

BRAINLINE TALKS WITH MICHAEL PAUL MASON

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What Happens to Survivors After the Injury

MICHAEL MASON: Historically, what's happened with brain injury survivors in America is that they are relegated to two or three different types of settings. The worst case scenario, they're considered so inappropriate or such a misfit in society that they might wind up in the penal institution of some kind. And that's a grievous mistake in my understanding of things. Many times they can wind up in mental health treatment facilities of some kind on a mental health track. So they could go through psychiatric crisis units. They could end up in institutions for the severe and persistent mentally ill. These are not appropriate places for someone with a neurological condition. Because a lot of times, these psychotropic drugs are blunting the one thing that a person needs in order to regain lost abilities. Oddly enough, the brain needs itself in order to heal itself. So these environments, these mental health environments, are often not the right place for someone with a brain injury.

The other alternative that America has historically provided is simply one of neglect. The person maybe put in a nursing home just because no other options exist. In which case, they don't receive any kind of therapy. They just sort of languish. And I've run across hundreds of those cases. Every year in America, 1.6 million people sustain a brain injury. But there are only about 5,000 long-term beds for those individuals. And so you can imagine that the grave shortage of services that is out there. It's quite frustrating.

MICHAEL MASON: The typical patient falls on the milder side of brain injuries. Something like 87 percent of that 1.6 million people per year sustain a milder brain injury versus a moderate or severe injury. And for those milder injuries, many people, you know, they will deal with the injury in such a way that it will

resolve more or less over a different amount of time. But what we're learning right now about brain injuries also kind of complicating our understanding of brain injuries is the fact that brain injury also is disease accelerative and disease causative.

And that means simply that once you have a brain injury, things are more likely to go wrong with you physiologically over the long run than had you not sustained that brain injury. It's because you're messing up the control center of your entire body.

People are made more vulnerable by brain injury in a variety of ways. And one of the ways that this can manifest, for example, is a seizure. I've come across numerous cases where the person may have been tackled on the football field or may have fallen down a flight of stairs. And six months later, they think everything's fine. They don't have the headaches anymore. But then a year later, they all of a sudden hit the ground and suffer a grand mal seizure. And they're convulsing and the muscles are contracting. And they go to the hospital. And they find out the terrible news that not only do they have a seizure, but it could happen again.

And suddenly, they have to re-examine their life in the concept of having epilepsy. All of this being from an injury that they thought was minor and they thought they would resolve, it's actually become a very serious issue. Other people who have sustained milder injuries may have problems with balance much later on in life. And they may not even notice that they find themselves avoiding activities that they once enjoyed. Swimming, for example, is something that requires a lot of balance and a lot of sense of balance. And people will sometimes give that up following an injury just because for some reason being in the water makes them uncomfortable.

MICHAEL MASON: Brain injury is also disease accelerative. And what that means is it can hasten up or hasten problems physiologically that may not have been much of a problem before. The most glaring example of this is in geriatric patients with brain injury. Many times geriatric patients fall and sustain a brain injury that way. Well, what they'll find out is that Alzheimer's will onset more prematurely in those patients than patients without brain injury.

MICHAEL MASON: In the hospital that I work for, for example, there's not a single patient in that hospital from Oklahoma. All of the patients have come from out of state just to go to this hospital. And I think you'll find at most rehabs in the country that's probably the case where many of their patients have also come from out of state as well. The truth is that there are so few of these specialty centers out there that people will travel great distances in order to get to them. In my book, for example, there is a young man that I wrote about who's a five year old named Brian Larson who had a brain tumor and developed severe problems as a result of that. His parents were actually looking at a school in Massachusetts. Although they live in California, they were willing to send him across the country to get the right kind of care. And that to me is a terrible injustice.

MICHAEL MASON: Geography plays a huge role in how well you will be after a brain injury. If you get a brain injury in Iowa, for example, there are so many support services in place already for you that you will not find yourself in as difficult a position as you may in other states. Just across the river so to speak in Nebraska, if you have a certain kind of brain injury there, say you have behavioral problems, there's almost nothing for you in terms of rehabilitation or support services or any kind of funding. So you could very likely just have to do without services. And this is a real tragedy. But it does matter where you live.

MICHAEL MASON: Often, there are not very many services available. And sometimes, you know, more often than not I would probably say you have to look beyond your state to find the things that you'll need.

MICHAEL MASON: If I were looking for brain injury help and I didn't know quite where to turn, I think the best phone call that I could make would be to the Brain Injury Association. That hopefully would lead me to a functioning Brain Injury Association in my state and maybe a support group. And those support groups are real information goldmines. You know, it's a place where people who know what's available locally will meet and help others navigate that very challenging system. And so that's one of the things that I would suggest starting with.

The other resource that is available to everyone, but isn't highly publicized is that every state has what's called a national state head injury administrator. You can find this person online by just simply Googling that and you'll be taken to a page that has all the information on the state head injury administrator where you live. And just opening up the line of communication with them should yield a lot of information about what kinds of services are available near you.

MICHAEL MASON: The Brain Injury Association of America is the lead organization for advocacy in the U.S. For professionals, there's the North America Brain Injury Society where it sort of has more of an academic feel to it. And then there are a number of smaller organizations, you know, like the American Association of Rehabilitation, nurses, for example, that act as support associations. So the brain injury association, North American Brain Injury Society and the National Association of State Head Injury Administrators are all very key. There is one accreditation association that's also very important called the American Academy for the certification of brain injury specialists. And what they do is they educate and train people to become certified specialists in brain injury. This is a very key certification to have at any facility that claims to be a brain injury specialty center.