

Coming to Terms with Sexuality and Head Injury



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The Demographics of the situation point out the problem. Head injuries predominantly occur to young people-those in their late teens, 20s and 30s. Head injury is thus most likely to happen to people at a time in their lives when they are establishing personal relationships and probably have become involved sexually. As one head-injured individual puts it, “Most head-injured people are beginning to get into their real sexual years.”

As head-injured individuals seek to adjust to a new way of life, part of the adjustment, although little discussed, is inevitably coming to terms with sexual concerns. To shine some light on this area- in the interest of helping others in similar situations to cope and to help professionals better understand the issue, several head-injured individuals agreed to be interviewed about their concerns and own adjustments. To respect their confidentiality, we’ll identify them only by fictitious first names: Bill, 28; Sarah, 29; and Jim, 27. All articulated their feelings eloquently and poignantly.

All sustained traumatic brain injury in motor vehicle accidents. Single both now and at the time of his accident, Bill lives independently in an apartment. Both Sarah and Jim live at home with their spouses. One of the three was a client in a New Medico facility; the other two received rehabilitation elsewhere.

Each was first asked to give a definition of sexuality. Said Sarah, “To me, sexuality is the way you perform around other people, the way your feel about yourself, and your own individual characteristics.”

Sexuality is everything about the way I deal with other people-not just the opposite sex, but just by whole being,” said Jim.

From each person’s perspective, how does head injury affect a person’s sexuality? Said bill, “Your own personal thoughts of yourself aren’t real high, and you worry about the thoughts that someone else might have about you. For myself, I can just say that my self-esteem was definitely affected.”

“I think that head injury affects a person in all ways,” said Sarah. “Of course, I think your self-confidence affects you in all ways. If you’re not self-confident to even present yourself, I think that greatly affects you sexually. I think sexuality is merely one of the basic instincts you try very, very hard to regain. You feel very broken with everything after a head injury. You’re very confused. But I think sexuality is one of the basic instincts that perhaps is maintained somewhere under the rest of your confusion.”

According to Jim, “I’m afraid of how other people are going to relate to me. Are they going to think I’m stupid or mentally retarded or something. Just talking with people

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who know I've had a head injury, they-I guess the word would be-patronize me.”

While none of the three says they received any sexuality education or counseling while they were in rehabilitation, they think it would have been helpful. It would have made a difference, as Jim put it, “if it just got me to relate to other people. My emotions got really mixed up, and if the therapists talked to me and let me know what was going to happen, and maybe some ways to deal with it or to deal with other people, it would have helped.”

And their views on what sorts of information or education would be helpful for a head-injured person while in rehabilitation treatment?

Said Sarah, “Well I think what would be most helpful is a simple statement that we know your sexuality exists-something to that effect-and asking how they can help you with it, sort of, and understanding yourself sexually.”

Each also offered particularly moving comments about their own particular situations-Bill, as a single person, and Sarah and Jim about the impact on their respective marriages.

Bill explained, “In many areas you're actually on a lower level that you were before. What I mean by lower level is you are just unable to do the things you did before. A girl you are meeting needs to be unbelievably smart just so she will be able to understand head injury much, much better, so she will know that you're not actually on a lower level. You just have difficulties with some things that come in the way from your head injury. That right there, I think, is the main, main, main topic. Will the other person be able to see the reality instead of just the thoughts from first sight?”

He continued, “I can just say that in the past few years that meeting girls-it's just something that I'm not comfortable with, I'm not very comfortable. It's tough. I think it's tough with everybody with a head injury. The things you used to think about when you meet a girl aren't even in your category of what you're thinking about. Your thoughts are just on troubles you're having with your head injury and on how to explain it, on how to get understanding from the person you're talking with.”

Jim commented, “I am so glad that I'm married already and don't have to deal with dating or anything like that, because I don't think I could handle it. Just the problems I have towards relating to other people, I don't think I could start off right now. I don't know how other people do it. I don't think I could get that close to a new person now after my head injury. I'm so shaky and I feel trapped inside myself that I don't feel I could put what I have to into a relationship.”

Said Sarah, “Part of the problem with sexuality is the age of most head-injured people. Most head-injured people are beginning to get into their real sexual years, are they not? And I think sexuality is very important. Counselors should bring it out and discuss it. And I think that would help. And I think very often sexuality tends to become confused

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with other issues—the issues of needing to be loved as a head-injured person, you just begin to feel in the way, especially as you remember and know if you aren’t able to do the things you previously did.”

She concluded, “So you begin to feel very much in the way, and your sexuality is very much connected with that. And if it’s not addressed, it becomes an issue with you—you think sexuality is another area where you are in the way. I think sexuality is very important, and I think it definitely needs to be addressed with head injury, and understood with head injury, and in fact allowed to occur with head injury. I think sexuality is very much connected with the feeling of wanting and wishing to be loved. And I think that it’s very, very important for head-injured people to know they are loved.”

The Spouse’s Perspective

The following is an interview with a 33-year-old woman whose husband sustained a traumatic brain injury in a motor vehicle accident involving a drunk driver. He received several months of hospital-based rehabilitation and has since been living at home. The interview was conducted by Tom Medlar as part of his research.

What are some of the ways in which a head injury affects a couple?

In the beginning I felt very neglected. I knew my husband was hurting and that he had been severely injured, but he tried to say it wasn’t his fault and that it was my fault, and I started feeling really bad. But through my own counseling, I realized it wasn’t all my problem, because we are a couple and it is our problem together and we need to deal with it.

Lets face it, sex is a real big issue with couples. We have no sex life, and there’s no interest on his part. He says it’s partly because of loss of feeling—he has very little feeling on his whole right side. He says that part of it is because he doesn’t physically feel the same way he did, but also he does not have the same emotional feelings or desires that he had before. I think he really is interested but rather than have another situation where there’s failure, he’d rather just avoid it. He can get an erection with a lot of effort, but it’s difficult to sustain. I think he feels inadequate, and I think that’s why he frequently gets angry when I bring up the subject.

It has improved. At first, I couldn’t even bring the subject up or approach him—I couldn’t even touch him without him getting mad. He never said it to me, but I got the feeling that if I touched him or hugged him, he would think I was trying to get something else so he just didn’t even want to touch me.

He was afraid he couldn’t perform so he didn’t want to touch me. Now at least he will hug me or kiss me or hold me, something like that, but not actual sex. And I think the reason for the change has been a lot of counseling for him.

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When he was in rehabilitation treatment, was this at all addressed-was there any sex education or counseling provided to your husband or were any issues brought up about the common sexual problems or relationship difficulties that would result from a head injury?

Never-and whenever we asked a question, the answer was always “It’s too early, wait another six months,” and at six months, it was “Wait another year.” Our questions were never adequately addressed.

Why do you think this is?

I think they really don’t know the answers, but I would rather be told that no one has enough information on that. It’s like they keep putting it off because they don’t want to deal with it-they really don’t know what to do, or what the real answers are. I think they just don’t have a lot of information on head injury and sex.

Do you have any recommendations on what issues should be addressed, both for the head-injured individual and for the spouse?

I definitely think that either individually or as a couple they need to be told that there are most likely going to be changes and what they might expect. Professionals could say, for example, that we’ve heard of any one of these six things happening and you might experience all of them, or one of them, or whatever. I think they need to prepare you more for what’s going to happen or might happen. If I had had more information on what I might be dealing with, it would have been easier.

At what point in the rehabilitation process would it have been a good time to start addressing this issue with you and your husband?

I think close to his going home. It would have helped me a lot before he came home, when he was still in the hospital. He went back as an outpatient almost daily-even then would have been good. It’s important to address it early, before it comes up, because when you first get into the situation and say, “What’s going on here?” it would be better if you knew a few things to expect.

His counselor tended to put the issue of sex on the back burner and say it’s more important to get my husband back at work or doing something else. But I disagree. I have to be honest-our marriage is falling apart and it’s not all because of sex, but that is a real big issue that needs to be addressed and they keep saying, “Well, we’ll talk about it another time.” Well, hey, this has been going on for months and months and months-when is that other time going to come?

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