

# TAKE CARE!

Self-Care  
for the Family  
Caregiver™

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## Discharge Planning: What Family Caregivers Need to Know

Sandy Padwo Rogers

Anyone who has ever helped transition a loved one out of the hospital knows the frustration, emotional distress, and exhaustion that results when you arrive back home only to realize that you are unprepared for what comes next. It is easy to forget what information you may need to know after your loved one returns home. It's also easy to feel completely alone and unsure of where to turn for help. But help should be offered as part of any hospital transfer, and if that help isn't offered right away, it's your right to ask for it.

"Part of the discharge process is making sure that what has occurred in the hospital has been documented and reviewed with the patient, family, and the next providers of care so that the patient transfer occurs safely," says Cheri Lattimer, RN, BSN, executive director of the Case Management Society of America and project director of the National Transitions of Care Coalition. "Families can and should be speaking up to make sure this is done."

Families must also recognize that with today's hospitalizations, transitions in care take place much more quickly than ever before. That's why it's crucial that you begin the discharge planning process at the time your loved one is admitted to the



hospital. "Everything about the hospitalization happens at rapid-fire speed," says Carol Levine, director of the Families and Health Care Project for United Hospital Fund. "This is not a time for leisurely decision making. If you get the feeling that a change in your family member's care is imminent, you must be prepared to act."

What can you do to help ensure that the discharge planning process goes as smoothly as possible? According to Lattimer and Levine, the following basic questions offer a good starting point for family caregivers to begin the discharge conversation with the medical team:

**1. Who will be responsible for helping me with the discharge planning process for my loved one?** This question should be asked at the time the patient is admitted to the hospital. If your loved one is entering the hospital through the emergency room, it would be best to wait

until he or she has been moved to a floor to ask this question. At that point, you should ask the first clinician who sees your loved one, whether it's a physician or a nurse.

Hospitals typically utilize either a discharge planner or a case manager to oversee the discharge planning process. These individuals may be RNs, social workers, or, in some cases, even pharmacists. In general, a discharge planner will assist with discharge instructions and education, coordination of home care or other care options at discharge, and transportation, if needed. The case manager has the responsibility for discharge planning as part of a larger job description that includes assessing the patient's and family

(Continued on page 7)

### INSIDE

2

*Economic Downturn Hits Family Caregivers Hard*

3

*"Help" Is Not a Dirty Word*

6

*Resources, Reviews & Whatnot*

10

*Planning for National Family Caregivers Month 2009*

11

*Caregiver Community Action Network Update*

12

*A Caregiver Poem: Nailing Jell-O® to the Wall*

13

*What Can I Do? Caregiver Questions*

## Economic Downturn Hits Family Caregivers Hard

Suzanne Mintz

The June 7 *New York Times* featured an article by John Leland, "Downturn Puts a Chokehold on Those Caring for Family Members," that highlights the economic difficulties that family caregivers are facing during this recession. Within the past few months, NFCA's corporate partner Evercare, in collaboration with the National Alliance for Caregiving, took a look at how family caregivers have been faring due to the recession and published the "Evercare® Survey of the Economic Downturn and its Impact on Family Caregiving," based on a survey of 1,000 family caregivers who provided care to someone over the age of 18 during the past 12 months.

You can read the *New York Times* article at [www.nytimes.com/2009/06/07/us/07squeeze.html?ref=us](http://www.nytimes.com/2009/06/07/us/07squeeze.html?ref=us) and the Evercare study at [www.caregiving.org/data/EVC\\_Caregivers\\_Economy\\_Report%20FINAL\\_4-28-09.pdf](http://www.caregiving.org/data/EVC_Caregivers_Economy_Report%20FINAL_4-28-09.pdf).

Here is a synopsis of the study's findings, which are very sobering.

More than 60 percent of survey respondents were providing personal care (activities of daily living, or ADLs) such as bathing, dressing, feeding, toileting, and transferring. The remaining 39 percent of family caregivers in the survey were helping their loved ones with at least one of the following instrumental activities of daily living (IADL): shopping, cooking, housecleaning, handling finances, transportation to doctor appointments, overseeing medications, etc. The study looked at five different aspects of caregivers' lives: employment, paying for caregiving, living situations, emotional impact, and quantity and quality of care.

The study found that, in no uncertain terms, the recession is having a negative impact on family caregivers in virtually all aspects of their lives.

- Fifty percent of working\* caregivers said they were less comfortable taking time off from work to provide care.
- Forty-three percent of working caregivers have had their work hours or pay cut.
- One in six caregivers (15 percent) says that the downturn has caused them to lose their job or be laid off.
- Thirteen percent say the economic downturn has led to increased caregiving expenses.
- Six out of 10 caregivers reported having difficulty paying for their own basic necessities.
- Sixty-three percent are saving less for retirement.
- Forty-seven percent reported using all or most of their savings.

No wonder one in three working caregivers reported having to work more hours or get an additional job. Twenty-one percent of surveyed family caregivers report moving into the same household with their loved one, almost doubling the number of co-residing caregivers and care recipients.

We all know that caregiving stress affects our emotions and our bodies. Not surprisingly, the economic downturn has increased stress about being able to continue to provide care.

It's not all bad news: Thankfully, the survey did find that while the recession has had a decidedly negative impact on family caregivers, 76 percent say the quality of care they provide has not diminished. ■

\* Working caregivers are defined as having worked at some point while providing care in the past 12 months.

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**H**ow many times have you thought to yourself, “If only I had some help”? It’s one of the top wishes that family caregivers list when sharing their stories with NFCA. Ironically, however, all too often it’s the family caregiver who stands in the way of getting that help.

Why is it so hard to ask for or accept help? What can family caregivers do to move beyond their or their loved ones’ feelings of resistance toward outside help? NFCA decided to seek the advice of two experts in the field of family caregiving: Mark Yaffe, M.D., associate professor of family medicine at Montreal’s McGill University and St. Mary’s Hospital Center, and Barry Jacobs, PsyD, director of behavioral sciences for the Crozer-Keystone Family Practice Residency Program in Springfield, Pennsylvania.

Dr. Yaffe and Dr. Jacobs offered their insights and advice on a few of the more common reasons cited by family caregivers for not requesting or accepting the help they say they need.

**“I’m embarrassed to ask for help.”**  
“Congratulations, you’re normal,” says Dr. Yaffe. “Most family caregivers feel this way and it’s a very valid feeling. It’s part of the challenge of being a caregiver.” In fact, according to Dr. Yaffe, studies have shown that when family caregivers are offered help, only about one-third will accept the offer. Why is this? “There is a lot of shame associated with asking for help and a fear that people will judge you for shirking your responsibilities,” says Dr. Jacobs. “I often hear the explanation, ‘Our family doesn’t take handouts,’ or, ‘No one will take care of my loved one as well as I do.’ Some people feel that admitting they need help means they have lost. In fact, the opposite is true. By not asking for or accepting help, they are setting themselves up to burn out and fail.”

## “HELP” Is Not a Dirty Word

It’s also helpful to recognize that everyone gets ready to accept help at a different point along his or her family caregiving “career.” Dr. Yaffe uses the analogy of the individual who wants to lose weight or quit smoking. Everyone becomes ready to make that decision at a different point and for different reasons. The same holds true for family caregivers.

Many family caregivers also worry about the reactions from others if they seek assistance. According to Dr. Yaffe, family values and expectations, along with religious beliefs and cultural values, can impact whether a family caregiver feels comfortable asking for assistance. Religious beliefs can become a source of stress and conflict as easily as they can be a source of comfort. It’s a challenge for any family caregiver to look at these outside influences to determine if they are constructive or destructive. It’s also important to remember that the fear of sanctimonious reactions from others cannot be accepted as a reason for not seeking help. It’s unlikely that these individuals have walked in your shoes.

**“I should be able to do it all myself.”**

The problem with this way of thinking, according to Dr. Yaffe, is that family caregivers tend to go from crisis to plateau to crisis without the realization that you are slowly being worn down by your circumstances. “Family caregivers don’t seem to have the ability to recognize the cumulative effects of each crisis,”

says Dr. Yaffe. “You need to ask yourself, ‘What is my limit of tolerance before I reach my breaking point?’ You also need to remember that being a family caregiver means you’re at an increased risk of having your own health issues and premature mortality.”

“It’s important to recognize caregiving for what it is,” says Dr. Jacobs. “There tends to be a discrepancy between how long a family caregiver thinks he or she will be providing care and how long the care recipient will need assistance. It helps to acknowledge from the outset that you are running a grueling marathon and you must replenish yourself along the way. Helping yourself allows you to continue helping your loved one.”

**“My loved one won’t accept assistance from anyone but me.”**

“It’s interesting what kinds of things people feel they need permission to do,” says Dr. Yaffe. “For instance, it’s OK to tell your loved one if he or she does something that is hurtful to you. It’s also OK to tell your loved one that he or she doesn’t have the right to take over your life. Caregivers need permission to say, ‘You are wearing me down. Even though I still love you, I need help caring for you.’ It’s a sign of strength to be able to say this. The key is to be open about your feelings of love, caring and commitment.”

Dr. Yaffe suggests that family caregivers have an honest dialogue with their loved ones about how to make things work over the short term and

*(Continued on page 4)*

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## Ask for Help

Continued from page 3

the long term. The idea is to solve the situation as a unit rather than as individuals. Take the care recipient through the decision-making process by having an open dialogue about the caregiving situation. "There's a four-letter word and it's 'TALK,'" says Dr. Yaffe. Dr. Jacobs agrees. "Care recipients need to know that they can give back to their caregivers by being flexible about who provides some of their care. They must understand that sometimes, providing loving care means bringing someone else into the home."

**"No one can help my loved one the way I can."**

Dr. Yaffe notes that some people find it more difficult to relinquish control

than others. "The idea of someone taking over can affect a family caregiver's sense of self-worth," he says. "The family caregiver thinks, 'If I give up this control, what else am I giving up? What else am I grieving?'" But family caregivers can redefine themselves if they are able to get help with some of their caregiving tasks. It's important to recognize the fact that there are limits to what you can do. If you are willing to seek help, it may allow you to spend more quality time with your loved one.

Dr. Jacobs suggests that it may be easier for some people to start with smaller steps, such as a meals on wheels program or a similar form of assistance that doesn't require relinquishing control over caregiving. In fact, accepting these forms of help may allow you to do even more for your loved one. Be open to accepting help with a few simple services and then try to be flexible as your loved one's needs evolve.

**"I have no one to ask for help."**

Family caregivers should be willing to consider a broad list of individuals when reaching out for help. Start with family, friends, and neighbors. They are the people most likely to be able to lift a hand and help you with day-to-day chores such as picking up groceries, preparing dinner for you and your family, and driving your kids to appointments. You may even get lucky and find someone willing to mow your lawn, a great task for college students who are home for the summer. If you are looking for advice, other family caregivers are a good place to turn. There are many forums, bulletin boards, and chat rooms you can access online. Just be careful to go to reputable sites. You may want to get started by checking out the disease- or condition-specific Web sites, as well as sites dedicated to family caregiving.

Some family caregivers have had luck turning to their faith communi-

ties. Members of the congregation might be willing to form a team to help you get over a particularly difficult time or even to help out on a long-term basis. You won't know until you ask.

Have you told your doctor that you are a family caregiver? You should. While some doctors may appear uninterested in your role, medical educators and community organizations are gradually sensitizing physicians to the needs of family caregivers. Doctors may not have all the answers about community services, but they need to be aware of the stress that you are experiencing. And as you learn about what your community has to offer, be sure to share this information with your doctor so that he or she may pass it on to someone else. "Family caregivers can and should become teachers to their doctors," says Dr. Yaffe.

"From my experience, there is some type of caregiver support infrastructure in almost every community," says Dr. Jacobs. "I have often found in my practice that a family caregiver's reluctance to seek out or accept help plays a larger role than not knowing where to turn for help."

Along with checking into community-based support and respite programs, Dr. Jacobs encourages family caregivers to be open to the use of home health agencies. "If you look for reputable agencies and you realize that you have to take your time to find the right match for your family, you may end up with someone who becomes a valued member of your family," he says.

For those who can't afford the services of a home health agency, try to find out if there are any services available from your local Area Agency on Aging or your county Department of Aging and Disability Services. "Ultimately," says Dr. Jacobs, "it's about being open to any new form of assistance that will allow you to ensure that the caregiving is sustainable." ■

## Are You Receiving NFCA's Monthly E-letter?

You don't want to miss it!  
It's full of news, resources,  
and action alerts.

Please send us your e-mail  
address and we'll add your  
name to our e-mail list. It's  
that easy — and it's FREE.

Be sure to check your  
junk/spam mail folder  
periodically to make sure  
NFCA's e-mails don't  
end up there.

## Where to Seek Help

### 2-1-1 US

The national 2-1-1 initiative offers a one-stop shop of resources by providing free and confidential information and referrals. As of April 2009, 2-1-1 serves more than 240 million Americans covering all or part of 46 states plus Washington, D.C., and Puerto Rico. The remaining states are all in various stages of planning and implementation. For help with food, housing, employment, health care, counseling and more, call 2-1-1 or go to [www.211.org](http://www.211.org).

### Eldercare Locator

The Eldercare Locator, a public service of the U.S. Administration on Aging, is your first step for finding local agencies that can help older persons and their families access home and community-based services like transportation, meals, home care, and caregiver support services. Go to [www.eldercare.gov](http://www.eldercare.gov) or call 800/677-1116.

### Faith in Action

Faith in Action brings together people of many faiths to help their neighbors in need. Faith in Action volunteers shop, cook, drive, or just check in on the millions of Americans with long-term health needs. To learn more, go to [www.fianationalnetwork.org](http://www.fianationalnetwork.org).

### Family Caregiver Alliance

The Family Caregiver Alliance's Family Care Navigator helps you locate government, nonprofit, and private programs in your area. It includes services for family caregivers as well as resources for older or disabled adults living at home or in a residential facility. Go to [www.caregiver.org](http://www.caregiver.org) and click on "Family Care Navigator: State-by-State Guide to Support Services."

### National Family Caregivers Association

NFCA maintains an extensive list of agencies and organizations that provide family caregivers with information, support and assistance. Go to [www.thefamilycaregiver.org/caregiving\\_resources/agencies\\_and\\_organizations.cfm](http://www.thefamilycaregiver.org/caregiving_resources/agencies_and_organizations.cfm) or call 800/896-3650.

### National Family Caregiver Support Program

The National Family Caregiver Support Program is available throughout the United States. It is administered in each county by an Area Agency on Aging. The extent of services varies by location. To learn more about this program, visit the U.S. Administration on Aging Web site at [www.aoa.gov/AoARoot/AoA\\_Programs/HCLTC/Caregiver/index.aspx](http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Caregiver/index.aspx).

### Well Spouse Association

Well Spouse provides emotional peer-to-peer support to the wives, husbands, and partners of the chronically ill and/or disabled. Go to [www.wellspouse.org](http://www.wellspouse.org).

## MEDICARE CORNER

### Medicare Pays for Some Family Caregiver Education

Did you know that Medicare will pay for certain types of family caregiver education when it's provided as part of a patient's medically necessary face-to-face visit? It's true, although your loved one's physician may not be aware of it.

A physician may be able to bill for family caregiver education as part of the counseling and coordination of care services provided during a patient visit, as long as the caregiver education directly involves the patient and is medically

necessary. This education can take place in a doctor's office or other outpatient facility, a patient's home or private residence, or an assisted living facility or other domicile.

Medicare's new publication "Tip Sheet for Providers: Caregiving Education" can be found under "Latest News" at [www.thefamilycaregiver.org](http://www.thefamilycaregiver.org). Download a copy for yourself and be sure to share the information with your loved one's physician.

*Medicare Corner is made possible by an unrestricted educational grant from Abbott Laboratories.*

As its title implies, the purpose of this column is to provide you with useful information and help you tap into new networks or learn about available products and services.

**Are you looking for a reliable source of health information online?** MedlinePlus contains authoritative, up-to-date health information from the world's largest medical library, the National Library of Medicine. MedlinePlus has extensive information from the National Institutes of Health and other trusted sources on more than 750 diseases and conditions. There are directories, a medical encyclopedia and a medical dictionary, easy-to-understand tutorials on common conditions, tests and treatments, extensive information on prescription and non-prescription drugs, and links to thousands of clinical trials. MedlinePlus is updated daily. Go to <http://medlineplus.gov>.

**Are you getting the most out of your pharmacy benefits?** Your Pharmacy Benefit (YPB) is a Web site designed to help consumers and family caregivers understand the value and make better use of their prescription coverage — whether they are covered through private insurance or Medicare Part D. Your Pharmacy Benefit resources focus on three stages of prescription drug coverage: choosing, understanding and using. The Web site provides information and resources that empower consumers to get the most from their prescription coverage. YPB is a collaborative effort of diverse public health organizations. To learn more, go to [www.yourpharmacybenefit.org](http://www.yourpharmacybenefit.org).

**Are you caring for an older loved one?** If you're caring for an older friend or family member, you've probably had questions about Medicare, the federal health insurance program for adults 65 and older and people under age 65 with disabilities. An easy-to-read overview, "Medicare Basics for Caregivers," is now available at NIHSeniorHealth.gov, the Web site for older adults from the National

Institutes of Health. This brief yet comprehensive introduction to Medicare gives family caregivers the basics and helps them find answers to their questions. Caregivers and others needing a general introduction to Medicare can find out about medical and hospital benefits, enrollment, billing, prescription drug costs, home healthcare, and much more. Go to <http://nihseniorhealth.gov/medicare/toc.html>.

In addition, the NIHSeniorHealth Web site features short, easy-to-read segments of health and wellness information for older adults that can be accessed in a number of formats, including various large-print type sizes, open-captioned videos, and an audio version. NIHSeniorHealth is based on the latest research on cognition and aging and is a joint effort of the National Institute on Aging and the National Library of Medicine. Go to [www.nihseniorhealth.gov](http://www.nihseniorhealth.gov).

**Do you know the signs of Alzheimer's disease?** The Alzheimer's Association has a new educational campaign aimed at increasing awareness of the 10 warning signs of the disease and the benefits of an early diagnosis. Early detection, diagnosis, and intervention are vital because they provide individuals the best opportunity for treatment, support, and planning for the future. To learn more about the 10 warning signs of Alzheimer's disease, go to [www.alz.org/10signs](http://www.alz.org/10signs) or call 877-IS IT ALZ (877/474-8259). To reach the Alzheimer's 24/7 Helpline, call 800/272-3900.

#### BOOK REVIEW

**You're Not You: A Novel** by Michelle Wildgen (Picador, 2007, \$14.00). Transformed: It's a word often used when you become a caregiver. Your

view of the world is transformed. Your view of the person you're caring for is transformed. Your view of yourself is transformed. *You're Not You* skillfully brings us along as several such transformations take place.



Bec is a college student who is just going with the flow. That is until, on a whim, she answers an ad for a "helper" for Kate, who has Amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease. At 36, Kate is not what Bec expects. Feisty and opinionated, Kate does not simply accept anything that happens to her. She demands as much from life, and from those around her, now as she did before ALS started taking its toll. This includes her husband, Evan. And it's where *You're Not You* reveals the rarely mentioned intimate repercussions of illness. Evan's limitations, and his ultimate retreat, prove to be the catalyst for Bec's transformation. By caring for someone who is, literally, losing touch with the world around her, Bec is forced to confront her own ambivalent lifestyle. But this is not, as Bec puts it, "like those TV movies where the person with the disease teaches everyone how to live." No, this is a story that's authentic, with hard decisions and not-so-sugary-sweet endings. Michelle Wildgen manages to illustrate the unexpected transformative effects that caregiving has on all concerned, all while crafting a beautiful story in the process. Come find some of yourself in *You're Not You*.

*You're Not You: A Novel* is available wherever books are sold.

The Book Review was provided by CCAN representative Liz de Nesnera.

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## Planning for Discharge

Continued from page 1

caregiver's situation; working with the clinical team to develop a treatment plan; facilitating any home care services that may be needed once the patient is released from the hospital; coordinating communication among the healthcare team to ensure a smooth transition for the patient; and advocating for the necessary funding, appropriate treatment, and treatment alternatives with the patient and family caregiver.

In addition to a discharge planner or case manager, other clinical professionals will be part of the discharge team. These may include any specialists who see your loved one in the hospital as well as members of the nursing staff. Find out if there is a specific discharge nurse or if the nurse on duty at the time of discharge will be handling this process. Ask what role each clinician will play in the process so that you know what to expect, including what information you will receive from each team member. For example, instructions about medications and follow-up care may be handled by a nurse who is not serving as the case manager. The more you understand about how the process works, the better position you will be in to help your loved one.

If it's possible, arrange to have someone with you at the hospital, especially on the day of discharge. "Discharge instructions are often extremely complicated," says Levine. "To make things even more challenging, the family caregiver is also trying to alleviate any anxiety that his or her family member is experiencing with regard to the transition. It's really important to have someone else on hand who can listen to instructions, ask questions, and provide general emotional support. It really does make a difference."

### 2. Do we have access to a case manager through our insurance plan?

Many insurance plans now utilize their own case managers, especially for patients who are dealing with chronic illnesses or disabilities. These individuals will be able to tell you what healthcare services will be reimbursed by your insurance provider and what assistance may be available to you, the family caregiver. This individual should serve as a patient advocate and family caregivers may request this support. Keep in mind, however, that an insurance company case manager must balance the patient's needs with limited healthcare resources and cost considerations, so you may want to ask for a second source of information and advice.

### 3. Have my loved one's records been sent to his/her primary physician?

These days, there's no guarantee that your loved one's physician will see him or her in the hospital. More likely, your loved one will be seen by a hospitalist, a physician who is employed by the hospital. It's important that your loved one's primary physician is updated on any hospitalization. If you are dealing with a chronic illness or condition, your loved one may be utilizing multiple specialists as well. These individuals, too, must be provided with all the hospital's records as soon as possible to ensure the best possible transfer. "The transfer of information is crucial to the continuity of care," says Lattimer. Find out what needs to be done to ensure that your loved one's records are transferred in a timely fashion. This includes getting the results of any tests that have been ordered but not yet documented in the patient's chart. Don't assume that just because you ask for this information to be relayed to the appropriate physician(s) that it will be. Be sure to follow up either with the hospital or with each physician's office. To be

### Don't Leave the Hospital Without It

Cheri Lattimer suggests that, at a minimum, family caregivers insist on the following before their loved ones are transferred out of any healthcare setting:

1. A medication list that has been reviewed and updated by the current healthcare team. This list should include information about what medications the patient was on before the hospitalization; what medications should be continued, resumed or discontinued after the hospitalization; and when refills must be obtained.
2. Follow-up instructions, including the name and contact information for any healthcare providers who need to see the patient after the hospital discharge, and when these visits should take place.
3. A clear summary of what's next for the patient, including what type of home care the patient may need and who will provide that care. There should also be a discussion about the family caregiver's ability to provide care, including his/her needs.
4. A copy of the hospital discharge summary.

safe, you may want to request a copy of the hospital records, including test results, for yourself. Just make sure to ask if there is a charge for this service and be prepared to pay a fee for your copy of the records.

### 4. What do I need to know to help my loved one when we get home?

You have a right to ask that all instructions be explained using language and terms you can understand. If you cannot get adequate explanations from the attending physician,

*(Continued on page 8)*

## Planning for Discharge

Continued from page 7

you should ask the discharge planner or social worker to explain everything to you. Similarly, if you don't understand any aspect of your loved one's care in the hospital or his or her future care needs, now is the time to ask.

Make sure you understand your loved one's medication reconciliation form. This is the form that lists all your loved one's medications prior to, during, and after the hospitalization. (Be sure to provide the hospital with a current list of medications upon admission.) Reconciling the patient's medications throughout the hospital stay is now considered part of the standard of care and you will receive a copy of this form upon discharge. If there are new medications prescribed in the hospital, make sure they don't negatively interact with or duplicate the medications your loved one has at home. You will also want to find out if you will have any difficulty filling these new prescriptions at your chosen pharmacy. Some pharmacies may not carry the drugs your loved one needs, particularly certain pain medications or very expensive drugs. If you need to have a prescription filled at the hospital pharmacy, it's important to find this out before you leave the hospital.

Make sure that all follow-up instructions are clear and that you are capable of performing any duties that may now be required to help your loved one. Are there new demands on you regarding the care that must be administered at home?

Let the case manager know what you feel comfortable doing and what help you need. If you are unable to perform any of the duties that will be required of you, now is the time to say so. "It's OK to say, 'I just can't do this. I need help,'" says Lattimer.

"The family caregiver must speak up at this time or there's a good possibility that the patient will end up back in the hospital." Keep in mind, though, that just because you feel you need additional assistance doesn't mean that your insurance company will pay for it. Someone from the hospital may need to advocate on your behalf.

"You need to make it clear when you will and won't be there for your family member," says Levine. "Especially if you don't live with the patient, now is the

time to let the case manager know that you are not there to help 24 hours a day."

If your loved one must transition to a skilled nursing or rehabilitation facility before coming home, the case manager should provide you with a list of options, help you find out what your insurance will cover, and help you explore your options so that you can make the best decision for your family. Try to ask for this information early in your loved one's hospitalization so that you have time to get advice and opinions from the healthcare team as well as others you trust. If your loved one is receiving a referral for home care, ask what these services should entail and then request a list of agencies from which to choose.

**5. Should I expect a follow-up call from the hospital after my loved one is discharged? If so, when will that call take place?**

A great number of hospitals now arrange for a follow-up call after the patient is discharged to make sure that the transition has gone smoothly. Ask if your hospital makes these calls and who from the hospital will be contacting you. If you will be getting called by someone who is familiar with your loved one's care, this may be an opportunity for you to get answers to any questions that arise after you've left the hospital.

Whether or not your hospital does make follow-up calls, you should find out who **you** can contact should you need any additional information after leaving the hospital. If you're told that you need to contact your loved one's primary physician, this is a good time to try to determine exactly when and how that physician will receive all the pertinent information.

The bottom line for all family caregivers: Don't be afraid to ask questions. "Even if you don't know what questions to ask, that's a question in itself," says Lattimer. "It's OK to say, 'Please tell me what I need to know to help my loved one.' It's also OK to ask for help understanding the transition process. The worst thing a family caregiver can do is **not** to ask for help." ■

*Sandy Padwo Rogers is the managing editor of TAKE CARE!*

## Please Donate to NFCA

Your tax-deductible contribution will allow NFCA to continue to help you and all of America's family caregivers.

Go to  
[www.thefamilycaregiver.org](http://www.thefamilycaregiver.org)  
or call 800/896-3650.



*"You have a right to ask that all instructions be explained using language and terms you can understand."*

## Discharge Planning Resources That Can Help

**Medicare** – Medicare offers comparison search tools for hospitals, nursing homes, home health agencies, medical equipment suppliers, and more. Go to [www.medicare.gov/default.asp](http://www.medicare.gov/default.asp). To download Medicare's brochure on discharge planning, which contains a checklist for patients and caregivers preparing to leave a hospital, nursing home, or other healthcare setting, go to [www.medicare.gov/Publications/Pubs/pdf/11376.pdf](http://www.medicare.gov/Publications/Pubs/pdf/11376.pdf).

**National Alliance for Caregiving** – The National Alliance for Caregiving offers an assortment of publications for family caregivers, including "A Family Caregiver's Guide to Hospital Discharge Planning." To download a copy of this brochure, go to [www.caregiving.org/pubs/brochures.htm](http://www.caregiving.org/pubs/brochures.htm).

**National Family Caregivers Association** – NFCA's tip sheets and how-to guides help family caregivers deal with the emotional and practical sides of caregiving. Brochures such as "Improving Doctor/Caregiver Communications" and "When Your Loved One Is Hospitalized" can be downloaded for free. In addition, NFCA's Communicating Effectively curriculum contains many helpful checklists, from how to communicate your loved one's symptoms in a crisis to preventing medication mishaps. These guides are also available for free. Go to [www.thefamilycaregiver.org/caregiving\\_resources/tips\\_and\\_tools.cfm](http://www.thefamilycaregiver.org/caregiving_resources/tips_and_tools.cfm).

**National Transitions of Care Coalition** – The National Transitions of Care Coalition (NTOCC) was founded by leading healthcare industry organizations to solve transitional care issues. NTOCC is chaired and coordinated by the Case Management Society of America in partnership with sanofi-aventis U.S. LLC. The organization has developed information to help patients and their caregivers better understand issues associated with transitioning from one healthcare setting to another and tools to help consumers as they navigate transitions. To access these consumer tools, go to [www.ntocc.org/Home/Consumers/WWS\\_C\\_Tools.aspx](http://www.ntocc.org/Home/Consumers/WWS_C_Tools.aspx).

**Next Step in Care** – The United Hospital Fund Next Step in Care Web site offers a range of guides and checklists designed to make patients' transitions between care settings smoother and safer. Next Step in Care aims to help family caregivers better manage transitions in care. Its tools can guide family caregivers in determining what

issues to consider, how to seek assistance, how to manage medications, and how to better communicate with physicians and other healthcare professionals. The guides can also help providers and family caregivers assess how well prepared the family caregiver is; what training and support, if any, he or she may need; and what tasks the caregiver cannot manage alone. These tools and checklists are available in English and Spanish and can be downloaded for free at [www.nextstepincare.org](http://www.nextstepincare.org).

**Partnership for Clear Health Communication at the National Patient Safety Foundation** – The Partnership for Clear Health Communication at the National Patient Safety Foundation promotes the Ask Me 3 program. The program is designed around the fact that communication breakdowns are the leading source of medical errors. Ask Me 3 advocates three simple but essential questions that patients should ask their providers in every healthcare interaction: What is my main problem? What do I need to do? Why is it important for me to do this? To learn more, go to [www.npsf.org/askme3/for\\_patients.php](http://www.npsf.org/askme3/for_patients.php).

### Finding Quality Care If Your Loved One Isn't Going Straight Home

If your loved one needs to be transferred from the hospital to another healthcare facility, make sure you do your homework so that you pick the facility that is right for your family. The hospital's discharge planner or social worker can provide a list of area facilities, but it will be up to you to decide which one you want to use. The following resources may help you narrow your search:

**Eldercare Locator** – The Eldercare Locator, a public service of the U.S. Administration on Aging, is your first step for finding local agencies that can help older persons and their families access home and community-based services like transportation, meals, home care, and caregiver support services. Go to [www.eldercare.gov](http://www.eldercare.gov) or call 800/677-1116.

**Nursing Home Compare** – Nursing Home Compare has detailed information about every Medicare- and Medicaid-certified nursing home in the country. You can also find information on other long-term care choices like community-based services, home care, or assisted living. Go to [www.medicare.gov/nhcompare](http://www.medicare.gov/nhcompare).

**SNAPforSeniors** – SNAPforSeniors offers a free online resource intended to empower users by providing them with the information and tools necessary to make informed decisions about senior housing. Go to [www.snapforseniors.com](http://www.snapforseniors.com).

# SpeakUp!

## National Family Caregivers Month

### Planning Ahead for National Family Caregivers Month 2009

This November, NFCA will once again coordinate National Family Caregivers Month, a time to thank, support, educate and empower family caregivers. As part of this year's celebration, NFCA will host our **2nd national Teleclass/webinar on Thursday, November 12**, for family caregivers across the country. This FREE one-hour session, entitled "**Safe & Sound: How to Prevent Medication Mishaps**," will be conducted via phone and Web. Stay tuned for more information and instructions on how you can register.

We are proud to announce that the following organizations have signed on as endorsers of National Family Caregivers Month 2009 and will be sharing and promoting information about NFC Month through their Web sites and outreach materials.

#### **Thank you to our 2009 endorsers (to date):**

Alzheimer's Association  
Alzheimer's Foundation of America  
American Academy of Nurse Practitioners  
American Academy of Physician Assistants  
American Association for Geriatric Psychiatry  
American Pain Foundation  
Amputee Coalition of America  
Association of Professional Chaplains  
Catholic Health Association of the United States  
Christopher & Dana Reeve Foundation  
Consumers Advancing Patient Safety  
DMAA: The Care Continuum Alliance  
Mental Health Foundation  
National Alliance for Caregiving  
National Association for Continence

National Association for Home Care & Hospice  
National Council on Aging  
National Health Council  
National Hospice and Palliative Care Organization  
National Multiple Sclerosis Society  
National Patient Safety Foundation  
National Respite Coalition  
Pain Connection-Chronic Pain Outreach Center, Inc.  
Pediatric / Adolescent Gastroesophageal Reflux Association  
Transverse Myelitis Association  
United Cerebral Palsy  
WE MOVE

If your organization wants to join the ever-growing list of NFC Month endorsers for 2009, please contact [Deborah.halpern@thefamilycaregiver.org](mailto:Deborah.halpern@thefamilycaregiver.org).

**For more information on NFC Month, please visit:  
[www.thefamilycaregiver.org/national\\_family\\_caregiver\\_month](http://www.thefamilycaregiver.org/national_family_caregiver_month).**

## NFCA's Michigan CCANers Participate in Town Hall Meeting

The National Family Caregivers Association and Congressman John Dingell (D-MI) joined forces on May 28 to host a town hall meeting in support of family caregivers and their loved ones and the need for healthcare reform. With the help of NFCA's Michigan-based Caregiver Community Action Network (CCAN) volunteers, NFCA arranged for two family caregivers to share with Congressman Dingell their experiences with the healthcare system, including the financial hardships they have encountered as a result of their caregiving. NFCA board member and CCAN director Linda Jones moderated the town hall meeting, which was attended by more than 50 people.

Pam McComb, a family caregiver from Ann Arbor, Michigan, shared her struggle to get medical services for her father, who has Alzheimer's



Participants in the Michigan town hall meeting included (left to right) Sallie Justice, Jane Cortez, Carolyn Anderson, Joanne Cruz, Egen Bonanni, Congressman John Dingell, Jennifer Kirkland, Patty Sampson, Deborah Halpern and Linda Jones.

disease. McComb said that even though her father has good private coverage as a Ford Motor Co. retiree, the paperwork involved in getting help for his increasing needs under a fragmented, uncoordinated healthcare system is a nightmare. "All of the agencies that provide

assistance should be coordinated," she said. Congressman Dingell assured the family caregivers in the audience that he would take their concerns back to Washington, D.C., where his office is working on drafting healthcare reform legislation. ■



**If you were hurt and couldn't speak, who would help your loved one?**

Everyone... if you were wearing ID jewelry designed for family caregivers like you.

NFCA is partnering with American Medical ID to create ID bracelets, pendants and dog tags that clearly alert people to the fact that you have a loved one who needs help.

**Mention NFCA & get a 10% discount off your purchase.**

(Deeper discounts on multiple purchases.) With each purchase, NFCA will benefit, too, by receiving a 10% donation from AMID.

Don't wait. Buy your specially designed ID jewelry today.



800/363-5985 or  
[www.IdentifyYourself.com/nfca](http://www.IdentifyYourself.com/nfca)  
 (use NFCA as the code when prompted)



National Family Caregivers Association  
 is very pleased to have



as its Founding Corporate Partner  
 for 2009.

In addition to collaborating with the NFCA on policy issues to drive healthcare reform, Intel is working to design products that can help improve care for people with chronic conditions and enhance well-being for them and their family caregivers.

## *Nailing Jell-O® to the Wall*

By Rose M. Trosper, 2008

There are just some things in life a person cannot do.  
Things like stopping the aging process, reversing a disease  
once it begins, cheating death, never experiencing sad-  
ness, keeping our children three years old forever, and  
nailing Jell-O to the wall.

I often ponder these and other impossible concepts when  
working with family caregivers.

It would seem that, for most, every day is an endless  
stream of impossible tasks, and futures that are uncer-  
tain, lives hanging in the balance, and enormous stress.

Why is it that once illness or disability moves in, friends  
and most family members move out and become a  
faint memory?

Is illness contagious? Does a disability jump from one  
person to another?

Do we stop being a friend or is it that we simply cease  
being a relative once we are no longer young, healthy  
and productive? Do we age quicker ourselves by the  
company we keep?

While this is certainly not true in every case, it is more  
accurate than most of us are comfortable acknow-  
ledging.

Elderly parents make excuses for grown children.

Grown children make excuses for elderly parents.

The sadness of a loved one growing older with the  
arrival of a disease or illness proves to be too much  
for many and causes us to seek that safe place called  
denial.

It is a vicious cycle and, in the end, no one ever wins.

If only the world existed to fully include our aging  
loved ones.

Society seems to deem those with youth and perfect  
health as those who are most deserving.

What about those who have vast stores of knowledge,  
not to mention marvelous memories, untold compas-  
sion, kindness, and great wisdom?

Is aging, illness or disability the prerequisite for being a  
person with no value?

No, we cannot stop the aging process or reverse a disease  
once it begins.

We cannot cheat death and we will, without a doubt,  
experience sadness many times over.

We cannot keep our children three years old no matter  
how hard we try.

But, maybe we are the generation who can nail Jell-O to  
the wall.

Maybe we are the caregivers who can begin to make an  
incredible difference.

If so, we are the ones who will make no excuses and will  
not accept any.

We will be the ones who will remain steadfast, loyal and  
unafraid.

We will be the ones who cherish and respect those lives  
once lived and all their many achievements.

We will be the ones who learn from decades of life's  
valuable lessons and the wisdom that is the end result.

Among all those impossible things that we might never  
accomplish in this world, we can be successful in  
doing what is really important.

That is, showing dignity, honor, and respect to our aging  
loved ones.

Not just for a day, but each and every day of their lives.

As caregivers, we can truly share with our aging and  
ailing loved ones the autumn of their lives.

We can be grateful for the time we have and the  
memories we share.

But, most important of all, we have the opportunity to  
make new memories that will sustain us.

Their past is their legacy, and the future is our legacy.

The time is now and the responsibility is ours.

We must show those whose time is yet to come how to  
be strong, how to give back, how to make a difference  
that is real, and, during that process, they just might  
learn how to nail Jell-O to the wall.

JELL-O® is a registered trademark of Kraft Foods Holdings, Inc.



*What Can I Do?* is a question and answer column aimed at helping to meet the needs of individual readers.

Answers to questions in this issue were provided by Barry Jacobs, PsyD, Director of Behavioral Sciences for the Crozer-Keystone Family Practice Residency Program of Springfield, PA.

Dr. Jacobs is a clinical psychologist who specializes in family caregiving issues. His first book, *The Emotional Survival Guide for Caregivers — Looking After Yourself and Your Family While Helping an Aging Parent*, was published in June 2006 by Guilford Publications. Go to [www.emotionalsurvivalguide.com](http://www.emotionalsurvivalguide.com) to learn more.

If you have a question you would like us to answer, please send it to:

What Can I Do?  
c/o TAKE CARE!  
10400 Connecticut Ave., Suite 500  
Kensington, MD 20895-3944  
e-mail: [info@thefamilycaregiver.org](mailto:info@thefamilycaregiver.org)  
Subject Line: What Can I Do?

**Q** I am 36 years old and the caregiver for my husband, who is 40. We've been married for 13 years, 10 of which have been consumed with one illness or another. It started out with a back injury when a cage had to be placed in his lower back. It was very stressful and crippled us financially. We got through that but then he became a diabetic with hypertension, high cholesterol, and many other issues. We were never able to get the diabetes under control. He then suffered a mild heart attack and had to quit work, at which time we moved closer to family. Unfortunately, we received no support. We decided that he should have gastric bypass surgery for health reasons. After he had the surgery, though, he became an alcoholic. No one told us this is very common with gastric surgery patients, especially when they lose too much weight too fast. This has pushed me farther and farther away from him, although I love him very much. Thank goodness I have my faith and a good job. I am feeling very tired and too young to be dealing with this much illness. I often wonder if he will ever be able to take care of me. Our intimacy has dwindled to just about nothing. I do go to Al-Anon and my kids go to Alateen. He is not actively drinking now but the personality and behaviors are still there. We just don't seem to communicate well. He is going in for another back surgery this month and I just don't know if I have it in me to deal with taking care of him. I don't like feeling this way but between work, kids, and him, I feel all used up. I don't feel I can say anything positive about my situation at the moment. He needs someone to talk to and I need time alone, peace, and a spouse who is not so sick. What can I do?

**A** Sometimes, illness brings spouses closer together. More often, it gradually undermines the love and intimacy in a relationship. Occasionally, it leads to disaffection and divorce. What accounts for these different outcomes? Certainly, the kind of marriage a couple had before illness occurred matters greatly; the stronger the historical bond was, the stronger the caregiving connection generally is. The nature of the illness also has its impact; the more severely disabling and chronic the medical condition, the greater the strain on the relationship. Other key factors include the proportion of positive versus negative interactions that occur between spouses and their capacity for maintaining mutual positive regard for one another, despite all adversities that arise.

Reflecting on some of these factors in terms of your marriage makes me greatly concerned. I don't know about the quality of your relationship early on, but your husband became disabled only three years after your wedding vows. His conditions have been longstanding, have negated his breadwinning capacity, and have been (in part) self-inflicted. When you say that he still acts like he's an alcoholic even though he is currently sober, it leads me to believe that he is often irritable and angry and that he doesn't treat you as well as you'd like. I therefore assume that the negative interactions between you outnumber the positive and that mutual positive regard was long ago replaced by emotional distance with periodic expressions of contempt.

None of this bodes well. There doesn't seem to me to be enough of the good stuff of marriage to easily

*(Continued on page 14)*

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## What Can I Do?

*Continued from page 13*

justify the many sacrifices you make. Unless you have an especially high tolerance for dissatisfaction, I strongly recommend you take steps to improve your marriage. Your husband's continued disability doesn't necessarily mean that the future of your relationship is hopeless. What's crucial is improving the quality of your interactions and the degree of connection between you, regardless of whether he is ailing or not. To that end, I'd suggest finding ways for him to contribute more significantly to the good of the marriage and family, as well as seeking means for the two of you to have more fun together. I also believe that you need marital therapy, with a pastoral counselor, perhaps, since you have a strong faith, but certainly with someone who understands the potentially deleterious effect of illness on relationships. It will take great effort with the right guidance to make your relationship the kind of winning partnership that lasts.

**Q** My father, who has Alzheimer's and diabetes, lives with his wife in Hawaii. He is in his 90s and she's in her late 70s. She is well-intentioned and caring, but not well-informed, and is in poor health herself. She is reluctant to have anyone else in their home, except my sister, who works full time and also cares for my disabled brother. There are no other relatives who live there. My sister goes to his apartment three times per week (it's a long drive) to bathe him, bring diapers, etc.

We are concerned about my father's safety. His wife put away his walker because she thinks it will weaken his muscles to use it, but he is frail and unsteady. She leaves him alone frequently for short trips, but he does not know how to use the

telephone. She and my sister and I have a good relationship, but my sister hasn't been able to impress upon her the importance of taking care of our father's needs, including making sure he gets to the doctor, gets out of bed, etc.

I am trying to do what I can to help my sister but I live very far away. We think that if we could get our stepmother to meet with someone skilled in helping caregivers make decisions, she might be willing to consider other options (e.g., home healthcare, a nursing home, even a part-time companion) so that she and my sister can get the help they need to ensure that my father is well cared for. But we don't know how to research our options and we don't know how best to present this to our stepmother. What can we do?

**A** Researching options for caregiving support services is the easy part. Go to the U.S. Administration on Aging's Eldercare Locator ([www.eldercare.gov](http://www.eldercare.gov)) and type in the zip code for your father's community. That will immediately bring you to a screen for his Area Agency on Aging, the local branch of the Department of Aging in his area, with contact information (phone numbers and Web site links) and a description of that outfit's range of services. This is the most expedient way of finding community-based resources for older Americans, including senior centers, home health companions, adult day-care programs, caregiver support groups, etc.

Presenting such resources to your stepmother is, of course, much harder. While it sounds necessary to convince her to accept greater help for your father, pressure tactics or a major confrontation may prove counterproductive. I recommend treading lightly and going slowly in your approach to her. In the best-case scenario, she will embrace greater support for him — and herself as well. In the worst-case scenario, she will feel irked that you are

questioning her judgment and intruding upon their life together.

Rather than sounding alarms about your father's lack of adequate supervision, I'd suggest inquiring in a caring way about her well-being. Tell her you know that your father's Alzheimer's dementia makes him a handful to care for and that she has been doing yeoman's work. But share your concern that his illness is a progressive one and that the toll upon her of caring for him will be cumulative. Ask her what she is already doing and what steps she's contemplating to take care of herself in order to be able to care for him as effectively as possible. Only then would I bring up available services they could utilize — not as a way of removing him from her control but of enhancing her ability to continue being his devoted wife and caregiver. Offer her only two or three services to consider. If she accepts any one of them, you'll know that your conversation has been successful. If she asks for more time to think about them, tell her you'll patiently look forward to hearing her thoughts. If she rejects outright all offers for services, tell her that you understand her perspective but, out of genuine concern for her, you'll feel it is your duty to continue to raise the issue in the future. In other words, be a pest but a charming and respectful one.

While you may have some influence with your stepmother, your sister is likely to have far more. I'd advise her to pursue the same kind of polite but persistent conversation with your stepmother. If your sister should suddenly decide that providing hands-on care for your father three times a week is too onerous, then your stepmother will probably take offers for outside services much more seriously. Until then, your stepmother may feel she can comfortably balk at even considering allowing outsiders into her home, knowing that your sister is scheduled to ride to the rescue at their house within the next day or two. ■

# Speak Up to Congress This Summer

*RIGHT NOW* the U.S. Senate and the House of Representatives are working on healthcare reform legislation. NFCA urges you to keep abreast of what's happening and to contact your legislators.



You can follow the debate in the newspaper, online, and by listening to actual presentations on the floor of Congress on C-SPAN (via your computer at [www.c-span.com](http://www.c-span.com) or check your local TV listings).

**NFCA's major efforts** regarding healthcare reform are focused on the following:

- Gaining recognition for the role of family caregivers in healthcare and providing family caregivers with the education and support we all need.
- Ensuring that comprehensive care coordination across providers and settings is a fundamental part of reform.

There are, of course, many other important issues in healthcare reform and thorny questions to answer, including how to provide universal coverage, how to pay for reforms, etc. But NFCA believes that if we can accomplish the goals above (which in principle are not controversial), family caregivers and our loved ones will have more control over our lives, will receive higher quality and safer care, will experience less stress, and will see lower healthcare costs.

**Now is the time to SPEAK UP** for a better future for all family caregivers and our loved ones. Contact information for your senators and representatives can be found at [www.house.gov](http://www.house.gov) and [www.senate.gov](http://www.senate.gov).

When speaking with your elected officials:

- Tell them your story and the importance of making healthcare patient- and family-centered.
- Tell them that providing comprehensive and well-coordinated care across all settings for those living with chronic illnesses and disabilities will improve quality and safety and reduce costs to the system overall.

The following Kaiser Family Foundation Web sites provide highly reputable and nonpartisan information about the healthcare reform debate. Go to:

[www.kaiserfamilyfoundation.org](http://www.kaiserfamilyfoundation.org)  
[www.kff.org/pullingittogether/022108\\_altman.cfm](http://www.kff.org/pullingittogether/022108_altman.cfm)  
[www.kaiserhealthnews.org/Daily-Reports/2009/June/03/Cost-Cutting.aspx](http://www.kaiserhealthnews.org/Daily-Reports/2009/June/03/Cost-Cutting.aspx)



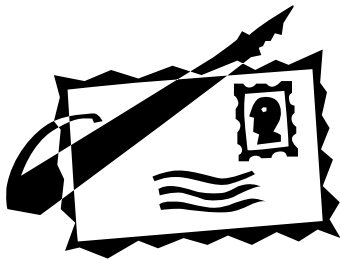
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**U.S. Family Caregiver Postage Stamp Campaign  
Initiated by NFCA's Caregiver Community  
Action Network**

Thanks to the hard work of NFCA's Caregiver Community Action Network (CCAN) state volunteers, a U.S. family caregiver postage stamp is now officially "under consideration" by the Citizens' Stamp Advisory Committee of the U.S. Postal Service. This remarkable effort was undertaken to honor this country's approximately 50 million family caregivers.

If you haven't already signed a letter of support, now is the time to add your name to this growing movement. Visit NFCA's Web site at [www.thefamilycaregiver.org](http://www.thefamilycaregiver.org) and click on the U.S. Postage Stamp button under "Events and Announcements" on our home page to sign an online petition or to submit an individual letter to the Citizens' Stamp Advisory Committee. Every signature helps!