

Weather *the* STORM

There's no magic formula to ensure a happy, smooth-running family life. But if you put some effort into it now, you'll ride out the crises more easily

By Tamara Stecyk | ILLUSTRATIONS BY CAROLINE HAMEL

Tania Jeffrey had a cold last November and was planning to visit her family doctor anyway when her 12-year-old daughter, Loni Hancock-Jeffrey, started throwing up. Thinking Loni had the stomach flu, Tania decided to bring her along to the appointment to see if the doctor could squeeze her in.

The pair set out for nearby Viking, close to their home of Holden, 100 kilometres east of Edmonton. In Viking, the doctor examined Loni. He did the usual routine, checking her ears and throat, before asking the girl to lie on her back on the examination table so he could manually examine her abdomen. He pressed on key spots on Loni's belly and found she had an engorged liver. He referred her to a clinic near the Grey Nuns Hospital where a pediatrician, in turn, sent Loni to see a specialist at the University of Alberta Hospital.

"There was a whack of blood tests and other tests done and she had a liver biopsy. I wasn't too optimistic. You get that feeling it was something bad," says Tania. She and her husband, Clayton, had their lives turned upside down on November 3, when her worry was confirmed and Loni was diagnosed with hepatoblastoma, a form of liver cancer. Loni began chemotherapy treatments the following day.

As treatment progressed, they were told that Loni would need a liver transplant. Loni's 24-year-old stepbrother, Kyle, was tested to see if he qualified as a possible living donor, a process in which part of his healthy liver would be transplanted to Loni to replace her diseased one. Unfortunately, doctors found that Kyle had too many veins in his liver, meaning that the surgery would be too risky for him. Doctors were reluctant to test Tania. As Loni's main support, they wanted her to be as able as possible to help Loni.

Loni was placed on the donor waiting list the next day – January 19. Her case was complicated by the fact that her chemotherapy, necessary to keep the cancer in check, allowed her a window of just five days per month in which her strength and white blood counts were high enough to receive a transplant. She was on the list less than 10 hours when her family got word that a donor liver had become available. "It was a miracle that it happened in that window of time," Tania says.

Families typically face everyday upheavals over the years, whether it's a child breaking a leg, moving to a new house or a losing a job. But how do families like Tania Jeffrey's survive a major crisis and still come out strong?

Devastating news, such as a child facing serious illness, can bring out healthy coping strategies for many families. Faye Hamilton, social



worker team lead at the Stollery Children's Hospital, says there's no perfect answer to deal with a health crisis. "There are no secrets. There is no one-size-fits-all solution for families. It's never going to be 'here's your happy healthy family.' Every family has strengths. For families who are facing crisis, think of strengths," says Hamilton.

Parents need to consider what resources are available to them, such as members of the extended family, friends, counselling and community supports. Physicians and nursing staff often notify Hamilton and her staff when families are thrown into a health crisis. (Some hospital units have automatic referrals; others don't.) Her team was referred to Tania Jeffrey's family as soon as a diagnosis was made.

"We work with the whole family to try to support them. We link them to community supports. We look at what is going around in their environment," she explains.

Tania sings praise for Donna Mondor, the social worker who was assigned to her family during Loni's chemotherapy treatment and liver transplant. "She was phenomenal. Whatever we needed, she dealt with. Even though she was our social worker, she was our friend. She was someone to talk to," says Tania.

The Jeffreys also met a psychiatrist and a child life specialist. These people typically provide psychosocial care to hospitalized children and their families as well other outlets for communication. The child life specialist soothes fears and helps kids and their parents cope with stress through therapeutic play and education.

Talking is key to remaining resilient during adversity, especially keeping children in the loop about what is happening. "Make sure the child is able to talk about what is going on for them, that their issues are seen as important. As a parent, our job is to reach out and get what our families or kids need. If you need support, go to people who can help you. Go to a therapist, if needed. It takes courage to go," says Hamilton.

She adds that it's important to start discussing all topics with children at an early age. "Start

communicating about little things so you can talk about the big things when they happen."

Since the Jeffreys live in Holden, they had to uproot their lives to the Stollery Children's Hospital during Loni's treatment, surgery and recovery. Clayton remained in Edmonton while he could and then went back to work after a couple of months.

"Clayton doesn't sit still. It was good for him to go back to work," Tania says. While Tania and Clayton were separated, they made sure they

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spoke by phone every day. "We tried to keep it as normal as possible," says Tania. Her point of view is that all families have a matriarch who holds the pieces together. While Loni was in the hospital, Tania provided constant reassurance.

"I told Loni every day how much I love her and that she's my hero. That helped her feel good about herself. When we found out that she was sick, I told her the main thing she had to do was to try her best to get better," she says. Tania advises parents to be honest with their children about the situation and make no promises that could be broken.

The Jeffreys also tried to keep a positive outlook about Loni's condition. "Ultimately it was my child who was going through it. We made big deals of the small victories she had. We always tried to find the sunny side of the situation. Even if I was having a crummy day myself, I didn't show that

to Loni," says Tania. "I would take time to have a coffee."

Taking time for yourself is essential to maintain a healthy balance during a tough period. Paul Bergen, manager of pastoral care, Aboriginal and multicultural services at the University of Alberta Hospital, sees many family members who are unwilling to leave a loved one's bedside for days. He advises family to look after their own needs and to trust the staff to care for the patient. "Be gentle on yourself and don't be too hard towards your own feelings," says Bergen. "Give yourself permission to do something of comfort or control."

Hamilton agrees. "Lots of parents don't take care of themselves when they have a sick child. Women are very vulnerable to this. Tend to yourself and your adult relationships," she says.

"Take time out for yourself. Sit down to watch your favourite TV show alone," advises Tania.

Bergen explains that people enter into a health crisis with coping tools from past experiences.



For example, if a family has used prayer in a past crisis, they may find it helpful again when a loved one is in the hospital. Some families use their spirituality as a coping tool but Bergen cautions to have an open mind during a crisis. Prayer can help provide a sense of peace but it doesn't necessarily provide a solution to the situation.

"Some people can look at a picture of the world and expand their view. Ones who can do that can weather crisis," says Bergen.

Tania drew on the experience of her father's illness and experience with transplants as a coping technique. Her father had Hepatitis C and received kidney and liver transplants in the early 1990s. He died in 2001. She says her family relied on laughter and positive thinking during his illness.

Bergen and his staff facilitate discussions about the meaning behind a health issue. They help families reconnect with what is important to them and give them an outlet for their feelings. Some people may feel they are going crazy during a health crisis, even though they are not the patients.

"Often times we help people be okay with themselves. We tell them this is a normal response, that they are not going crazy. Struggle will be part of this experience because it is a horrible experience," says Bergen. He confirms Tania's family's approach that laughter is good medicine. "Laughter can be a marvellous sign. Humour can be an essential tool. People who can laugh sense things deeply," says Bergen.

"Find something to laugh about," Tania agrees. "Find the good in what you have. Have an attitude that things could always be worse."

Be sure to support each other, not just the sick family member. "Notice your kids' strengths. Really notice how good a parent you are and value your own role as a parent. What you bring to your family impacts your family's health," says



Hamilton. "Notice how you can get through the hard times." She adds long before a health crisis hits a family, parents should look at their values. Consider how your family balances work and life and try not to over schedule.

"Have time to goof around. Don't let work and family overwhelm. Make sure your family is high on your priority list. Be proactive and model how your family should look. How you act affects all of your family," Hamilton says.

The Jeffreys weathered their crisis and have returned to their life in Holden. Loni is back to being a typical 12-year-old, arguing with her parents over homework and chores. Her mom couldn't be happier. They celebrate that their petite, blond daughter is healthy and alive. "Loni is amazing," says Tania. **YH**

Resources

If you're not sure where to turn for help during a health crisis, support is available. In the Edmonton area, call 211, an information line that can hook you up to different community organizations. A similar service is available in St. Albert by phoning 459-6666, and 464-4242 in Strathcona County. Services for pastoral care at the University of Alberta Hospital can be reached at 407-7165. Capital Health Link, at 408-LINK, is another resource.

Tips for healthy, happy families

Take action today to strive to be a family who can overcome adversity. Faye Hamilton, social worker team lead at the Stollery Children's Hospital, has some tips for families to be stronger, healthier and happier.

- 1) Appreciate the uniqueness of your family and try not to compare yourselves to other families. Celebrate what makes your family one of a kind.
- 2) Learn about each of your children and remember that each will require different things from you based on their unique nature and developmental stage. Children and youth, by their nature, are in a constant state of change. Each stage brings new skills and levels of understanding as well as new challenges.
- 3) Tailor your parenting to each child. Don't worry about keeping things "fair." Fairness is that each child receives what he or she needs to do well in the world. What works for one may not work for another.
- 4) Talk to people whose children have grown up and ask them what they would do differently if they were to raise children again.
- 5) There are no second chances as parents. Not meant to scare, this point reminds us that our choices matter and that being a parent is a job requiring care and attention. It's especially important to remember this when you're trying to balance your family life. Make sure that your family is high on your priority list. Kids need parents to be an active part of their lives.
- 6) Try not to over schedule your family life. It's important to have hang-out time. Often the best family conversations occur while doing mundane tasks.
- 7) Keep your adult relationships strong.
- 8) Model what you would like your family to look like.
- 9) Start communicating about the little things so you can talk about bigger issues.
- 10) Remember the influence of developmental stages on a child's behaviour. For example, an adolescent is doing his developmental "job" when he pushes his parents away. It's a step on the long path to maturity and independence.
- 11) Don't forget to have a sense of humour and be able to laugh in difficult situations.