

COPING WITH SEXUAL PROBLEMS AFTER TBI

In the past few years, this Research and Training Center has interviewed hundreds of individuals about their lives after experiencing traumatic brain injuries. People were eligible to be part of this sample if they viewed themselves as someone who has “experienced a brain injury and has a disability.” A comparison group of individuals without a disability was also interviewed. These samples included men and women from all regions of New York State — from rural areas, the cities and suburbs. People as young as 18 and as old as 65, of all races, income levels and life experiences participated in this research. In each issue of *TBI Consumer Report*, we will share some of the insights resulting from these interviews. Here we focus on **SEXUAL ACTIVITY AND PROBLEMS**.

What was the starting point for this research?

In 1993, the RTC asked a panel of 50 people with TBI to talk about health issues; many mentioned sexual problems since brain injury. This discussion led to the RTC’s developing a detailed interview about sexual problems people (with a disability or not) commonly experience. From the RTC study (see box at left), 322 individuals with TBI and 264 with no disability answered these questions about sexual activity and problems. Although the TBI and ND groups included many different types of people, the average person was 38 years old and white. Each group had an even number of men and women. Members of the TBI group were largely unemployed and high school graduates, while persons in the ND group were largely employed and more often college graduates. People with TBI varied greatly in severity of injury, and had been injured on average nine years prior to the interview.

What did we find?

Women When women were asked if currently they were in a relationship and if they had engaged in sex in the past year, **women with TBI and those with no disability (ND) responded very similarly**. Three out of four women in each group had engaged in sex in the past year; about two out of three in each group currently were in a meaningful relationship. Thus, for females, TBI apparently had little effect on their engaging in sex or their becoming involved with and maintaining relationships with potential sexual partners.

However, our results suggest that the *quality* of sex is reduced after TBI, as women with TBI reported many more sexual problems than did women in the ND group. Of the 14 types of problems* asked about in

“I don’t have the same energy for sex that I used to. I’m upset and so is my husband.”

“I’ve felt that way, too. But, I got some help, and now I am beginning to feel more like I used to.”



the interview, compared to women with no disability, women with TBI more often stated they had inadequate energy for sex, low sexual drive, problems in initiating sex and in becoming aroused, painful sex, inability to masturbate, problems in reaching orgasm and in vaginal lubrication, discomfort in positioning themselves during sex, discomfort in moving about, less bodily sensation, feelings of being unattractive and discomfort with having their body seen during sex. The average woman with TBI reported between two and three of these sexual problems, while the average woman in the ND group experienced between zero and one.

What are the factors that predict more sexual problems? Being **depressed** or having an **endocrine** (hormonal) problem were the strongest predictors that a woman with TBI would have more sexual dysfunction. Also, women who were injured when older reported more problems than those injured at a younger age.

Men When men were asked about current relationships and engaging in sex in the past year, **men with TBI and those with no disability responded very differently from each other.** Only about half the men in the TBI group, compared to about 85% of the men in the ND group, had engaged in sex in the past year. Less than half the men with TBI currently were in a meaningful relationship, compared to three-fourths of the men with no disability. Thus, for males, TBI apparently has a strong negative effect on their staying involved with sexual partners and on their engaging in sex, a result we did not find for females with TBI.

The results for men suggest (as was found for women with TBI) that the *quality* of sex is reduced after injury, but **this does not happen to men to the same degree as for women.** Thus, men with TBI *did* report more sexual problems than did the men in the ND group; but on average they report only one to two problems, compared to the average man in the ND group's reporting zero to one. Men with TBI stated more often than the men in the ND group that they had inadequate energy for sex; low sexual drive; problems in initiating sex, in reaching orgasm, and in maintaining an erection; discomfort in body positioning and in body movements; less bodily sensation; feelings of being unattractive; and discomfort having their body seen during sex.

The factors associated with a man's having more sexual problems were similar to those found for women. For men with TBI, being **depressed** was the strongest predictor of sexual dysfunction. Also, men who were older expressed more problems than those younger.

What should you do if you have sexual problems?

First, this study suggests that **being depressed is strongly associated with increased sexual problems for both men and women post TBI.** Logically, the first thing to do is to "fix" your depressed mood, since this may go a long way in "fixing" your sexual problems. If you are depressed (or have

*Sexual dysfunction questions were adapted from a questionnaire developed by Dr. A Jackson of the University of Alabama.



a hunch that you are depressed), **seek professional help to deal with your depression.**

Second, in the study, sexual problems were not found to resolve nor increase over time. This suggests that sexual difficulties can emerge at any time post TBI and that waiting for your sexual problems to spontaneously “go away” may not be the best solution. Again, you should **seek professional help to deal with your sexual problems.**

What type of professional should you be looking for?

You should seek the help of a mental health professional **who is familiar with TBI, who specializes in helping people cope with depression, and who is comfortable discussing sexual difficulties.** Be prepared for *your* initiating the discussion of sexual problems with this individual, as many professionals avoid such discussion unless initiated by the client. Once you raise your sexual concerns, you can determine if the professional appears comfortable with the discussion, and thus will be able to explore with you reasons for your sexual difficulties. If you do not feel the professional is comfortable discussing this, seek a referral to another professional who is. To obtain potential referrals, you can call the Brain Injury Association in your state (or visit www.biausa.org for the phone number), or consult with your local rehabilitation hospital or mental health clinic.

What are the treatment options you should consider?

Medications for mood. If depression is contributing to your sexual problems, you will need to see either your physician or be referred to a psychiatrist to discuss the possibility of your taking an antidepressant medication. Be certain that the physician is knowledgeable about the impact of TBI on both the choice and dosage levels of medications selected. It is important to question all medication side effects, since some antidepressants may actually worsen your sexual difficulties, an outcome you want to avoid! (Guidelines for what your role should be when medications are prescribed were discussed in *TBI Consumer Report #4*, which is available by writing the RTC or on our Web site (www.mssm.edu/tbinet).

Medications for sexual functioning. New medications, such as Viagra and other sex-enhancing drugs, have been effective in addressing erectile dysfunction in many men without a disability, and they have also been used to enhance the sexual enjoyment of women. Although the benefits of sex-enhancing medications for individuals with TBI have yet to be studied, you may want to discuss with your doctor a trial of this type of medication.

Individual and couples counseling. Our results suggest that establishing and maintaining a relationship with a sexual partner may be challenging after TBI, especially for men. Furthermore, the quality of sex is often reduced after TBI for both men and women. These issues appear to be even more



germane for individuals who experienced brain injury when older. *Individual counseling* with a professional who can comfortably discuss your sexual difficulties and mood is strongly recommended. Sessions should focus on open discussions of your sexual fears and changes in your sexual abilities post TBI. Individual counseling should be followed (or combined) with couples counseling, in which both you and your partner are seen in joint sessions. We stress the need for *couples counseling*, as sexual difficulties by nature require the cooperation of you *and* your partner to address difficulties that affect you both. Joint counseling enhances open communication between partners and permits shared planning of alternative approaches to enhance sexual enjoyment.

Referral for endocrine workup. In this study, women with TBI with a reported endocrine (hormonal) disorder more often experienced sexual difficulties. If you are concerned about having a possible (but as yet undiagnosed) endocrine disorder, you should ask your physician to provide a referral to a specialist, who will do a neuroendocrine workup. Common symptoms of an endocrine disorder include rapid weight gain or loss, irregular menses, and changes in hair and skin texture. Appropriate treatment is likely to decrease many of the sexual difficulties experienced by women with endocrine disorders post TBI.

In sum, although many people with TBI in our study reported that they are doing 'just fine' in terms of their sexual lives, for the many others whose stories right now have no such 'happy endings', **getting help is a must**. For some people, this will focus on ways to help them establish and maintain lasting and meaningful relationships. For others, help will focus on reducing problems that occur during sexual activity. For others, both of these parts of achieving a satisfying sexual and emotional life will need attention at the same time.

To find out more: This study has not yet been published; contact the RTC or our Web site (www.mssm.edu/tbinet) to obtain information on its publication: (Hibbard, M.R, Gordon, W.A., Flanagan, S., Haddad, L., & Labinsky, E. Sexual dysfunction after traumatic brain injury. Submitted for publication.)

"Going for couples counseling has really helped my wife and me talk about our problems and figure out ways to make things better."

"I'm not married, but my self-help group is helping me as I try to meet someone I might like."

TBI Consumer Report is a publication of the Research and Training Center on Community Integration of Individuals with Traumatic Brain Injury and is supported by Grant Nos. H133B30038 and H133B980013, to the Department of Rehabilitation Medicine, the Mount Sinai School of Medicine, New York City, from the National Institute on Disability and Rehabilitation Research, United States Department of Education. The contents of this report do not necessarily represent the policy of the Department of Education, and readers should not assume endorsement by the federal government.