



THE FAMILY: PLANNED ADJUSTMENT TO HEAD INJURY

Good morning. It's a real pleasure for me to be here with you. I've met a few of your people over a number of years. I've met Ray Rempel and Bev Mantell on the telephone in my position with the National Head Injury Foundation, and tried to assist them in their efforts; but they were also helpful in sharing information with me. When Ray spoke with me earlier in the summer, he suggested we talk about day to day, practical advice. The kinds of adjustments that you need to make, the kinds of things families needed to know to survive.

Many times we rely on Mother Nature to solve our problems. Or we say, time will cure our ills or heal our minds, and time will mend our broken hearts. Our expectation is that there's a natural order to life. Traumatic head injury doesn't fit that picture, I don't think, for either the family or the head injured people. It's my feeling that head injury rehabilitation and adjustment requires intervention. We have to really, actively get involved in changing the catastrophe that has befallen us. This is a crisis for which you have no preparation and no experience. So, in order to overcome those obstacles, families need information and support to help the head injured person and to help themselves gain some segment of control in their lives.

The goal of my presentation is to help provide some new information and new insights on the adjustment process; to suggest some new options for managing your life; and I want to encourage you to be risk takers to get your needs met.

Over the years I've spoken to many families and professionals, and mostly it was on the telephone when they called the National Head Injury Foundation for information. Sometimes the callers knew what they wanted. They wanted names of physicians, or rehab facilities, or lawyers, or whatever. But other times callers would call, and they really didn't know what they wanted, and they'd end up saying, "What do you do?" meaning the National Head Injury Foundation. And it wasn't that they didn't know what to ask. They had so MANY questions; they didn't know where to start. So the families need to start their head injury education in the emergency room, and you need to be informed every step of the way; you need to know what's happening. Typically, families would say nobody talked to them, or they just got little pieces of information which weren't helpful, I don't think that's always the case. I think that people usually try to talk to you.

But, you're in this state of shock and it's hard to remember things. So even though people might have given you information, you weren't able to retain it. You have to take care of yourself and your brain only handles what you can manage. If in the family there are five people, each of those five people may have different time frames for reacting and different sensitivities to the feelings that they're dealing with.

What I suggest to the health professionals is to have the families immediately get this kind of a spiral notebook, or a three-holed binder, or something they can call a journal. Because people have trouble remembering, they need to write down what their questions are, what the information is that you've given them. But they also have to put a name with the information; they need to have a source to go back to in case they need to get clarification on something you said. Maybe in the back part of the journal they'll want to put some of the personal feelings they're going through. It turns out that, in time, a lot of families feel a need to write a book or a manual, and share with other people. It's to give them some sense of where they've been and how far they've come. And I think that's really helpful for them to do.

When you don't have the information needed, you really feel out of control. You already feel victimized because this accident has happened. Much of the time the accident was not the head injured person's fault and you feel like you are at someone's mercy. You need to become a part of the Rehab team very early. They need to draw on your experience; and you do have expertise in understanding your family member. You know the person best, know the kind of person they are, what they respond to best, and you need to share this with the rehabilitators.

We also have to think about the patient. If the patient is awake, he/she might be confused. Perhaps they were just unconscious for a brief period of time and they might have amnesia surrounding the events of the accident. What happens in the emergency room, the staff there might ask the person certain questions, and the person may not remember what happened, have no complaints and they will be discharged. These are the patients that in three to six months have a great deal of problems. What happens though, when the minor head injury, and I say "minor" in parentheses, because every head injury causes a lot of long-term problems, but the minor head injury, if not diagnosed, results in the head injured person feeling like they're crazy because nobody is validating these differences they're noticing in themselves.

Their lack of concentration, their fatigue ability and other things all get to be a problem, and of course it spills out right into the family, and to the workplace.

If the patient is more seriously injured and you need more information, you may have trouble finding the doctor in charge at the emergency room and getting the information you need. How many of your neurosurgeons make rounds at six o'clock in the morning? Is that by design, or is it because of the busy schedule? You need to find someone to speak with. If you're in a hospital that does not have a very fine neuro-team, I think you're at a disadvantage, because early diagnosis and early treatment is important as it sets the stage for future recovery. Family involvement is crucial for your benefit and the patient's welfare.

I'm sure if I asked, the majority of you would say that physicians said your person might not live, and if that person lived he'd be a vegetable. That's very hard to accept. Most people don't accept it, and you want to find the doctor, or whoever is telling you this, and you want them to give you some hope. You want to help make your loved one survive by whatever means available. You want to energize this injured person and help him/her wake up.

Now that I've made public your personal experiences, let's talk about the adjustments that you will be going through. Most professionals, if not all, would say that family involvement in the rehabilitation process is probably one of the most significant factors. You can have wonderful surgeons and psychiatrists, and therapists, but unless there's a family to support the patient and to give input to the team, the patient might not make the kind of

progress that you've hoped for. When your person goes from the acute hospital to a rehab setting or another setting, the new staff, a lot of times, assumes that you've already been well-educated, and that you're a person that looks very well together. They don't always think to ask you how are you doing and they need to do that. If they don't ask you how you're doing, you let them know. After all, this is a new facility and you have to learn to trust all these people who are caring for your person. So learn to communicate. You will need to learn how to initiate conversations. Use your note book or journal when you have quiet times. When questions pop into your head, write them down so that you can get answers later.

And another thing for families to remember; the professionals taking care of your family member are working for you. You or your insurance company have engaged them to be responsible for the care of your person. So, don't you think you should have the right to have some input into how they do their work? Not that you're going to tell them how to do their work as professionals, but you need to let them know that you care, and that you need to be informed and that you have information to share with them. Don't be shy. Learn as much as you can, because you're going to need it later.

Say your person is 20 years old when he/she is injured. They might be in the hospital three months, six months, maybe a year. They are going to probably live 40 more years to their usual old age. Who's going to be responsible for this person when they leave the hospital? Who is going to take care of them for as many years as they need supervision? Sometimes these people need supervision for the rest of their lives. If you don't learn early what rehabilitation is all about, or you're trying to get your questions answered after discharge you will be at a disadvantage. Even if you are many years down the road right now, it's not too late to start with a journal to record important information, because there will be times when you will need it in a hurry. And there's no time during an emergency then to be searching for information that you need quickly but can't find because it's on a scrap of paper somewhere.

You need to be prepared for a ride on an emotional roller coaster. A small gain in your person's rehabilitation process and your spirits will soar. A little setback or complication, and your emotions plummet. Hopefully, in time, you will not experience the intensity of those emotions that you did earlier, and hopefully you won't stay in the down periods as long as you did before, because you have developed better coping skills, and you'll be able to get through that bad time just a little better than before.

Families lead a double life. A lot of your time is spent at the hospital or the rehabilitation centre, but there's also a life for you when at home. Those family members at home have their needs too. Often when it is a young adult that was injured there may be other young people living at home with the parents, and other children that have gone through school and are now living away from home. Suddenly this man and wife, who thought they were going to start the next stage in life together, now have a dependent child at home. The head injured person might be treated as a thirteen year old when he comes home, and that's hard to manage for that person, because they remember that they were living independently before. The reason they are being treated like a thirteen year old is probably because they're acting like one. So, it's a major adjustment. And we often wonder how do families and how do head injured people get the energy to get through all that they have to go through each day.

As I speak of the adjustment process, we need to remember that the responses at various stages of recovery may be repeated over time. And, you can expect to go on having various reactions. As I go along, I might repeat certain things and, I guess, those are the things that I perceive to be important to you.

You have many more decisions that you'll have to make as time goes by. It is very difficult having a dependent person that you may have to assume some responsibility for. You have to worry about the daily routines, the

schedules, therapies, appointments, leisure activities, and so forth. These become the extended rehabilitation for which the family may be responsible and which is necessary to keep the patient from regressing.

There are a lot of legal concerns that people are not advised about early on, and I want to mention them for your consideration now. In the States we have names for these; I don't know what there are called here. There's guardianship the court will promote someone as a guardian for the head injured person if they cannot assume responsibility for their person or their financial matters. The legal guardian normally takes care of the legal end of the legal business, but is not legally responsible for the person's actions. And then there's a conservator, a person that's appointed to manage the financial affairs and has no jurisdiction relating to matters of the person.

I know of a situation regarding a head injured person and nobody thought about the legal needs. There was a court case regarding his accident and a large amount of money was awarded to the head injured person. Nobody was legally responsible for him, and he spent that lifetime settlement in three months and the family could do nothing about it. So, please consider the mental status of your person and whether there needs to be some legal measures taken to safeguard them or their money.

If your person, who sustained the head injury, was working and had health insurance and is now not working, you need to find out who is going to keep the payments for the health insurance. If payments are not made and the health insurance lapses, that causes problems. Lawyers don't always think of these things, because they don't really understand head injury. Hopefully you have been successful in your head injury groups in educating some of your lawyers.

Another big problem is when head injured people want to drive cars. What's the criteria for allowing the person to resume driving? You might think well, you need to be seizure-free for some period of time, or the doctor may say in six months you can drive, or a year. What about the person's behaviours? What if they have memory problems and they get in the car, they go somewhere, and they forget why they are there, forget how to get home? What if they have a bad temper and someone pulls in front of them and they lose their cool? We have to consider the outcome when we give these people privileges. They have to be ready for them.

Sometimes head injured people get arrested. How do you prove to the judge, or whoever, that this person has a problem, and needs special care, and special testimony, and doesn't need to be incarcerated?

I already mentioned the emotions that you have to deal with. Each person reacts in their own time, in their own way and then they're ready. In some families the accident brings them together, and the family pitches in, and it's a "rah-rah" team, and they do pretty well. Other times, families are fragmented. I know some families where the siblings couldn't even go to the hospital to visit the person, it was too upsetting. Among teenagers, and even among parents and children, (I have three children, so I speak from experience), life is not always rosy with teenagers. Sometimes there are issues between them or between parents. When an accident occurs, those issues become very prominent in the person's life. And I call it "excess baggage" that we have to deal with. You assume some guilt here, and think "Oh, if only I hadn't done this or if I hadn't done that", or whatever. Perhaps counselling is needed to help people get through. One thing I caution you against, we need to experience our hurts, our anger, all of those emotions, but don't get stuck at a certain level. Experience your emotions, learn from them, and grow from them.

I'd like to suggest some reading for you. One is by Elizabeth Kubler Ross and that's mentioned on your reading list "On Death and Dying". You're wondering why I'm telling you about this. Head injury changes the person we knew and we have a new person with whom to get acquainted. You really have to go through the grieving process so you can move on with your life. This book might give you some insight. Dr. Kubler Ross is well-known for her work in

this area. If you're having trouble with your faith, and wondering why this happened in your life, this is a wonderful book, "When Bad Things Happen to Good People". What I do when I'm reading these books is to use a piece of paper, or an index card, and I write the page and then a sentence from that page that's very meaningful to me. Then when I need to come back and get some comfort or insight, I can refer to my notes quickly. You might consider trying something like that as you do your readings.

I just recently got the book "Missing Pieces" when I was in Colorado. It was written by a woman whose husband suffered a head injury as a result of a surgical procedure. And it's rather strong, I feel. She lets you know that she's hurt and she's angry, but she also lets you know how she copes with the situation. This book has a different tone to impart because it is from a spouse rather than a parent and although it is helpful there are no remedies to make the hurt go away.

I'm suggesting these to you for several reasons. Every single head injury is different, but there's a certain commonality to all of them, and if you can benefit by other's every day experiences, it might save you from going through a lot of the problems on your own. Continuing about emotions, you know there are certain events that trigger our emotions. We need to be prepared for them.

I had a personal tragedy in my life, and I know that recovering was difficult for me; and for head injured people it's the same way. The first Thanksgiving and the first Easter and the first holiday following your person's injury is difficult because you have a stranger among you and people may have trouble accepting him/her. Things are different now. So even if that holiday isn't what it was before, you can build new traditions, but you have to work on it, and you need to remember that you aren't alone. Maybe your son's or daughter's classmates are graduating high school or college. And this is difficult for you, because you're realizing some of your dreams are shattered, and your person wasn't a part of that graduation and that's another emotional downer.

For anyone in the audience who is hurting, deal with your hurt. Talk to someone about it. Don't be crazy and say, "I can do it myself." I am a person who has trouble asking for help, but I found that when I did ask for help, I had a lot of friends out there wanting to help and it made a difference in my life. You will find the same. These books I've suggested will help you also. You need to come through stages. Just when you're feeling things are pretty good, one wrong thing can upset the apple cart, but you'll go on and you'll be fine. I can tell you about one person I talked to on the phone some time ago who called for information. I questioned this woman about her head injured husband and his behaviour. She said, "You know, his behaviour is really great." And I was pleased to hear that, but it turned out that prior to his accident, he had a problem with alcohol. When he drank too much he was very abusive, and they had a very difficult life together. The head injury changed her life, because he no longer was abusive to her, but it turned out that he's also very passive and he has changed a great deal. So it's sort of a happy/sad situation.

On the cognitive level, you are trying to regroup and you're trying to get reorganized and get your life together. That takes energy. Socially, I feel that a lot of you have noticed changes. Some of your friends and some of your family members don't come around the way they used to before, and that's difficult. You need people and you need support.

Let's talk about you survivors, how you're overcoming obstacles. You need to figure out where you are now, where you want to be, and how you're going to get there. Some folks manage fine on their own, and others get professional help. Do what you have to do. I've talked to a lot of people who say they never look back, they only look forward. Yesterday is a spent penny. In my own life I look back once in a while to see the experiences that I've had, and how they help me in the future. Look back and see how you're feeling, how you managed before when you were in a similar situation. How did you manage? Were you a really laid back family, didn't let things bother

you? Were you a really tight family, where problems brought you together? Was it a sort of splintered family, where it's hard to get decisions made and problems solved?

Think of your expectations. Are you expecting more of yourself than you were able to accomplish before? If you are, you might try talking to someone, so you will not set yourself up for failure. There are a lot of problems in families. Perhaps the head injured person was a free spirit.....the one who caused all the problems in the family. Can we really expect that person now is going to be part of the family again when they had separated from the family before on difficult terms? Who is the decision maker in your family, or do you do things by family council? You might need help getting all these things together.

We talked about counselling. What does that mean? Does it mean you're weak and you can't help yourself? No, it means you're smart enough to allow yourself the opportunity to benefit from someone else's experience. You can go to private counselling, mental health centres, perhaps there is a minister, priest, rabbi, whatever. Perhaps there's a trusted friend, your support group, whoever. Find a person to talk to. These support groups are important too, and I'll speak about those a little more later on. But reach out to them.

In the States we have a provision for respite care which is meant to provide rest for the family from their caregiving duties. There are categories of eligibility for respite funding which provide two weeks per year. This can be done in segments in hours, if they only wanted to go out for an evening, or weekend, or longer to equal two weeks.

The mother shouldn't be the only person managing the problems. There have been studies done, and it is estimated that about 75 percent of the time, the mothers assume responsibility for managing the person with head injury. When head injury is added to the usual family decisions and burdens, the responsibility becomes fairly overwhelming. And here I might talk a little about information sent to me. There's a study that calibrated worrying. Some of us worry about everything! There are things that we should worry about, but we also expend a lot of energy worrying about things that may never happen. But this little card said about 40 percent of our worries never happen, they are really not important enough to be worried about. And then there was 35 percent of things already happened, that we continue to worry about; and 15 percent turns out better than expected; 8 percent are needless concerns; and 2 percent of our worries are really justified. So we need to take an inventory of our life and prioritize our worries. We need to conserve our energy to deal with that 2 percent of justified worry.

I'd like to break things down into segments, because it makes it more manageable, and then we can at least realize these small successes, even though we can't solve all of our life problems. If you have a head injured person at home, break down the household tasks. Involve that person if possible. The mother doesn't have to do all the shopping, transportation, appointments and recreation for the head injured person. Let other people assume responsibilities for some of these tasks. Have the survivor help with meals, maybe breakfast, or dinners, or weekends, or whatever suits you. Other family members can help with driving. Maybe you can even share with other families, so you don't have to do all the driving to appointments. Leisure and recreation time requires a great deal of planning, and extra time to carry it out. Maybe in your support group you can take turns doing these kinds of things. Usually you have one person in the family who likes to do research, making phone calls, getting to the bottom of things. They want to know why things are happening or not happening with therapy, programs, or funding. Let that person assume responsibility for making the phone calls to insurance companies, or agencies, or let them get the information together and bring it back. This way, when everybody has part of the action, and part of the responsibility, they are also more invested in the process and find gratification in being part of the family team. And this is important for the head injured people too. I just came from a workshop where the head injured people were telling the audience, "We need to be needed". How often do we act for, make decisions for, speak for

our head injured person, even if that person is capable of making decisions regarding their life whether they want to be done for or not. We're going to make it easy for them but in fact we are taking away their motivation and their self-esteem. And we wonder why head injured people have outbursts of temper.

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