

Maggie Strong wrote in her marvellous book, "Mainstay":

"To be married to someone ill and to watch a man or woman you love suffer means you mourn. You mourn...the suffering of the mate and your lost self- the one who could feel dependent, who could ask to be indulged, the light-hearted you, and often with chronic illness you mourn a lost or reduced sexuality."

Anita Tejedat, the wife of someone with chronic pain, wrote:

"What about the person who is not the one with the illness? Yes, how about me? How am I doing? No one ever seems to ask. A selfish thought when I'm not the one who has the disease...my pain...is the pain of sharing my life, my love, my hopes, my dreams, my future, with someone whose life seems to be shattered and all those things stolen from him...I'm scared because my own life... and future are so connected to my love's that I wonder what will become of me."

A research study in America, looking at spinal cord injury survivors and their caregiving partners, found that caregiver spouses deal with substantially greater stress, depression and other negative symptoms than those not providing care.

Another study, looking at spouses of spinal cord injury patients found that they tend to be proud of what they do and generally content in doing it, deriving pleasure from the 'extra' help they gave their sick partner.

Whilst a few admitted that this work was a burden and tiring, almost all did not want people from outside the family to help their loved one.

Family members of people with chronic illness do tend to be vulnerable to exhaustion, stress and illness.

Richard Holicky has written a helpful article available online, titled "A Labor of Love: Beating Stress in Long-Term Caregiving" ( [\[1\]](#) )

He has researched caregiving for six years and talked to various family members involved in caregiving.

He reports that many find that caregiving gives their lives meaning and purpose. Some say that it has made their lives worse and "their worlds smaller."

Holicky divides the negative consequences of caregiving into 4 areas:

1. **Stress and emotional challenges:** including anger at the unfairness of life (often directed at medical professionals); loss of trust in the future; fear that things will get worse; worry about who will look after the caregiver if he/she falls ill; resentment over lost dreams, plans, altered lifestyle; guilt for feeling any emotion other than compassion; frustration, sadness, anxiety, sense of isolation, loss of personal time>>depression

2. **Burnout/role overload:** family caregivers, typically women, perform many chores: *Swiss Army Wives*

! Volume of work and variety of roles may result in loss of personal time (and identity), loss of sense of control; loss of free time equates with increased stress. Fatigue may be cumulative and lead to functional decline, health complications. Women tend to internalise stress more and may be involved in more intimate care.

3. **Family relationships:** "Disability is often a third partner in a marriage," (Holicky); as we have seen, illness skews relationships; caregivers may tend to protect the ill partner from emotional upset or even ignore destructive behaviour such as excessive drinking or using higher than prescribed doses of medication; studies report decline in sexual intimacy between caregivers and disabled spouses.

4. **Caregiver health:** long-term caregivers are likely to report more pain, more doctor visits, poorer health and more rapidly declining health than those who don't provide care; back injury, chronic fatigue, sleep deprivation, headaches, poor nutrition, gastric upset. Caregivers may ignore their physical, emotional, social, spiritual and intellectual health needs

Other common problems include:

- Social isolation
  
- Poor communication>> deteriorating personal relationship
  
- Depression

Possible solutions:

- Refuse to let the illness take centre stage
- Ensure you have outside social contact
- Get out of the house
- Join support groups
- Delegate chores if possible
- Improve relationship with ill partner
- Improve sexual relationship; if necessary, delegate intimate care
- Make sure you are not the 'forgotten person'
- Ensure personal time; leisure activities are a necessity not a luxury
- Ensure good diet, adequate sleep, exercise

Holicky stresses:

"Providing care...while often a labor of love requires the skill and grace to ensure your own mental and physical well-being...a critical part of the care you provide is self-care."

Scientists at the University of Alabama developed Project FOCUS, a problem-solving training programme for caregivers of patients with spinal cord injury.

**FACTS:** get the facts, define the problem, goal is to solve that problem. What information will

you need to assist in solving the problem? Utilise whatever resources are available including expert advice. "No question is a dumb question."

**OPTIMISIM:** be optimistic (but realistic). If possible, use a role model of someone who handles problems effectively and consider how they would feel in this situation. Re-assert to yourself that you CAN do this.

**CREATIVITY:** brainstorm and think of as many ways as possible to solve the problem; think laterally; later on you can work out the best ways.

**UNDERSTANDING:** make sure you understand the problem and also the consequences of any course of action you may be thinking of undertaking; consider potential obstacles to achieving your goal.

**SOLVE:** the final step; given the correct information (facts, ideas, understanding), you can develop a plan of action; implement the plan, achieve the goal; assess the outcome (does it match your expectations and goals? If not, go back and try another idea from your list). Avoid being impulsive.

### **Resources:**

Princess Royal Trust for Carers (UK) [www.carers.org](http://www.carers.org) Tel: 020 7480 7788

Family Caregiver Alliance (US based): [www.caregiver.org](http://www.caregiver.org)

Mainstay, Maggie Strong, 1997, Bradford Books

Chronic Illness and the Family: A Guide to Living Every Day, Linda Welsh and Marian

Betancourt, 1996, Adams Media Corp.

The Other Victim: How Caregivers Survive a Loved One's Chronic Illness, Alan Drattell, 1996, Seven Locks Press

Overextended and Undernourished: A Self-Care Guide for People in Helping Roles; Dennis Portenoy, 1996, Johnson Institute

The Caregiver Survival Series (4): Positive Caregiver Attitudes; Preventing Caregiver Burnout; Creative Caregiving and The Magic of Humor in Caregiving; James R. Sherman, 1995-1996, Mosby Lifeline

Helping Yourself Help Others, Rosalyn Carter, 1994, Times Books.

Beyond Chaos: One Man's Journey Alongside His Chronically Ill Wife, [Gregg Piburn](#)

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[1] [www.newmobility.com/review\\_article.cfm?id=271&action=browse](http://www.newmobility.com/review_article.cfm?id=271&action=browse)