

## **Tipping Point #5: Inability to transfer**

*By Donna Krasnow, MA*

If you use a wheelchair, you know how much transferring you do during the day. When you first began to use the chair, it may have been easy to swing yourself from your bed to the wheelchair, from your wheelchair to the toilet, from your wheelchair to your favorite recliner in front of the television and then back to your wheelchair when it was time for bed. But your transfer abilities may diminish over time. If so, you may prolong your independence by using a transfer board or installing grab bars in key locations to provide necessary support. But your abilities may deteriorate to such an extent that you are no longer able to transfer yourself no matter how many grab bars you install. If the family member or caregiver who assists you is not strong enough to manage transfers, you could be in serious trouble. We have heard many stories about clients who slid onto the floor in the middle of a transfer. If family members were unable to get the client back into the chair or bed, they may have had to call the fire department for assistance.

Inability to transfer is a critical moment in MS and is, by definition, a tipping point. This tipping point is so significant that, if you do not figure out ways to deal with your transfer needs, you may have to move to a care facility. We all know that such a move greatly affects quality of life. We, therefore, cannot state strongly enough that you need to be proactive if this tipping point occurs so that you can stay in your home as long as you want.

1. If you have private insurance, review the terms of your policy. What services and expenditures are covered? Does your policy cover visits by Occupational Therapists (OTs) who can assess your home and identify strategies to assist with transfers? Does it cover costs of buying or renting devices that assist transfers? Is in-home care covered? If you must move to a skilled nursing facility, is any of the cost covered by your policy?
2. Meet with an accountant and an elder lawyer to review financial planning and living trusts. It is important to be proactive on how to best use your financial assets so that you can stay at home as long as possible. Will you be able to hire private home care? How can you protect your assets? What must you do to eventually qualify for MediCal (and IHSS if still available)?
3. If you do not have private insurance, have you begun the process of qualifying for MediCal? If not, make an appointment with Social Services to start the qualification process. Please keep in mind that

this does not guarantee that the government will take care of your needs

4. It is important to keep lines of communication open about the challenges of transfers. Discuss the following scenarios with family members. How might you resolve each of these challenges? We include some ideas to consider.
  - You cannot transfer yourself but you are not bed-bound; you are able to sit in your wheel chair for much of the day. How will you handle morning and evening transfer needs? Is a family member prepared to get you up, dressed and into your wheelchair in the morning and then reverse the procedure in the evening? If not, how will you hire and pay for caregivers to do the same morning and evening assistance?
    - (Review your insurance policy, qualification for social service programs and your financial resources.)
  - You have a family member or hired caregiver who is strong enough to assist with transfers. How will you protect this person from injury so that he or she remains healthy and can continue to assist you?
    - (Consider meeting with a physical therapist to review effective transfer strategies.)
  - Your spouse/family members are becoming angry and expressing frustration about the amount of time and energy spent in caring for your needs. How can you address these feelings so that both your and their needs are met?

(MSQLP has a monthly support group for caregivers in Seaside. See the list at the end of this newsletter for meeting times and locations. This gives caregivers an opportunity to express feelings, share solutions to challenges, and learn from others who have similar experiences. You won't believe how much better you may feel when you realize others understand. In addition, can you and your caregiver pursue family counseling?)
5. Keep physically active so that you can help your caregiver in the transfer process. Explore the Adaptive PE program at the community college nearest to you. All the local community colleges in the Tri-County area have Adaptive PE programs.
6. Have an Occupational Therapist visit your home to discuss ways to address transfer challenges. There are durable medical devices that can be purchased or rented that raise a person from a horizontal position (in bed) to a sitting position so they can be

transferred to a wheel chair or onto the toilet or bath seat.

A Hoyer-type lift is bulky and needs lots of room in which to operate but if the room is available, it works. The person assisting you puts a sling around your torso and then uses the hydraulic lift system to raise and lower your body to where it is needed. If you have private insurance it may pay for its rental. If you have private funds you can purchase systems that are less bulky that can raise or lower your body into needed positions. Some have mechanical arms that reach around your body and lift you or lower you into place. Others have a sling that, like the Hoyer-type lift, is placed around your torso and then a motor from a track in the ceiling lowers or lifts you into the position needed. You are then moved along ceiling tracks into the bathroom or into position to be lowered into your wheelchair. The obvious advantage of these systems is that the motors do the work of lifting. The disadvantage is that these systems are expensive.

7. Use the resources of Centers for Independent Living (CILs). These centers provide free services to the disabled so that they may remain independent as long as possible. Their free services include: Information and Referral; Individual and Systems Change Advocacy; Benefits Counseling; Housing Assistance; Personal Assistance Services; Peer Support; Independent Living Skills Training; and Assistive Technology, to persons with disabilities who live in the Tri-Counties. Their offices are located in Salinas, Capitola, Hollister, Monterey and Soledad.
8. Housing options—the theme of our February 2009 newsletter was transitions in housing for those dealing with disabilities. It includes articles that describe how our clients have made their homes more accessible including use of some devices that assist in transfers. Another article describes how to select housing that is best for you based on accessibility needs, availability and affordability. It ends with an interview with Kurt Lemke who now lives in a skilled nursing facility in Santa Cruz. He moved to the facility after he was no longer able to transfer by himself. To read the issue, go to our website: [www.msqlip.org](http://www.msqlip.org) and click on the newsletter link. Scroll down and click on the February 2009 issue.
9. If you have not completed an Advance Care Directive (a health care proxy form—the one that we especially like is the Five Wishes) and a Physician Orders for Life-Sustaining Treatment (POLST) as described in step 12 of Tipping Point #2, now is the time to do so. These documents identify how you want to be

treated if, or when, hospitalization is needed and you are unable to speak for yourself. Do it now. You do not want others to make these decisions for you or to carry the burden of making these decisions. It is your responsibility. If you have already completed these documents, review them, make revisions if needed and file them with family members and your doctors.

10. Attend an MS support group. If you have not yet attended an MS support group, consider it now. All are accessible to persons in wheelchairs. Group members will have advice and stories to share about their experiences with transfer issues. Use their knowledge to improve your own life. See the end of this newsletter for the list of meeting times and locations of support groups in the Tri-Counties.
11. Continue to share your thoughts, beliefs and experiences with the members of your personal support group: those people with whom you can share what you are going through. If any member wishes to attend a caregiver support group meeting, encourage them. It will give them a chance to talk with others who support persons with MS. Share your written and online resources with them; information will empower them as well as you.

**List of agencies that might help:**

Center for Independent Living (refer to item #7 above).

318 Cayuga St, Suite 208, Salinas 831-757-2968

1350 41st Avenue, Suite 101, Capitola 831-462-8720

288 Pearl Street, Monterey 831 649-2969

438 Benito Street, Apt 30, Soledad 831-678-4713

1111 San Felipe Rd. Suite 107, Hollister 831 636-5196

Alliance on Aging of Monterey County may help with counseling and advocacy for health insurance and tax counseling, has an ombudsman for long term care and provides peer counseling program. Telephone: 800-510-2020

Senior Network Services in Santa Cruz: 831-462-1433

Offers a senior resource directory, counseling on housing issues, insurance and money management, assistance in finding caregivers and respite care.

# The Best Thing We Did When My Husband Could No Longer Transfer Himself . . .

—Donna Krasnow

What options do you have when you can no longer take care of yourself and want to stay in your home? If you have the money or qualify for assistance, one option is to hire a caregiver. When my husband and I faced this problem, Gary was 48, our 2 children were college-age and no longer lived at home and I was a full-time high school teacher.

Gary had been diagnosed with MS when he was 30. By the time he was 48 he could barely move his hands, arms or legs. He could no longer operate his motorized wheelchair or feed himself. Thankfully, we had a motorized lift that I used to move him between his bed and wheelchair. I don't know what I would have done without it because I could not lift him myself. He used a catheter so I no longer had to struggle to get him into the bathroom.

But by the time he was 48, I knew we needed more help. Even though the high school where I worked was incredibly supportive and gave me a schedule that allowed me to be home by 1 pm most afternoons, Gary no longer felt safe alone. I couldn't stop working to take care of him full time: we needed my income to survive. We decided to hire a caregiver Monday to Friday, from 7 to 1. Even though it would be expensive and we did not qualify for financial support, we decided to finance it ourselves. It was the only way Gary could remain safely at home.

## **Challenges we faced and solutions we developed:**

1. I had no idea where to find a competent caregiver I told everyone I knew we were looking for a caregiver. About 3 weeks after I put the word out, Gary's Physical Therapist called with a recommendation. We interviewed the woman she recommended and hired her. She was with us for the last 5 years of Gary's life.
2. No one wanted to come at 7:15 am (when I left for school). We had the phone company install a phone button (this service is free for anyone who is disabled) that I pinned to Gary's pillow when I left at 7:15. If he turned his head and pushed the button, he was connected to the operator and could contact me, 911, or a neighbor if he needed help. This gave him a sense of security while he waited for the caregiver to arrive at 8 am.
3. No one was willing to work a teacher's schedule: 180 days a year. They wanted work every week of the year—including my school holidays and summer vacations—I had to agree to hire the caregiver for 52 weeks a year. This made the expense much greater than we originally anticipated but I found that the extra free time it gave me was important for keeping my sanity. I used these hours to do errands, visit friends, or take long walks with the dog.
4. The process of legally hiring a household employee is daunting—so many forms and regulations required by the State. I contacted the State—first by telephone and later via their website—and started working my way through the forms. Within a few months the process had become easy. In reality many caregivers want to be paid under the table. I needed the tax deduction,

however, and would not consider this. Also, it is against the law. Both my life and that of my husband improved after Francia came into our lives. I now went to work with the knowledge that Gary was safe. When I came home Gary had been bathed and fed. The physical therapist taught Francia how to do simple leg and arm exercises with Gary so that he was physically more comfortable. His room was tidy, the kitchen was neat, and even his laundry was done. I didn't have to rush home to feed him or find out what problems needed immediate resolution. Instead I was able to sit and talk with Gary and compare notes about our days. Gary had someone who became a companion and friend. I had someone who made my life less stressful. Because of a wonderful caregiver, Gary was able to remain at home until he died in 2002.