

## Changing Roles in Caregiving

**Source:** Produced by BrainLine.org by Victoria McDonough and Brian King

**Video Link:** <http://www.brainline.org/content/multimedia.php?id=2887>

**Dr. Angelle Saunder:** Traumatic brain injury affects the family in a variety of ways. One of the biggest ways is that there are role changes after traumatic brain injury. And every family has certain roles. Some of them are really concrete roles like someone goes to work and makes money, someone does the housework, and then there are also different emotional roles.

So, you know, sometimes a person may be the rock of the family, the person that people turn to in times of trouble, or that someone else may be the joker of the family so they make everybody laugh when everybody's feeling stressed. So there are a lot of different kinds of roles that family members can have.

After a traumatic brain injury there are a lot of role shifts and role changes, and what often happens is one family member may take on too many roles and they can get what you call "role strain". So the most typical example of this is when a male has a traumatic brain injury and maybe the male was the primary bread winner before the injury and his wife may or may not have worked.

But even if she did work, after the injury she may be in a position of being the primary bread winner, being the only income—source of income to the home and at the same time she can't really relinquish other roles. So that people who were husbands who are home after the injury and are not able to return to work cannot necessarily take on other roles like being the primary person who transports the children back and forth.

They may not be able to drive after an injury or they may not be able to manage the finances because they have cognitive difficulties which give them trouble with that. So it ends up being that one person, maybe the wife (but different people can assume these roles), have to take on a lot of different roles and that results in a lot of stress and in people becoming overwhelmed.

Now some of the other family changes that happen are more in regard to relationships, so one is that there can be a lot of changes in communication after injury. Some of them are due to the direct effects of the injury. So, for example, the person with the injury may have what we call "impaired social communication" where they may not be able to pick up on nonverbal cues that other people give them.

They may not be able to read emotions in other people, not have the same empathy that they did before and that, of course, results in changes in the family relationships. Also, after an injury everything in the family seems to revolve around the injury.

So whereas before they may have sat at the dinner table and talked about their day, now they talk about how they're gonna get money or how they're gonna get services for the person with injury, so that just the normal day-to-day family interactions become very focused around the injury and they lose that warmth and affection that they had before.

I think if you had a good relationship before the injury that you're able to maintain that after injury, even though it's difficult at times. And naturally people before the injury had various types of relationships and so any problems that were present before the injury are gonna, of course, be exacerbated after the injury.

I think that the communication patterns are extremely important, so if there are problems, if people feel comfortable sitting down and talking with their family members about the problems, then that's gonna result in more strengthening. And if they didn't have good communication patterns before, then it's gonna be problematic.

Family therapy can really help and, unfortunately, that's not one of the things that's focused on after injury. Many insurance providers won't even pay for family therapy unless it's specifically to help the person with injury develop better cognitive strategies or go back to work. So the focus on the family as a whole and the family relationships is often not there, but therapy can really help to repair relationships.

You have to develop communicational patterns. So if they were not there before, the important thing to do is to find new ways to communicate. You should not communicate when you're angry, so it's important to find time that you can sit down together and talk about any problems that exist when you're not very emotional.

And when you become very emotional, it's important to take that time away. And I think after a brain injury, especially for the primary caregiver who's the primary person who's caring for the person with injury, that person often does not have much time away from the person with injury.

So all their interactions are in situations which might be rather tense and so it's important for the caregiver to take that time away and then to be able to come back and talk about any problems that exist in a calmer way. There are a couple of different ways that caregivers can find time for themselves.

One is that if they have the support of family and friends, they can ask someone else to come in and sit with the person with injury and then they can go take time for themselves, go to a movie, go meet a friend for coffee.

Now sometimes caregivers don't have that support and if a caregiver does not have that support and they feel like they are always in the home with the person with injury, there are still some things that can be done. There are very few people with injury that actually require someone to be sitting in the room with them 24 hours a day.

Mostly it's the case that the person with the injury just needs someone in the home. So there are different things that can be done that caregivers can plan into their schedule – that at a certain time each day they're gonna go into a room by themselves, take a hot bath, have a cup of hot chocolate, watch a movie, whatever they find to be relaxing.

So you get really overwhelmed when you're in the same situation day in and day out, and so it's really important to plan those activities. It sounds silly but if you don't schedule them, they often don't happen. So having into your schedule some planned time for yourself is really important.

It's really easy for family members to become stressed when other people are offering them advice and they feel like the advice is not good. Or even if the advice is good, they feel overwhelmed because so many people may be giving them different advice. So it's important to remember that these people are trying to help.

So while it's easy to become overwhelmed and become angry, people are meaning well and each person doesn't know that there are tons of other people offering you advice. So if you take that perspective, you might think about it differently and not be as upset.

If you are upset, which is a natural reaction, then the best thing to do is to remember that you know the person with injury best and that you are the person who is best—who are best—is best equipped to help them and to know exactly what circumstances are happening in their lives and in the home.

So you're the best judge. So listen to advice, try to process it calmly and then really make your own decisions and seek out whatever other information you need. You may have to find professionals that you trust and ask for answers. So the doctor that you see may not be the person to give you advice if you're not comfortable with that person.

But there are a lot of different supports and a lot of different websites that you can go to to try and find advice that you feel comfortable with. And in the end it's gonna be your decision to make.

Social isolation is one of the most common problems after traumatic brain injury and it's not just for the person with injury but it is also for the family members. And part of that is that people that were once friends often don't understand the changes that the person with traumatic injury has gone through.

And in the beginning, right after the injury, there's a lot of support for the person with injury and their family, and people are gathering around, even acquaintances that didn't know them well before are gathering around, bringing food over, really providing support.

And as time goes on, that support dwindles and people go back to their lives, and the person with injury and their family become increasingly more isolated. An important thing to help with that is to get out and try to develop new relationships. Sometimes it's easier to develop new relationships than to go back to the old relationships because the people that you meet after the injury don't have a comparison to compare how things were before the injury.

And one way to do that is to go to social group meetings like church meetings. The YMCA is a great place because they have a very all-inclusive philosophy. So try to find community organizations like the YMCA, like multi-service centers, like church groups where people are generally more accepting of a diverse variety of characteristics in people, and that can usually lead to formations of new relationships.

And if it doesn't lead to formation of really close relationships, it at least has the person with injury out in the community socializing, feeling productive and feeling good about themselves. Unfortunately, there are very few guidelines and very little research into the effectiveness of different community integration programs.

When you think about community integration, one thing to think about is it means getting out into the community and doing activities that everyone else is doing. So if you're looking at rehabilitation programs which propose that they're helping people with community integration, one of the things to look for is are they taking people out into the community, are they involving them in activities or do they have them all the time sitting behind a computer and, you know, doing computer games, computer programs.

Sometimes there are certain computer strategies and computer games that can actually help people develop certain skills that they can then use in the community. So I'm not saying that all rehab involving computers is bad, but you really need to look at the amount of time that the rehabilitation staff are getting people out into the community.

After a traumatic brain injury things are gonna be different and people are gonna have difficulties with activities that were once very easy for them. And so the most important thing is to get them involved in an activity like, for example, learning to ride a bus.

And then they're going to have problems but you cannot always predict with a hundred percent accuracy what types of problems they're gonna have just from looking at them in a rehabilitation setting. So it's best to get them out into the community doing an activity, figure out what problems they're having doing the activity and then develop strategies to help them with those problems.

So, again, the most important thing, and even if you're not in a rehabilitation program, the most important thing is to get the person with injury out doing activities, looking at the situation, figuring out what problems they have and then coming up with strategies to get around those problems.

Because that means that the strategies that you teach to them are gonna be generalizable (ph.) to their real world setting and help them to get back to their communities activities. One of the most important things that can happen to improve the field of rehabilitation is that overall public awareness of traumatic brain injury be increased.

So one of the greatest barriers to people having community integration is that people don't understand traumatic brain injury. If you talk to the average person, they've never heard of traumatic brain injury. Many people have heard of stroke but most people have not heard traumatic brain injury.

And people with traumatic brain injury usually look normal. If you look at them, they don't have a lot of physical disabilities. There are exceptions but for the most part physically someone looks like nothing is wrong. But they're still having difficulties with some cognitive abilities and they're still having difficulties with processing emotion and with some social interactions.

So people in the community often don't understand what's happening. In today's society we really have made a lot of accommodations... [buzzing noise] ...people with physical disabilities, and so we have ramps for our people in wheelchairs and people—if a person is in a wheelchair, usually people want to help them.

But no one really understands if someone has a traumatic brain injury how to help them. And, in fact, they may interpret some of the things that a person with traumatic brain injury does as being a personality characteristic, and that is off-putting to a lot of people.

So increasing overall public awareness of traumatic brain injury, I believe, is the best way to help people become integrated into the community. And going along with that, more resources are very important. I think that increasing public awareness is a first step toward getting more resources for persons with brain injury.

Some different states in recent years have been able to lobby the congress to pass laws to increase funding for cognitive rehabilitation, but I believe that in some states it's still the case that cognitive rehabilitation is excluded from some insurance companies' policies.

And so it's really important to increase awareness of needs so that there's more funding and more resources for persons with traumatic brain injury. Most people with traumatic brain injury do not get rehabilitation, and there are a lot of rehabilitation facilities but most of them require insurance funding.

And, unfortunately, the majority of people who have a traumatic brain injury do not have insurance. So there is an instance of a person that I worked with who did not have insurance who I saw in the county rehabilitation facility and I referred them for post-acute cognitive rehabilitation services at the Tier Challenge Program.

And, unfortunately, if someone has an injury and does not have insurance... In Texas there is only one way that a person with traumatic brain injury who does not have insurance funding can get rehabilitation services, and that is to go through the state (ph.) vocational rehabilitation agency.

And so there is, unfortunately, a wait list for those services. So a person that I referred for services got onto a wait list and in spite of frequent calling to their project manager for their case with the state rehabilitation agency, was unable to get into a post-acute cognitive rehabilitation program until almost a year after injury.

Now, of course, there's spontaneous recovery that happens within that first year. So that person was getting better everyday without having rehabilitation but not making as much progress as he could have made if he had gotten the rehabilitation early on.

So by the time he was able to get entry into the post-acute cognitive rehabilitation program he had made a lot of gains to the point that they did not think that he needed intensive services so they did not have him in daily services but they had him going a couple of times of week, which was appropriate for him at that time cause he actually had made a lot of advances.

But he could have returned to work earlier and could have gotten out into the community earlier if he had gotten those services within the first three months after his inpatient rehabilitation discharge rather than nine months later.

So that is one of the frustrations in working with people with traumatic brain injury, especially those who don't have insurance like in the county hospitals, because you know they need services. There are very few funding services to get them these services. And this particular person that I worked with had tremendous family support.

So he was able to be happy in spite of the fact that he was not doing the activities that he wanted to do and not feeling extremely productive. Many people don't even have that family support. So it's really important to increase funding services for persons with brain injury and not just with private insurance, because traumatic brain injury is not an equal opportunity disorder.

It actually happens more to people from minority backgrounds and more in people from disadvantaged socioeconomic backgrounds, and these people are unlikely to have insurance. So most of the people who have traumatic brain injury actually do not get services.

Even though a lot of rehabilitation is focused on the people who have gotten services and a lot of the research that looks at rehabilitation effectiveness, of course, is looking at people who got rehabilitation to look at the effectiveness... So there's this whole other group of people who have not gotten services and who are sort of lost in the system.

The brain is going to heal on its own naturally over time. There's a certain amount of spontaneous recovery that happens in the first year to two years after injury. And there's nothing that can really be done to speed up that process, however, there's a lot that family members can do to help people not become mentally inactive during that time period where they may not be working or may not be getting out of the house much.

So while doing computer games or while doing crossword puzzles may not actually speed up your brain's recovery process, it can at least keep people mentally active, and that's important. Also, there's a lot that family members can do to help the person with injury develop compensatory strategies that can be used in the home.

So if a person has memory problems, there are different strategies that can be used to help them get around those memory problems so that it doesn't have as much of an impact on their activities. And there's actually information on different types of cognitive strategies that family members can use on a website that we have as part of our rehabilitation research and training center grant.

And the website is [www.tbicomunity.org](http://www.tbicomunity.org). And on that there is a project called "Training Family Members as Paraprofessionals" that has slide presentations in it that contain different strategies that caregivers can use to help with fam—with fam—to help a person with traumatic brain injury develop compensatory strategies in the home.

The number one advice that I would give to caregivers is to take care of yourself. Caregivers find this extremely difficult to do. They feel that they should be focused on helping their loved one to get better after injury and that they should not be focusing any time on themselves.

But if caregivers don't focus time on themselves and don't manage their own stress, they're not gonna be able to help the person with injury. So the best thing that caregivers can do is make sure that they keep themselves mentally and physically healthy so that they can be ready to help the person with injury.

So that's [*sic*] means taking time for yourself, planning time into your schedule to do little things that can help you relax and also getting as much support as you can, reaching out to other people, reaching out to brain injury associations, making sure that you have the support that you need.

