

Powerful Patient #13

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Caregiving, Part 3: Taking Care of Harry

The Caregiving experience is stressful for the patient as well as the caregiver. Whenever possible it is good to negotiate the changes in roles and responsibilities that occur. Both the patient and the caregiver need to work on evolving the relationship in ways that work for both parties and meet the medical goals.

As you listen to the two interviews in this program, please think about

- Compliance
- Attitude
- Negotiation



June and Harry, in 2002

We speak with June, who at age 90 is the primary caregiver for her husband Harry, who has vascular dementia. They were married in 1941, and knew each other for ten years before that.

Together they have gone from Level 1 care to Level 5 care as Harry's needs have escalated, and with increasing care from their children and from home health aides, but their wish is for Harry to stay in his home.

Their son, Jim, is also actively involved in his father's care. We speak also with Jim about his own attitudes and experiences as a caregiver for his Dad.yourself.

1) Our Guests

June is a retired elementary school teacher in Memphis, Tennessee. She has always been active in civic affairs, and spent 20 years as the volunteer Librarian for the professional library at the Memphis Zoo. She and her husband Harry have lived in the same house since 1954. They have three children, eight grandchildren, and sixteen great-grandchildren.

Jim is a father of five girls, grandfather of eight, and is also supporting his mother in taking care of his father in the parents' home, 40 minutes away from his own home.

2) More About Getting Help

As needs escalate, don't be shy to ask for help. Usually your own doctor's office is a good place to start.

Support groups for the medical condition you are dealing with can also be extremely helpful. The Alzheimer's Association has good hints and support groups for people dealing with any form of dementia. It is not possible to make a definitive diagnosis of Alzheimer's until after death, so any condition involving dementia can seek help from the Alzheimer's Association. <http://www.alz.org/index.asp>

Your doctor can assist in getting help from the visiting nurse association, or a rehabilitation center, if needed for help in improving the medical condition. In the case of von Hippel-Lindau disease, for example, there is the VHL Family Alliance <http://www.vhl.org>

Once it is clear that a situation is not going to improve, many insurers including Medicare will withdraw payment for rehabilitation services. Hospice can be a great assistance for degrading conditions. Hospice services vary from region to region.

<http://www.hospicenet.org/>
a resource for people facing life-threatening illnesses

<http://www.cancer.gov/cancertopics/factsheet/support/hospice>
A fact sheet on organizations that provide hospice services

<http://www.hospicefoundation.org/>
Hospice Foundation of America, with information about how to select a hospice, links to publications, and videos.

3) More about devices

Remember that as a caregiver, you must be sure that both you and your patient are not going to get into a situation you can't handle. You don't want to strain your back, fall with the patient, or otherwise endanger yourself by undertaking too much. Ask for help, and/or get advice on assistive devices that have helped others.

Other devices that can be useful. Most of these can be either rented or purchased, depending on the length of time they will be needed. Craig's list or the local Penny Saver newspaper can be a good source for used equipment. www.craigslist.com

- Amplifier for the door bell for people with hearing impairments
- A flasher for the telephone for people with hearing impairments.

- Adding a railing to steady older people climbing even one or two steps at doorways
- Adding a pull-bar in the bathroom to help prevent slipping. Removable Tub Bars can be added temporarily.
- Adding a bath chair to provide a seat in bathtub or shower.
- Adding a ramp when a wheelchair is in use. Jim made a ramp out of plywood, and added traction strips.
- Hospital beds can be rented or purchased.
- Wheelchairs come in many styles. For people transferring from bed to wheelchair, the kind with sides that remove can be helpful.

Jim mentioned a lift to raise a patient out of bed and put them into a chair, or vice versa. Here are some sample devices that might be of assistance:

<http://www.gimmealift.com/>

<http://www.just-patient-lifters.com/>

<http://www.patientlift.net/>

Even though Jim is tall enough to have leverage, and strong enough to transfer his Dad his sisters and other helpers are not. Having the lift allows Jim to get help from others to share the work, so that he can take some time for his own wife, children, and grandchildren.

Be Well,
And be a Powerful Patient