

Counselor, Chiari Mom, & Chiari Patient

As part of our ongoing look at how Chiari and syringomyelia affect families, we wanted to know from a psychology/counseling point of view what impact an illness like Chiari can have. We found the perfect person to answer our questions in Nancy Fontaine.

In today's society, most women wear more than one hat, and Nancy Fontaine is no exception. In addition to being a wife and mother of three boys, Nancy is a trained counselor with experience in dealing with families and children with medical problems. Nancy has relevant experience in her family life as well; her son Jack was recently diagnosed with Chiari and underwent surgery. Nancy herself has endured symptoms for years and was diagnosed with Chiari shortly after Jack.

Given her unique background, we put Nancy In The Spotlight to see what we could learn...

Tell us about your professional background

F: I have a Master's Degree in rehab counseling with a minor in marriage and family therapy. I started my career doing foster care placement in child investigation cases, I've done psychological assessments for Social Security Disability cases, and I've done family therapy. Recently, I've done work with adoption cases - where the parental rights have been terminated - and I see a lot of kids with disabilities and medical needs.

What impact does a serious, or chronic, illness have on a family?

F: It completely changes the family dynamics. Let's look at a family where the husband/father is an alcoholic and then he decides to get treatment. Often the family will break up. It seems strange, he finally stops drinking but they get a divorce. It's the same thing [with an illness], a family develops a way of working and everyone has their roles. To stereotype, the husband is the breadwinner and the protector of the family, the wife is the nurturer, she takes care of the family, if someone gets sick, she takes care of them. So, if the husband gets sick, all of a sudden he can't go out and earn the money or protect the family, so his role in the family is gone. That can be very tough on him and his wife. Likewise, if she becomes sick, now she needs care and the husband has to take on the role of caretaker and often she will have a very difficult time with that. So it completely disrupts the family dynamics. Some families can transition very well and some can not. I don't remember the exact statistic, but with MS, something like 70% of the husbands of women who are struck with MS end up leaving, whereas women almost never leave the husband in this situation.

Are there any predictors of what type of family will be able to adjust successfully?

F: I don't think there is, sometimes you think this family will be able to handle it and they can't. You think this family will be in real trouble and they rally through. Although, I think if a family is already having trouble dealing with the stresses of life, birth of children, moves, etc., they will have a harder time dealing with it.

How does a counselor evaluate an individual's, or family's, needs?

F: During an in-take we determine why they're there and what their needs are. Often people come in and say what their needs are. As they keep coming, their needs may change. At the start they may say, the problem is my teenage son. Then, it turns out the son is just a symptom of the overall problem.

Is it usually one person coming in, or the whole family?

F: A lot of time it's only one person because that's the only person willing to come in. We like to see the whole family, but if we can only see one person, that's better than not seeing anyone. You're a product of everyone in your house and what's going on impacts everyone in the house so it is best to see everyone. A lot of times the husband won't come in. He's afraid he'll be blamed or is afraid of changes. Often the wife will come in and we say let's invite the husband to come in, but often he won't.

What is the theory behind how counseling helps people?

F: There are many theories out there, so in general most therapists take an eclectic view. They take a piece here and a piece there and develop their own style based on their personality. I mostly use Cognitive/Behavioral techniques, which is focusing on how your thoughts impact your behavior and how that leads to a pattern that is dysfunctional. If you can change your negative thoughts and behaviors, you can change your life. If you keep doing the same thing time after time, you can't expect different results. If you view your spouse one way, can we put a different frame around it and maybe view them in a different way and think of them in more positive terms. In other words you can not change anybody else. I can't change my husband, but I can change my reaction to him, I can change my thoughts about him, I can change my behavior towards him. And you might be surprised how much a person will change in relationship to you. So I try to get people thinking, it doesn't matter what the other person is doing, you can only control you. You wouldn't believe how much power you have in your own person and how you go out in the world.

How different is it when a child is affected versus a parent?

F: In some ways, although it is devastating to the parents, the marriage can stay in tact because they still have their roles. The dad can be the breadwinner and the mom can be the nurturer and they have a common goal, 'We have to rally around this child.'

Do you think in general it results less often in the breakup of families?

F: As long as there's no ability to blame, in other words there wasn't an accident. Personally, when my son had his surgery, I felt, thank God my husband is here. What would I do without him? There were times when I was spent and he was the only other person that could take over for me. I'm sure other families feel that way too. Your spouse is the only one that really understands the situation the way you do. That

is a strong commonality, even if you're divorced.

You mentioned blame. In general, if a child gets sick do moms tend to feel guilty even if there's no basis for it?

F: I can't speak for moms everywhere, but I do think they often have that sense, did I do something wrong? When my son, Jack, was diagnosed with Chiari, I immediately thought could it have been something I took - like a medication - during the pregnancy. It ended up being genetic, so it was something I had done.

How did that make you feel?

F: I didn't know, so there was nothing I could've done. It didn't make me feel good, but on the other hand I was glad we found it for him, so that he didn't have to grow up with it not knowing. I had to go through an awful lot to get a proper diagnosis. I had to push and push and push to get him an MRI, so part of me feels at least I pushed and got the right treatment.

Is there evidence that counseling helps people cope with the impact of a chronic illness?

F: I think so. Some people are very closed-minded to it. They don't believe in it. And those people are very hard to reach. There is evidence that some people do very well in a group setting, where even if they're not talking, they're hearing about other people's problems. Also, they gain support from other people going through the same thing, so they don't feel all alone. It's really bad to be going through something like this and to lock yourself in the house and to be all alone. We are social animals and we need other people. That's one thing counseling provides, someone to talk to. Sometimes it's a place to come and have an outlet and get the support you need to make it through the week and be strong for your family. I think counseling is helpful.

Then is a lot of the benefit from providing a safe environment to say whatever is on your mind?

F: Right, and also to maybe to meet other people going through the same things, so you don't feel so alone in what you're going through. I think sometimes when your body betrays you, it's frightening, but when you hear other people talking about it, it's not so frightening.

When should an individual - or a family - seek professional help?

F: Whenever they feel like they can't deal with it anymore. When they feel real down or locked in. A lot of times people, even family, don't really understand and they say things that don't help and even make things worse. They don't know what to say or how to help.

Is the counseling usually short-term or long-term?

F: It used to last 6 months to a year, but the insurance companies are moving towards short-term therapy which is about 6 weeks, which I don't think is long enough. I should note that a lot time people will go in for 6-8 weeks, but then come back for a check-up. That is completely normal.

How should someone go about finding a counselor for their situation?

F: I'm not sure of the best answer to that question, but I would say shop around. If you go to one and it doesn't feel right, go to another one. Find someone who feels like a good fit to you. My advice is to ask anyone you know in the field or sometimes clergy can recommend someone. There's a lot of counselors out there and not all of them would be right for a specific situation.

Turning to your personal life, how has Chiari impacted your family?

F: It was very hard to get Jack diagnosed. The doctors had talked down to me so much, that after the MRI, I was prepared for them not to find anything. Then they called and said he had a Chiari, which I had never heard of, and he had never heard of it. He wanted me to see a neurosurgeon, but said there would be no surgery. We went to the neurosurgeon and he holds up the MRI, and Jack's in the office with us, and he says this child needs surgery. I felt like I had been hit by a truck. I was totally unprepared for it. I thought the whole thing was handled poorly and for a whole month I was in a daze. We went to a different surgeon for a second opinion who we felt much better with. The second doctor checked for a syrinx. In the meantime, I'm trying to wade through all the information. I could think about nothing else, I was completely consumed. I kept thinking, how I am going to let them open up his skull? How could I get through it?

How did your other children react to the situation?

F: I don't even know because I was in such a fog. Our youngest kept saying, I have to have brain surgery. They had explained risks in front of Jack, and the surgeon said something about dying, so Jack was going around saying, 'I have to surgery and I could die.' Every time I heard that I cried. It was really hard because he's only 7 years old. I was a wreck

In a way you already answered this, but given your background, do you feel you were better prepared to deal with it than most people?

F: No, it was just so hard. It was a big thing.

Do you feel like you've made it through the ordeal?

F: Yes. In the end it was just two really bad days. He was in ICU for two long days, but then he got better really fast. It's only been a few weeks but he's doing well.

Have you had a chance to gain some perspective on how this has changed your family?

F: I will say that my perspective is that when things get really tough my husband and I pull together, we don't bicker and fight. We work together very well. I will say that when I was trying to find out what was wrong with Jack, everyone was against me. I felt like when I left the room people were saying, isn't it a shame that she can't accept her child just isn't right. But my husband never said that.

What practical advice do you have for a family dealing with Chiari and/or syringomyelia ?

F: Try to pull together; don't get caught up in bickering and fighting. Work together and don't let the stress pull you apart.

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