

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 who view themselves as non-disabled was also interviewed. These samples include 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 HEALTH.

## What was the starting point for this research?

At the beginning of our research program, we gathered together a panel of 50 women who had experienced brain injuries to talk to each other about the state of their health since TBI. In sharing their thoughts, they discovered that they were “not alone” in having problems such as weight gain, headaches, balance problems, change in body temperature, change in the texture of their hair and skin, and the like. Many of these women noted that their symptoms, which often had continued over several years after injury, were dismissed either as unimportant by the medical community or as unrelated to TBI.

This panel’s discussion led us as researchers to want to find out more. The next step was to review what existing studies reveal about the long-term health effects of TBI. Surprisingly little scientific information was available on what happens to health over the ‘long haul’ after TBI. We decided, therefore, to do a formal study including both men and women. From the RTC study (see box at left), we asked over 300 people with TBI and nearly that number of non-disabled individuals about health problems they were experiencing at the time of the interview. We report here some of the findings, particularly those in which people with TBI differed *most* from the non-disabled sample.

*“Since MY injury, I just haven’t felt like MY self.  
For one thing, I’m not sleeping well.”*

*“I sleep okay, but I have awful headaches and  
I’m cold all the time. MY doctor says  
this is not from the brain injury. I disagree.”*

## What did we find?

Many of the complaints the women's panel had expressed were also found in this study, which has larger samples of males and females and where people with TBI and those with no disability are compared:

- ▶ Balance difficulties, sleep disturbances, frequent headaches, seizures, spasticity and loss of urinary control are examples of the chronic neurological problems found significantly more often in the TBI group. Nearly 60% of people with TBI in our study reported current, long-term difficulties with balance and sleep.
- ▶ Body temperature changes and hair or skin changes were also found significantly more often in the TBI sample than in those with no disability.
- ▶ People with TBI experienced arthritic conditions more often, too.

*Within the TBI sample, we found the following:*

- ▶ Women were more likely than men to have a thyroid condition, headaches, sleep disturbances, loss of urinary control, frequent colds, arthritic symptoms and changes in weight, hair/skin or body temperature.
- ▶ As individuals age, they are more likely to have sleep disturbances, loss of urinary control, arthritic changes and thyroid problems. This doesn't mean that just seniors have these problems, but that with each passing year the probability increases that these problems will emerge, whether the person with TBI is 20 or 65.
- ▶ Individuals with more severe injuries were more likely than those with only a brief loss of consciousness to experience each of the health problems mentioned except thyroid problems. They were also more likely to experience frequent sinus infections and blood pressure changes.

# What do these findings mean for people with TBI and professionals?

If you, a person with TBI, are experiencing health problems that began after your brain injury, you are certainly not alone. And, if you have any of the symptoms discussed here, you might take this report to your doctor for him or her to evaluate. Also be aware that if you are a female or have had a more severe injury, and with each passing year, you are more likely to have (or develop) the kinds of health problems reported here.

- ▶ If you have balance difficulties, you should ask your doctor to test you for a possible vestibular dysfunction. Positional treatment programs offered in post-TBI rehabilitation may be helpful. Medications, such as sedatives, should be carefully evaluated by your physician. You may want to obtain a neuro-ophthalmology examination from an eye doctor familiar with brain injury.
- ▶ If you have sleep disturbances, you should discuss this with your physician. Evaluation of sleep problems should include a thorough history of such problems, medication review and an assessment of your bedtime routines. As necessary, a polysomnographic (also known as a sleep lab) evaluation should be considered. Most important, medications to enhance sleep should be tried. Physicians who specialize in brain injury often recommend low-dose serotonergic or noradrenergic anti-depressants. Some consumers have also found herbal teas or melatonin useful, which are sold in health food and drug stores, with no prescription needed.
- ▶ If you experience loss of urinary control, a urological assessment and workup by a physician should be pursued. When appropriate, you should be taught bladder management routines that can be integrated into your daily life.

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- ▶ If you have arthritic complaints, the need for assessment is clear. Anti-inflammatory medications may be prescribed, as necessary. Many consumers report improved arthritic conditions when they relocate to drier climates or pursue a long-term exercise program.

For health care providers, these findings suggest that TBI may have severe long-term consequences on health — problems that may reduce quality of life. Specific suggestions are noted above. We have reported on only some of what people with TBI shared with us and will expand on these data in future publications. These results are being published in the *Journal of Head Trauma Rehabilitation* (Hibbard MR, Uysal S, Sliwinski M, Gordon WA. Undiagnosed health issues in individuals with traumatic brain injury living in the community. 1998;13[4]).

The importance of this research is that it demonstrates very clear patterns of differences between health symptoms of people with TBI and of a non-disabled comparison group. Because this research is based solely on self-report, no medical tests were available to validate the reported problems. We believe, however, the self-reports, obtained through in-depth individual interviews, validly represent perceptions of people with TBI. In the future, studies that include medical testing are needed to corroborate these findings.

*"I'm glad to know I'm not the only person  
with a brain injury who has sleeping problems."*

*"Yeah. But, I'm even more glad to know  
that I can do something about it."*

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