Craig Hospital
Redefining Possible for People with Spinal Cord and Brain Injuries

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Caregiving

You've lived with someone who is spinal cord injured for some time. Perhaps you're feeling more tired, more blue, more isolated than you want to. You may find yourself with different priorities than your partner, especially where things like work, children, education or creative expression are concerned.

The problem? You're not disabled, your partner, son or daughter is. Research is showing that wives, husbands, significant others – those who provide care – are at risk of developing significant problems of their own. If you provide care for your loved one — or if you receive care from one – read on …

Research and Caregivers

Researchers continue to study the physical consequences of aging with spinal cord injury, but often ignore the other people in the spinal cord injury survivor's life. What happens to those around the survivor as they, too, age?

An ongoing research project with long term survivors, sponsored in part by Craig Hospital, recently polled spouses of long-term survivors to learn more about what happens to caregivers and to their relationships over time. The findings reveal predictable areas of concern: emotional issues, role overload, more frequent health problems, and changed family dynamics.

Who Are The Caregivers?

In the Craig study, 124 spouses of long-term spinal cord injured persons were surveyed. Ninety percent were women, so keep that in mind as you read through these findings. Their average age was 52 and, on average, they had been married 29 years.

In general, the spouses reported being more depressed, having different priorities, and having their needs less well met than their SCI spouses or partners, according to several questionnaires which measured depression, stress, needs, and priorities each partner reported in his or her life.

In general, non-disabled spouses reported significantly more emotional symptoms of depression, like crying and feeling blue, than their spinal cord injured spouses. Nondisabled partners also showed more physical signs of depression as well, such as sleeplessness and loss of appetite. Furthermore, non-disabled spouses had more stress, more nervousness and more feelings of being unable to cope than their disabled partners.

Finally, the SCI survivors and their spouses also had many differences in their priorities. Spouses considered learning, creative expression, self-understanding, work, and material comforts to be less important than their disabled partners did. They rated having children as more important than their disabled partners. They said their needs for having a close relationship with their spouse were *less well* met than their SCI partners, and their needs to work or help others were lower.

Is it the Caregiving or the Injury?

But there's more: those wives and husbands–in this study, mostly wives – who had the dual role of spouse *and* personal care provider reported *even more* symptoms and problems. They reported more signs of depression – loss of appetite, sleeplessness, feeling sad, crying – than those not providing care. These caregiving spouses also reported more physical and emotional stress, anger, resentment, fatigue, as well as feeling happy less often than their non-caregiving counterparts.

Results were analyzed in a variety of ways to identify the sources of stress depression and negative emotions. Here's what we found:

- Younger caregivers seemed to have more stress than older ones
- Younger caregivers and caregivers whose partners used condom catheters to manage their bladders had more depression
- The act of caregiving itself seemed to bring stress, nervousness, and depression with it. In fact, it was the feelings of those who provided personal assistance that accounted for virtually all of the differences between spouses and their disabled partners.

In other words, non-disabled spouses or partners who provide care are at greater risk and more prone to depression, stress and nervousness than those partners and spouses who do not provide care.

What could I be doing?

Studies of those who care for individuals with other disabilities have reported similar findings – unmet needs, differences in priorities, fatigue, anger, and depression. In addition, they worry about the future – who will provide care when they become too old? Who will take care of them if and when they need help? Because of these similarities, there's reason to believe that what helps spouses of people with *other* disabilities will also help caregiving spouses of spinal cord injury survivors too.

Some of the things that have been found to help are:

- Maintaining equality within the relationship and finding ways for both partners to make significant and meaningful contributions – such as through working, parenting, various household chores or money management
- Maintaining family support and functioning –especially during transition times
- such as moves, kids leaving home, starting or quitting work – by emphasizing the importance of each member to the family, keeping communication open through family meetings and staying in touch with extended family
- Getting help with those highly confining, restrictive and physically demanding tasks which place caregivers on someone else's schedule – doctor appointments, bathing, bowel programs, etc. – or getting help in times of greater need, such as when *you're* ill or need bed rest
- Having some backup help lined up and available–relatives, friends, neighbors, Visiting Nurses Assoc., local volunteer organizations – *before* the need actually arises
- Keeping in touch with friends, having people over or visiting them, going out on your own occasionally – to help decrease isolation, joining or starting a caregiver support group –not to share war stories, but to share ideas, resources and coping skills
- Preserving your own health by exercising, eating well, or managing stress, even if these activities cut into caregiving time
- Doing what it takes to feel in control – making and keeping a schedule, making informed decisions taking enough time for yourself to know when you need a vacation, a break, a night out or even time to be sick.

Caregiving spouses talk about how important communication is between partners and within the family as a whole. They also talk about something called *respite care*. This allows caregivers to get away from relentless and potentially overwhelming responsibilities for a day or for several weeks by having skilled care personnel stay in the home, or by having their partner stay in a facility which provides an appropriate level of care. Check with home health care agencies or Independent Living Centers for more information. As one longtime caregiver asks, "How many married couples spend 24 hours a day together – every day?"

To the Caregiver

Your job as a caregiver may feel like it never ends. You may feel as though your caregiving responsibilities are the most important ones you have. You may feel guilty if you occasionally take time to think about yourself. But, your needs are important as well.

What's more, by not paying attention to those needs, you place *yourself* at risk of not being able to provide the level of care you *want* to provide, especially as *you* age. If caregiving is important to you, taking care of yourself and staying healthy emotionally, spiritually and physically will help insure that you will be much more able to give your spouse or partner the help they need.

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