charge. Luckily, I now try to keep myself informed and up to date by keeping records. It is easier due to what I have learned and not due to help from the medical staff."

"We needed the chart to help us make decisions regarding the need for Alexandra's surgery. We wanted to make an informed choice."

**Health Provider Discussion Questions:**

1. Has this situation ever happened in your professional practice?
2. How did you deal with the situation?
3. What are your thoughts regarding patients and families having access to the patient's chart?

**Parent Discussion Questions:**

1. Have you ever requested access to you child's chart? What happened?
2. What are your thoughts regarding parents' rights in accessing their child's chart?

### **Family Interview with Connor and Lise**

Connor and Lise have a daughter Alexandra. Lise's brother lives with them and he helps out. Connor's mother lives in Olds and sometimes comes to help. Connor has a sister but not from here. Lise has two sisters, one in Calgary and one in Strathmore. Her mother lives in High River but is sick and unable to help. Lise's father lives in France. They have a network of friends who help out in many ways but they are scared of Alexandra's fragile condition to help care of her. They have hired a student to help with her care.

Alexandra was born premature with genetic abnormalities. She is deaf, has a heart murmur along with feeding problems and seizures. Alexandra has had surgeries for her heart and stomach. Connor and Lise shared their thoughts regarding Alexandra's health care experience.

### **Salient Themes:**

#### **VII System Policies and Procedures**

2. Policy changes
  - c. continuity of the Health Information Act across settings

### **Learning Elements:**

- Information sharing with patient and family
- Collaborative relationship

"At the Foothills Hospital, parents are encouraged to read the chart and at the Children's Hospital, you are not allowed. It is frustrating not being able to read what has happened to your child throughout the day."

"We asked why the policy regarding parents reading their child's chart was so different between the two hospitals. They said they did not know. Some people would say, "Well the doctor will sit down and read the chart with you and explain everything." It really never happens. No doctor has the time to read the entire file. Even if they could try, where do you start because the chart is so large?"

"They come and ask every single day what is the history, and they go over the complete history which is mildly irritating. They still won't let you check the notes so they take their own notes. One person will write it down. They will go and hand it off to somebody else and they will go off with that rather checking the original order and then it becomes a bad case of the hearsay being horribly wrong. They need to be double checking with the parents. Where as at the Foothills, we actually read over the notes and said, "No, no, it is actually this." They would make the corrections right there and then everyone would be on the same page. That seemed to work a lot better."

### **Health Provider Discussion Questions:**

1. What are your opinions regarding families having access to the patient's chart?
2. Does this impact family centred care practice?

### **Parent Discussion Questions:**

1. Reflect on your experiences in having access to your child's health care information. What is the impact of different procedures on the family centred care experience?

## **Appendix – Family, Child & Youth Interviews Full Transcriptions**

The fully transcribed family, child & youth interviews can be accessed in a separate document by calling the Child Health Information Specialist at the:

**Southern Alberta Family & Community Resource Centre (FCRC)  
c/o Alberta Children's Hospital  
2888 Shaganappi Trail NW  
Calgary, AB  
T3B 6A8**

**403-955-FCRC (3272)**

**or**

**1-877-943-FCRC (3272)**

This resource can also be downloaded from the Southern Alberta Child & Youth Health Network website under the *Publications* tab

**[www.sacyhn.ca](http://www.sacyhn.ca)**