



Craig Hospital

Redefining Possible for People with Spinal Cord and Brain Injuries



Family Caregivers of Veterans with Spinal Cord Injury

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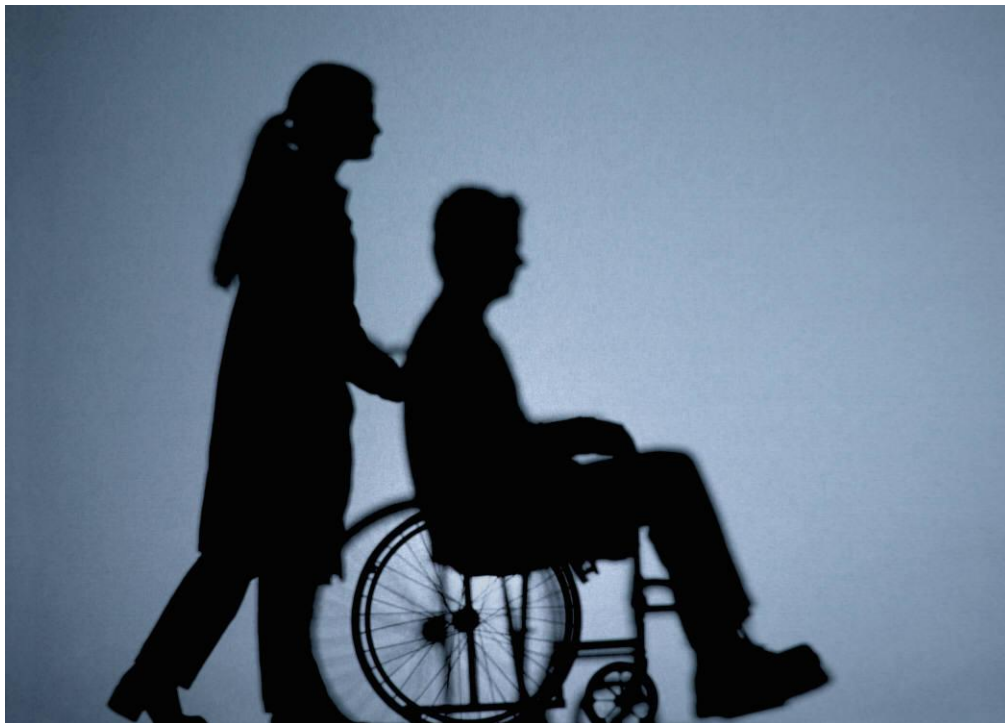


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Caregiver Facts

- Approximately 42 million family caregivers in the US
- Caregivers provide an average of 18.4 hours of care per week
- Approximately 70% of people with SCI receive care from family members
- 50% receive care *ONLY* from family
- Over 40% rely on *ONLY* one person in the family to provide care



- ◎ **Economic value of unpaid contributions from family caregivers - \$450 billion/year**
 - **Approaching the total expenditures for Medicare**
 - **More than total spending for Medicaid**
 - **Nearly 4x Medicaid long-term services and support**
 - **More than total spending (public and private) for nursing home and home health care**

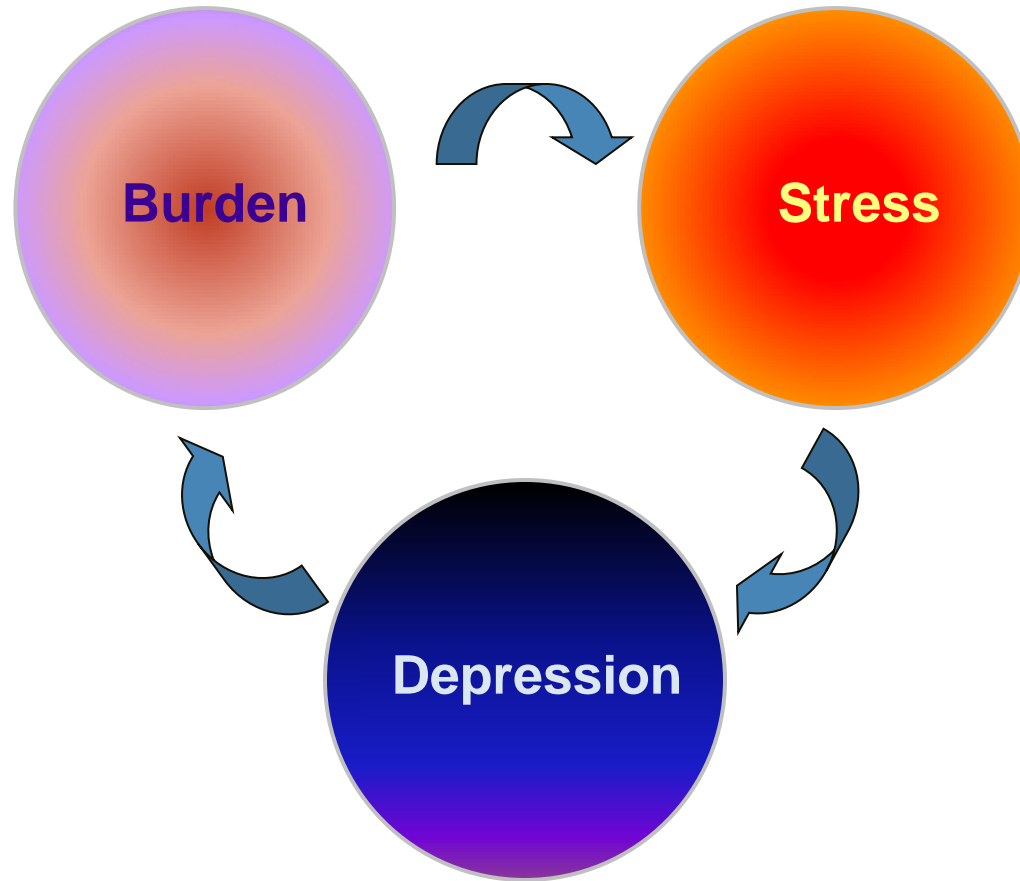
Veteran caregiver facts

- **11% of all caregivers of adults have served in the armed forces**
- **17% of their care recipients are veterans**
- **The typical caregiver of a veteran whose illness, injury or condition is service-related is a woman taking care of a spouse or partner**
 - **96% of caregivers of veterans are women**
 - **70% are spouses or partners**

	Caregivers of Veterans	Caregivers of Adults Nationally
Female caregiver	96%	65%
Spousal caregiver	70%	6%
Lives with care recipient	80%	23%
Primary caregiver	82%	53%
Caregiving for 10 years or more	30%	15%

- Caregivers of Veterans – Serving on the Homefront. Report of study findings, November 2010

Caregiver strain





Impact of caregiving

	Caregivers of Veterans	Caregivers of Adults Nationally
High emotional stress (4+ on a 5-point scale)	68%	31%
High physical strain (4+ on a 5-point scale)	40%	14%
Stopped working or took early retirement (among those who worked while caregiving)	47%	9%
High financial hardship (4+ on a 5-point scale)	50%	13%

- Caregivers of Veterans – Serving on the Homefront. Report of study findings, November 2010

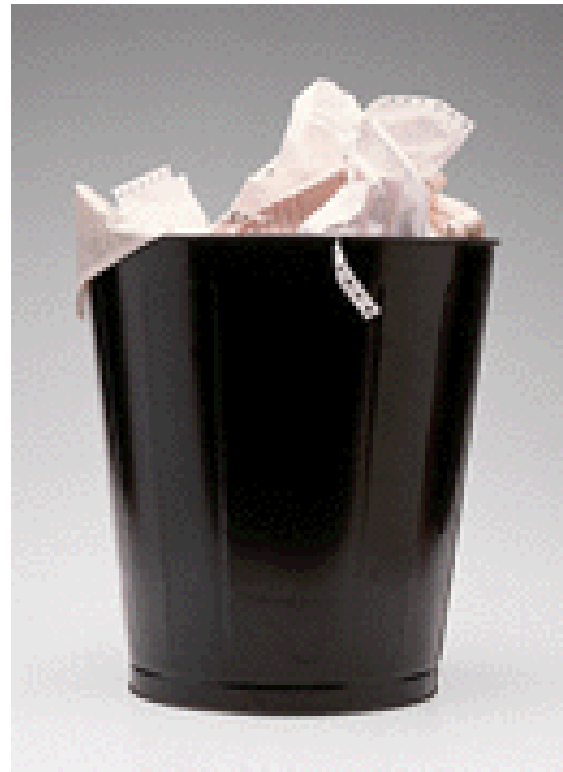
Two sides of the story

- ⦿ **Not all aspects of being a caregiver are negative**
- ⦿ **Can be beneficial for both the caregiver and recipient of assistance**
- ⦿ **Can provide feelings of self-worth for the caregiver**
- ⦿ **Satisfaction in helping someone you love**
- ⦿ **May foster closer family relationships**



Why study family caregiving in veterans (or anyone) with SCI?

- ⊙ **Most caregivers studies have been done with people who care for a partner/family member with Alzheimer's disease**
- ⊙ **Difficult to translate these findings to spinal cord injury**



Purpose of the studies

- ⊙ **Gain insight into family caregiver issues from the caregivers themselves**
 - ⊙ **Positives**
 - ⊙ **Negatives**
 - ⊙ **Effect on life and activities**
 - ⊙ **Effect on family**
 - ⊙ **Sources of strength**
- ⊙ **Use the information to develop an instrument to assess caregiver distress and benefit in SCI**
- ⊙ **Confirm question development with participating caregivers**



Purpose of the studies

- **Strengths**

- **Focus group technique**
- **Ethnic/racial diversity**
- **Relationship diversity**
 - **Spouses**
 - **Siblings**
 - **Parents**
 - **Children**

- **Improve ability to identify specific areas of distress and benefit**

- **Enable clinicians to have relevant information to work with individuals based on their personal and family needs**



Participating centers for the studies

- **Participants for the study drawn from 4 current or former SCI Model Systems**
 - **Craig Hospital - Colorado**
 - **UAB – Alabama**
 - **Kessler – New Jersey**
 - **Santa Clara Valley Medical Center – California**

- **Participants for the veterans study drawn from 3 VA centers**
 - **Denver, Colorado**
 - **Richmond, Virginia**
 - **Seattle, Washington (pending IRB approval)**



Participants

- **Civilian caregivers (n=74/16 groups)**
 - Mean age = 52.5 years
 - 85% female
 - 61% Caucasian
 - 54% spouse
 - 37% parent
 - 9% other relative
 - Mean years caregiving = 8.25 (<1-48)
 - Mean hours/day caregiving = 8.00

- **Caregivers of veterans (n=41/7 groups)**
 - Mean age = 59.0
 - 95% female
 - 51% caucasian
 - 78% spouse
 - 10% parent
 - 12% other relative
 - Mean years caregiving = 11.8 (<1-52)
 - Mean hours/day caregiving = 9.9



Family members with SCI

- **Civilians with SCI**

- **Mean age = 44.8 years**
- **76% male**
- **60% tetraplegia**

- **Veterans with SCI**

- **Mean age = 59.2 years**
- **98% male**
- **54% tetraplegia**





What are the *Positives* the family caregivers telling us?

- ⦿ “I don’t know how to put that – it’s kind of the total gratitude that you get from the person even when things aren’t going good in other ways, like in your marriage...sometimes you have issues and stuff but there’s always that gratitude.”
- ⦿ *“When my wife is able to fall asleep it’s kind of an acknowledgment that she trusts me to take care of things. ...there’s a level of intimacy that really, really binds us together.”*
- ⦿ *“Being with your loved one. For me, it’s...I haven’t lived with or near him for a long time so now I get to see him on a daily basis and know where he’s at and how he’s doing on a daily basis.”*



Positive themes

- ◉ **Change in self-awareness**
- ◉ **Closeness of family**
- ◉ **Increased compassion**
- ◉ **Learning**
- ◉ **Feeling appreciated, needed**
- ◉ **Still having family member with you**
 - ◉ “Any time I see on the news now that a 19 year old was killed...my heart just goes out to their family so much more than it would have before.”



What are the *Negatives* the family caregivers telling us?

- ⦿ “Your time is not your own.”
- ⦿ “It’s the hardest work I ever had to do.”
- ⦿ “I think the way I see it is that my life is over.”
- ⦿ “I think you get the brunt of their anger – their frustrations and mood swings.”
- ⦿ “I believe that the caregiver sometimes needs a little caring from the person that you give care to, to let us know that they care. It would be a help. Sometimes I used to get the feeling that he doesn’t care.”
- ⦿ “It burns you out...it can take a toll on you.”



What are the *Negatives* the family caregivers telling us?

- *“I think it was four years before I even sat down to eat a meal. I have to feed him so I literally stand there and a lot of times I pick off his plate...”*
- *“When you go to bed at night you’re totally exhausted, but then I have to get up at night about 3 ½ hours later to turn him, and then he wants me to fix him eggs, and then I can’t do that. I have a gas stove and I’m just terrified that I’m forgetting something. You know, you’re just – you’re half asleep. ”*
- *“When I have to go somewhere and my husband being a quadriplegic, I have to get him dressed and myself and it takes us 4 hours to get out of the house alone, doing everything you have to do. By the time I get him into that car, I’m exhausted before I even start the car. You know? I’m exhausted.”*
- *“It’s just like when they are an infant again. They’re just a 200 pound infant and just as demanding.”*
- *“I think sometimes for me is I have a hard time finding joy in life because of dealing with exhaustion, because of dealing with bowel care accidents...”*



Negative themes

- ◉ **Lack of time for self**
- ◉ **Exhaustion**
- ◉ **Lack of spontaneity**
- ◉ **Lack of understanding from others**
 - ◉ Not acknowledging the full scope of caregiving
- ◉ **Lack of appreciation from family**
 - ◉ Person with SCI
 - ◉ Other family
- ◉ **Unexpected events – injury, illness**
- ◉ **Dissatisfaction with hired carers/agencies**
 - ◉ Poorly trained, inconsistent
 - ◉ Unable/unwilling to do certain tasks – bowels
- ◉ **Strain on family relationships**



Health issues

- ① “You know, you get back pain and this and that, but I find that my real issue was more mental stability, you know, with the attitudes...that you go through. I kind of lost a little of my mental stability.”
- ① “I feel like I’m tired and I don’t get enough sleep sometimes. Particularly if something is going on where I’m having to go back and forth and I just feel drained.”
- ① “...the physical – it’s so long term....for us, this is the rest of our lives.”



Health issues

- ① *“I was diagnosed with breast cancer after my husband’s SCI...The first words out of my mouth when the doctor gave me my diagnosis was “what’s going to happen to my husband?” It wasn’t like “what about me?””*
- ① *“...one day I just started crying profusely. It was like, oh my gosh, and I wasn’t embarrassed because I had been holding everything in. We went to the doctor and I didn’t realize how my health was – mental, physical...”*
- ① *“I had a heart attack. The diabetes that I have, that’s a contributing factor, but I really do think it was from stress.”*
- ① *“I’m at doctors’ offices four times a week, and I totally didn’t take care of my own health and now I’m paying for it, but I had no choice. I just had no choice.”*



Health issues

- ⦿ **Fatigue, sleep deprivation**
- ⦿ **Back pain and injury**
 - ⦿ Unable to rest in order to heal
- ⦿ **Generalized pain**
- ⦿ **Emotional strain**
- ⦿ **Depression**



Sources of strength

- ⦿ “You have to pray – it would be like a ship without a sail.”
- ⦿ “And just don’t focus on the bad. Just leave all that alone. It’s got to be done. It’s all you can do. You got the strength – you just got to find the strength in you. It’s in you already.”
- ⦿ “...I told God I’ve been trusting Him all this time to take care of my son and I would continue to trust Him and God touched me at that moment and I was in peace ever since. I’m still in peace and I’m still trusting God that he will walk again, so God is our strength.”
- ⦿ “I draw on my motivation, just from a sense of duty to my mother...”



Sources of strength

- ⦿ *“I still love him, even if he drives me insane.”*
- ⦿ *“I think just the satisfaction that I get from him appreciating everything I do for him and expressing that – just keeps you rolling along.”*
- ⦿ *“A lot of mine is my husband’s positive attitude.”*
- ⦿ *“I think you can find strength from some outside activities that you have, like church or clubs, different clubs, and from friends. I find mine sometimes just from walking. I like to walk in the morning and that’s my time. I spend that clearing my thoughts and getting my activities together – what I need to do and that’s when I take the time for myself.”*



Sources of strength

- ① **Faith**
- ① **Love**
- ① **Family network**
- ① **Friends, co-workers, faith community**



What changes have caregivers experienced?

- ① “We used to be very active and take a lot of little road trips or vacation with my parents and we haven’t done a single thing since the injury five years ago. We’re homebound.”
- ① “My life is limited because we...did a lot of things together and we just can’t do them anymore. Hobbies or stuff like that – you just can’t do it anymore.”
- ① “We can’t go to a lot of our friends’ houses any more because they live in apartments or he can’t get through the door.”
- ① “For me it’s been not being able to have a job. That’s probably been the hardest thing.”



What changes have caregivers experienced?

- ⦿ *“It’s changed everything, you know. You don’t get out any. You lose contact with all your friends and you can’t participate in any family things...or whatever, that are away from your house, so consequently everything that I’m involved in has to be done at my house. He can’t get in most places so, you know, it’s changed everything, you know.”*
- ⦿ *“I had to give up my freedom. I was going to spend time with the grandchildren.”*
- ⦿ *“I gave up me-time.”*
- ⦿ *“I feel cut off from my community and the volunteer work I used to do.”*
- ⦿ *“You sacrifice your plans. You sacrifice a career. Like I said, I’m going from uphill to downhill, you know, trying to get yourself out of that hole.”*



Changes experienced

- ⦿ **Work**
- ⦿ **Finances**
- ⦿ **Travel and leisure**
- ⦿ **Role in family**
- ⦿ **Privacy**
- ⦿ **Loss of friendships – lacking commonalities**
- ⦿ **Home situation (moving or redesign)**

What can be done to help?

- **Encourage caregivers to seek support and assistance**
 - **Talk to other caregivers**
 - **Recruit the whole family to help**
 - **Recruit community resources**



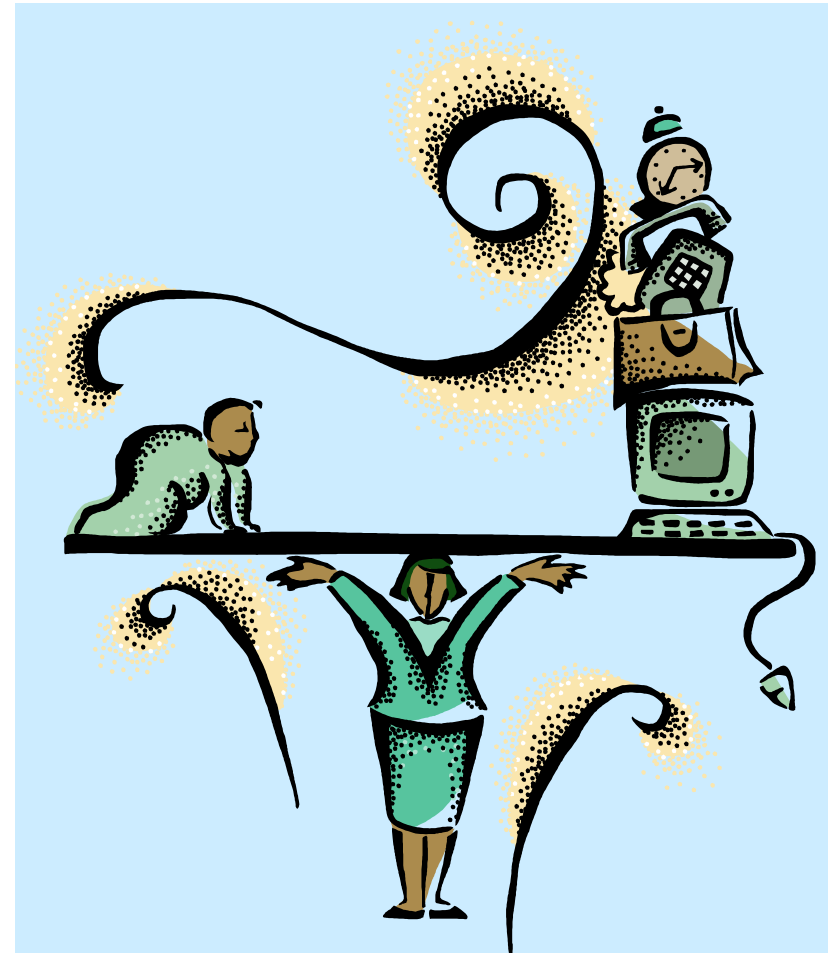
What can be done to help?



- **Acknowledge the amount of work**
- **Confirm that it's ok to feel bad now and then**
- **Encourage pursuit of healthy lifestyle**
 - **Diet**
 - **Exercise**
 - **Rest**

What can be done to help?

- **Provide information on resources prior to discharge**
- **Be available post-discharge for trouble-shooting**
- **Help caregivers be realistic about what they can control**





Summary

- ◉ **Caregivers are learning a new role**
 - ◉ **This takes time, energy and can be frustrating**
- ◉ **Realize the positive opportunities**
- ◉ **Opportunity to enforce one's own competence**
- ◉ **Provide stress management information early on**
- ◉ **Re-evaluate needs, problems on a regular basis**



Summary

- ⦿ ***It is critical to care for the caregivers***
 - ⦿ **They are often the only lifeline for the veteran with SCI**
 - ⦿ **They provide a valuable and often irreplaceable service**
 - ⦿ **Their needs are often overlooked**
 - ⦿ **If their health/well-being fails, so will their loved one with SCI**



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