



Craig Hospital

Redefining Possible for People with Spinal Cord and Brain Injuries

Provided as a courtesy of
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Long Term Caregivers: For Better and For Worse

No one plans on spinal cord injury. “No one” includes you, the spouse, the family, the person who provides care—as well as the survivor. Yet you’ve been there, all this time. And by now you know that there’s not much out there in the way of support for spouses, friends, and family. You say you feel neglected?

The Forgotten Person:

At first, survival was everything. As time went by there were medical complications and quality of life issues to worry about, then the fights for accessibility and equality, for benefits and entitlements. Through it all, you, the caregiver, fought the good fight, stayed in the background, and seldom complained.

After all it wasn’t you dealing with all the tough physical, emotional, and social stuff. Or was it?

Stress:

Some research has been done on people who give care – whether to a person with spinal cord injury, someone with Alzheimer’s disease, or to an elderly relative – and it all points toward stress.

Everybody has stress, but caregivers have more of it. This results in health problems, sleep disorders, and all the other effects of stress you read about in the popular press. In one group of caregivers studied – people who had been caring for a family member with quadriplegia for an average of 7½ years – 75% had higher stress levels than the general population.

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More stress:

Stress often shows up as burnout: defined as physical and emotional exhaustion. Its symptoms include diminishing self-esteem, a negative attitude, a loss of concern for others, and/or a loss of focus on your own life. It's real. It happens.

And since 40% to 45% of people with spinal cord injury survivors utilize caregivers, there must be a lot of it going around.

The Roots of Stress:

If you're a caregiver experiencing stress, it may help to realize that you're not alone. When caregivers get together, the same concerns emerge over and over again. They seem to fall into four categories:

Loss of Personal Time and Space

- Disability itself never takes a holiday and neither does caregiving. Where do you fit your life into all the things that have to be done for someone else? Your own needs routinely take a back seat to caregiving, childrearing, working, and other responsibilities about which there is no choice. And if a new problem comes along, the time to deal with it comes out of your own free time, not out of caregiving time. Research shows that when free time goes down, stress goes up.

Social Isolation

- Caregiving does nothing for your social life, and the frustration and fatigue that often go with it can further separate you from the company of others. You may no longer hold down a job and the children may be grown. You feel you can't leave the house. You may have spent your entire adult life caring for children, parents, and/or spouse, and you're not getting any younger yourself. You miss exposure to friends and family, to entertainment and relaxation, to the occasional novel experience. That's stressful.

The Quality of the Relationship

- Many caregivers complain that they don't have good, two-way communication with the person receiving care. In one researcher's study group, only 60% said they got along with their spouses. Many feel they treat their spouses better than their spouses treat them, and others perceive personality changes in their partners – such as a new passivity or loss of interest in child rearing or in the relationship itself. Sex lives sometimes go downhill.

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Endless worry

- Caregivers worry that their spouse's condition will worsen. They worry about their own health. They worry that they can't continue the level of care they managed when they were younger, yet they also worry that someone else won't do as good a job—not an unrealistic concern. They worry about finances. Will providing cares, or even a nursing home placement, make the spouse poverty stricken as well? And who, eventually, will care for the caregiver?

Solutions:

You may not be able to do anything about the disability, but you can do something about how it impacts your time, energy, and quality of life. Nowhere is it written that, simply because you provide care for someone with a disability, you may not have a life of your own.

Recruit additional help

- If finances permit, give strong consideration to getting some help and dividing the delegated work load between two or more part-time personal assistants. They can share on-duty time, help each other when time off is essential and significantly reduce stress for you. Don't put all your eggs in one basket.

Support groups

- Share your feelings. One very successful group was started by a few wives of men with disabilities. Besides providing mutual support, they devoted one of their twice-monthly meetings to a specific topic and invited a speaker – for example, someone to talk about financial planning for long term care. You might start your own support group – for names of other caregivers at independent living programs, rehabilitation centers, and your chapter of the National Spinal Cord Injury Association or the Paralyzed Veterans of America. If you're a computer user, you'll find dozens of disability-related groups exchanging ideas.

Improve your relationship

- Research indicates that the better you feel about your relationship with the person receiving care, the less stress you will have. Talk with him or her. Get counseling. If there is serious conflict, invite a third person – one you both know and trust – to help mediate. The results can be gratifying: spouses with the highest morale generally attribute it to the continuing companionship and good relationship they have with their partners.

Avoid isolation

- Invite people in. Cultivate friendships. Make that family of yours show up once in a while, even if all they do is bring in gossip and fast food once a month. Research shows that people who have more frequent visitors—that's right, not only high-quality, memorable or long visits, but just frequent ones—report lower stress levels.

Get out of the house

- Go somewhere, anywhere, alone or with friends. Arrange things so the tasks you're most worried about – bowel care and skin management, perhaps – are done before you leave. Family, neighbors, or even paid services can often cover for you at least for a few hours.

Respite care

- Consider outside help for longer periods. Look for local respite programs that can provide you with an extended break from your usual routine. Try religious organizations – you probably don't need to be a church member – or ask at area hospitals. Check out elder day care programs – some of them can provide trained caregivers during the day, at their place or yours.

Innovate

- You might start a care-swapping program in which several caregivers take turns covering for one another. Or share one attendant that several of you hire. Consider students majoring in health care and related professions, who are often required to do volunteer work. Why not with you? And your spouse? It's a jolt to have a stranger providing intimate care, but it's a jolt that goes away with familiarity. He or she may even welcome the variety, especially if it makes your life more workable.

Get your finances in order

- Regardless of how little or how much you have, get some help sorting through insurance policies, retirement programs, social security, and other government entitlements to find out what there really is to draw on. Keep in mind that specific benefits and programs change from year to year, so re-check periodically.

The remembered person:

You may sometimes feel like the forgotten person, but that's all the more reason to remember that you have your own needs and goals and life. Finding ways to acknowledge and nurture your personal life will bring new energy and enthusiasm into your life as a partner, friend, and caregiver.

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