

TAKE CARE!

Self-Care
for the Family
Caregiver™

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Speak Up: Protect Your Loved One During Transitions in Care

Sandy Padwo Rogers

It's a situation no family caregiver wants to think about: Your loved one suffers an exacerbation of his or her condition or a new health crisis and ends up in the hospital. All of a sudden, your carefully balanced lives get turned upside down as you find yourself navigating a stressful and confusing healthcare system while preparing for the possibility of even more intensive caregiving. What you may not realize is that the minute your loved one enters the hospital, you already need to be planning for his or her transition home.

According to the Colorado-based Care Transitions Program, "the term 'care transitions' refers to the movement patients make between healthcare practitioners and settings as their condition and care needs change during the course of a chronic or acute illness." This includes everything from transferring between hospital floors to a discharge from the hospital back home. While it's typically the patient's return home that can be the most stressful time for the family caregiver, it's necessary to be vigilant at every stage of care, even during a change of shift at the nurses' station.

What can go wrong during a transition in care? The reality is, many things. "When any transfer occurs, even from one hospital floor to another, the plan of care should be

transferred as well," says Dr. Patricia Tomsko Nay, medical director for the Office of Health Care Quality, Maryland Department of Health and Mental Hygiene. "Unfortunately, even if all pertinent information makes its way into the patient's chart, it may still be missed by the new members of the healthcare team. The family caregiver needs to question anything that doesn't make sense because there's always the possibility that instructions were missed or never communicated. The family caregiver must be proactive." Dr. Eric Coleman, director of the Care Transitions Program, agrees. "Family caregivers need to understand that healthcare is very reactive," says Dr. Coleman. "That means that they need to be active participants in the team — to know what to say and who to say it to. Don't assume anyone is in charge. Chances are you are the only one asking these questions."

Planning for Discharge

"Ten years ago when we began to examine what was going wrong when patients transitioned back home, we found that the family caregiver wasn't prepared — technically, emotionally or financially," says Carol Levine, director of the Families and Health Care Project for United Hospital Fund. "Since then there's been a lot of emphasis placed on provider-to-provider coordination but another core problem

we discovered is that the family caregiver was not being consulted on or properly prepared for what was in store in terms of providing care. People are moving around the system far more quickly today than ever before. The transition process is a much more rapid one."

Both Drs. Coleman and Nay stress that the discharge planning process really must begin at the time of admission. "With high staff turnover

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Experienced Caregivers*

Fifteen Years and Counting

Suzanne Mintz

It's hard to believe that 15 years have passed since Cindy Fowler and I began the National Family Caregivers Association. Back in 1993, most people were unfamiliar with the term "family caregiver." They didn't understand what we did and why it was so difficult. Cindy and I had to explain to people why we started NFCA and what and who a family caregiver is. That's not the case anymore. Today, it's hard to find a person who hasn't heard about family caregiving or doesn't know someone who is providing care.

Anniversaries are always a time for looking back as well as forward, and we've been doing both at NFCA. We've put together a short list of what we consider to be our most important accomplishments and a statement of what we hope to achieve in the future. Thank you for helping us become the responsive, relevant organization we are today, and for the opportunity to help you along the way. We hope you will continue to help us achieve our goals and that you will share NFCA's message and resources with all the current and future caregivers you know.

What We Are Most Proud Of

Family Caregiving Has Been Defined

- When NFCA began, family caregiving was viewed solely as an aging issue. For NFCA, it has always been an issue that transcends the lifespan, encompassing families with a special needs child, a soldier son or daughter disabled by war, a young couple dealing with a diagnosis of MS, or siblings caring for their mother with Alzheimer's disease.

- Today, patient advocacy groups, the government, and the media recognize family caregiving for what it is. NFCA has helped open America's eyes to the true reality of what it means to be a family caregiver.

Change Is Happening

- Through articles, presentations, media interviews, and testimony before public officials, NFCA has helped family caregivers begin to identify themselves as part of a large minority whose personal story is echoed in households across the country.
- National Family Caregivers Month, which NFCA developed into part of our national culture, inspires national, state and local proclamations; media attention; and educational programs in local communities.
- Legislation such as the National Family Caregiver Support Program and the Lifespan Respite Care Act has been enacted.
- States are taking action to provide services to family caregivers.
- Corporate America is investing in programs to support employees who are family caregivers.
- The media now regularly publish stories about caregiving families and the need for systemic change to improve their health and well-being.

Family Caregivers Are No Longer Alone

- NFCA has made great strides in helping family caregivers recognize that they are part of a 50 million person minority; in that process of recognition, they have become empowered to act on behalf of themselves and their loved ones.

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The National Family Caregivers Association understands the importance of the upcoming presidential election on the future of healthcare in this country. With this in mind, we want our members to be aware of the candidates' healthcare proposals. Thanks to the Kaiser Family Foundation, we are pleased to present this valuable comparison tool for your consideration. Remember, there's no better time to make your voice count than during a national election.

2008 Presidential Candidate Health Care Proposals: Side-by-Side Summary

This side-by-side comparison of the candidates' positions on health care was prepared by the Kaiser Family Foundation with the assistance of Health Policy Alternatives, Inc. and is based on information appearing on the candidates' Web sites as supplemented by information from candidate speeches, the campaign debates and news reports. The sources of information are identified for each candidate's summary (with links to the Internet). The comparison highlights information on the candidates' positions related to access to health care coverage, cost containment, improving the quality of care and financing. Information will be updated regularly as the campaign unfolds. Check www.health08.org for updates.



health08.org
Election news, analysis and events

	John McCain	Barack Obama
Party Affiliation	Republican	Democrat
Stated goal	<ul style="list-style-type: none"> • Provide access to affordable health care for all by paying only for quality health care, having insurance choices that are diverse and responsive to individual needs, and encouraging personal responsibility. 	<ul style="list-style-type: none"> • Affordable and high-quality universal coverage through mix of private and expanded public insurance.
Date plan announced	<ul style="list-style-type: none"> • October 11, 2007 	<ul style="list-style-type: none"> • May 29, 2007
Overall approach to expanding access to coverage	<ul style="list-style-type: none"> • Remove the favorable tax treatment of employer-sponsored insurance and provide a tax credit to all individuals and families to increase incentives for insurance coverage; promote insurance competition; and contain costs through payment changes to providers, tort reform and other measures. 	<ul style="list-style-type: none"> • Require all children to have health insurance, and employers to offer employee health benefits or contribute to the cost of the new public program. Create a new public plan, and expand Medicaid and SCHIP. Create the National Health Insurance Exchange through which small businesses and individuals without access to other public programs or employer-based coverage could enroll in the new public plan or in approved private plans.
A. Requirement to obtain or offer coverage	<ul style="list-style-type: none"> • No provision. Opposes mandates for coverage. 	<ul style="list-style-type: none"> • Require all children to have health insurance. • Require employers to offer "meaningful" coverage or contribute a percentage of payroll toward the costs of the public plan; small businesses will be exempt from this requirement.
B. Expansion of public programs	<ul style="list-style-type: none"> • Give veterans ability to use their VA benefits to pay for timely high quality care from providers in the best locations. 	<ul style="list-style-type: none"> • Expand Medicaid and SCHIP. • Create a new public plan so that small businesses and individuals without access to other public programs or employer-based coverage could purchase insurance. Plan coverage would offer comprehensive benefits similar to those available through FEHBP. • Coverage under the new public plan would be portable.
C. Premium subsidies to individuals	<ul style="list-style-type: none"> • Provide a refundable tax credit of up to \$2,500 (individuals) and \$5,000 (families) to all individuals and families for the purchase of insurance. • Provide income-related premium subsidies, in addition to the tax credit, to individuals enrolled in the Guaranteed Access Plan (see item "F"). 	<ul style="list-style-type: none"> • Make federal income-related subsidies available to help individuals buy the new public plan or other qualified insurance.

(Continued on page 4)

John McCain

Barack Obama

D. Premium subsidies to employers	<ul style="list-style-type: none"> • No provision. 	<ul style="list-style-type: none"> • Provide small businesses with a refundable tax credit of up to 50 percent of premiums paid on behalf of their employees if employer pays a "meaningful share" of the cost of "a quality health plan." • Provide federal subsidies to partially reimburse employers for their catastrophic health care costs if the employers guaranteed that premium savings would be used to reduce employee premiums.
E. Tax changes related to health insurance	<ul style="list-style-type: none"> • Reform the tax code to eliminate the exclusion of the value of health insurance plans offered by employers from workers' taxable income. • Allow individuals owning "innovative multi-year policies" that cost less than the tax credit to deposit the excess into expanded HSAs. 	<ul style="list-style-type: none"> • No provision.
F. Creation of insurance pooling mechanisms	<ul style="list-style-type: none"> • Work with states to create a federally-supported Guaranteed Access Plan for people who are denied coverage due to pre-existing conditions. Premiums in the plan would be limited and financial assistance given to those below a certain income level. 	<ul style="list-style-type: none"> • Create a National Health Insurance Exchange through which individuals could purchase the public plan or qualified private insurance plans. • Require participating insurers to: offer coverage on a guaranteed issue basis; charge a fair and stable premium that is not rated on the basis of health status; and meet standards for quality and efficiency. • Require plans of participating insurers to offer coverage at least as generous as the new public plan. • Exchange would evaluate plans and make differences among them transparent.
G. Changes to private insurance	<ul style="list-style-type: none"> • Promote competition and individual choice of insurance by allowing insurance to be sold across state lines. • Encourage innovative multi-year insurance products. 	<ul style="list-style-type: none"> • Prohibit insurers from denying coverage based on pre-existing conditions. • Children up to age 25 could continue family coverage through their parents' plan. • In market areas where there is not enough competition, require insurers to pay out a "reasonable share" of premiums on patient care benefits. • Prevent insurers from abusing monopoly power through unjustified price increases. • Require health plans to disclose the percentage of their premiums that actually goes to paying for patient care as opposed to administrative costs.
H. State flexibility	<ul style="list-style-type: none"> • Give states flexibility and encouragement to experiment with: <ul style="list-style-type: none"> - Use of private insurance and per episode payments under Medicaid; - Alternative forms of access, insurance policies and providers and different licensing schemes for providers. 	<ul style="list-style-type: none"> • Maintain existing state health reform plans if they meet minimum standards of the national plan.
Cost containment	<ul style="list-style-type: none"> • Adopt malpractice reforms that limit frivolous lawsuits and excessive damages and provide safe harbors for practice within clinical guidelines and safety protocols. • Promote competition among providers by paying them only for quality and promote use of alternative providers (e.g., nurse practitioners) and treatment settings (e.g., walk-in clinics in retail outlets). 	<ul style="list-style-type: none"> • Invest \$50 billion toward adoption of electronic medical records and other health information technology. • Promote insurer competition through the National Health Insurance Exchange and by regulating the portion of health plan premiums that must be paid out in benefits.

AN ELECTION OVERVIEW

John McCain

Barack Obama

Cost containment (continued)

- Invest in prevention and care of chronic illnesses.
- Increase competition and reduce administrative overhead costs of private insurance by permitting sale of nationwide insurance (i.e., not regulated by the states).
- Require drug companies to reveal the price of their drugs; allow re-importation of drugs; and encourage faster introduction of generics and biologics.
- Provide consumers with more information on treatment options and require provider transparency regarding medical outcomes.

- Improve prevention and management of chronic conditions.
- Initiate policies to promote generic drugs, allow drug re-importation, and repeal the ban on direct price negotiation between Medicare and drug companies.
- Pay Medicare Advantage plans the same as regular (traditional) Medicare.
- Require hospitals and providers to publicly report measures of health care costs and quality.
- Promote and strengthen public health and prevention.
- Reform medical malpractice while preserving patient rights by strengthening antitrust laws and promoting new models for addressing physician errors.

Improving quality/health system performance

- Change provider payment to encourage coordinated care (e.g., pay a single bill for high quality heart care rather than individual services).
- Provide Medicare and Medicaid payments for diagnosis, prevention, and care coordination and bar payments for preventable medical errors or mismanagement.
- Require transparency by providers with regard to medical outcomes, quality of care, costs, and prices.
- Establish national standards for measuring and recording treatments and outcomes and use technology to share information on "best practices."
- Promote deployment of HIT to improve chronic disease care and to allow doctors to practice across state lines.
- Where cost effective, employ telemedicine and clinics in rural and underserved areas.

- Support an independent institute to guide comparative effectiveness reviews and required reporting of preventable errors and other patient safety efforts.
- Reward provider performance through the National Health Insurance Exchange and other public programs.
- Address health disparities, promote preventive care and chronic disease management, and require quality and price transparency from providers and health plans.
- Require health plans to collect, analyze and report health care quality for disparity populations, and hold plans accountable.
- Reform medical malpractice while preserving patient rights by strengthening antitrust laws and promoting new models for addressing physician errors.

Other investments

- Support federal research related to science-based care and cure of chronic disease.
- Promote education of children about health, nutrition, and exercise.
- Support public health initiatives to stem obesity and diabetes and deter smoking.

- Expand funding to improve the primary care provider and public health practitioner workforce, including loan repayments, improved reimbursement, and training grants.
- Support preventive health strategies including initiatives in the workplace, schools, and communities.
- Support strategies to improve the public health infrastructure and disaster preparedness at the state and local level.

Financing

- Not yet specified although indicates that cost containment measures would make insurance more affordable.

- Campaign estimates cost to be between \$50 to \$65 billion a year when fully phased in. Expects much of the financing to come from savings within the health care system. Additional revenue to come from discontinuing tax cuts for those with incomes over \$250,000.

Candidate

John McCain
Barack Obama

Source

<http://www.johnmccain.com/Informing/Issues/19ba2f1c-c03f-4ac2-8cd5-5cf2edb527cf.htm> - May 19, 2008
<http://www.barackobama.com/issues/healthcare> - July 21, 2008
<http://www.health08.org/candidates/obama.cfm> - September 5, 2007
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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.

Do you need help paying for prescription medications? Novartis has a new program aimed at helping patients pay for the medications they need. Patient Assistance Now is a comprehensive resource designed to provide patients easier access to the medicines and information they need to manage their health. The program provides information on how to access prescription assistance from Novartis as well as other companies. It also contains links to disease- and condition-specific information, clinical trials, and more. Go to www.PatientAssistanceNow.com or call toll free 800/245-5356.

AstraZeneca has announced a modification to its patient assistance programs Web site, AZandMe.com. The Web site now has a more direct link to the information that is important to consumers, including: an overview of the AZ&Me™ Prescription Savings programs; an eligibility screener that will identify which program is best for you; and an online application tool program aimed at those without insurance and those with Medicare Part D. Go to www.AZandMe.com or call 800/292-6363.

Are you looking for disability information? DisabilityInfo.gov is an award-winning federal government Web site designed to provide people with disabilities access to the information they need quickly and easily. The site links to disability-related programs and services from numerous government agencies and is a one-stop shop for those with disabilities who wish to participate fully in the workforce and in their communities. The site connects users to information and resources on a wide range of disability-related topics, such as: benefits, civil rights, community life, education, employment, health, housing, technology and transportation. The site includes a state and local re-

sources map, making it easy to locate disability-related information in specific areas. For more information, visit www.disabilityinfo.gov.

Are you over 50? The Agency for Healthcare Research & Quality (AHRQ) has released healthcare checklists for men and women age 50 and over, with recommendations on screening tests, prevention medicine, and healthy lifestyle behaviors. The checklists are founded in evidence-based recommendations from the U.S. Preventive Services Task Force. Family caregivers may want to use these checklists to ensure that they are addressing all the necessary healthcare issues for their loved ones as well as themselves. The women's checklist can be found at www.ahrq.gov/ppip/women50.htm. The men's checklist is at www.ahrq.gov/ppip/men50.htm.

Are you caring for a senior with transportation needs? The National Center on Senior Transportation (NCST) has a Web site aimed at providing extensive resources toward the advancement of transportation options for older adults who wish to live more independently within their communities. The Web site has a special section for older adults and their caregivers that provides information and free resources, including directories of transportation-related services, information about safe driving, and more.

The National Center on Senior Transportation (NCST) is funded through a cooperative agreement with the U.S. Department of Transportation, Federal Transit Administration. NCST is administered by Easter Seals Inc., in partnership with the National Association of Area Agencies on Aging (n4a). To learn more, go to www.seniortransportation.net and click on "For Older Adults and Caregivers."



BOOK REVIEW

An Uncertain Inheritance: Writers on Caring for Family edited by Nell Casey (William Morrow/an Imprint of HarperCollins Publishers, 2007, \$24.95).

Family caregivers are often at a loss for words when asked to explain how we *really* feel.

"How do you do it?" is often the question of well-meaning friends. Next time you're asked, hand them *An Uncertain Inheritance* and they may get an idea. But *you* read it first. Nell Casey has compiled 19 essays by 19 different writers telling 19 unflinchingly real stories of family caregiving. This is family caregiving laid bare, with each writer's heart and soul exposed. We all go through tough times. We feel guilty. We think we're the only ones who feel this way and we rarely talk about it. But the writers in this book are brave enough to do just that. And that fact alone can take a weight off of our collective shoulders. That's not to say that this book is one long diatribe on the stresses of family caregiving — not at all. It's a collection of heartfelt, very personal stories that cover the gamut of the family caregiving experience — from caring for a spouse or parent at home to long-distance caregiving. The experiences related in this book show us that we're never the same as when we entered the family caregiving world; but we can survive and come out on the other side, transformed and with hope. Give this book to your friends so they can understand. Read it yourself so you can feel connected.

An Uncertain Inheritance: Writers on Caring for Family is available wherever books are sold, by calling 212/207-7000, or at www.harpercollins.com.

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

Fifteen Years

Continued from page 2

- NFCA helps thousands of family caregivers every day through various means:
 - 35,000 family caregivers read TAKE CARE! each quarter.
 - 11,000 family caregivers read NFCA's monthly e-letter.
 - 400 family caregivers call the help line each month.
 - More and more caregivers visit NFCA's Web site, www.thefamily-caregiver.org, each month. August was our busiest month ever, with 87,188 visitors, almost a third of them exploring the site for the first time.
 - There are Caregiver Community Action Network (CCAN) volunteers in 37 states plus Puerto Rico.

What We Plan to Achieve in the Next 15 Years

Educate Family Caregivers

- NFCA will build on its existing educational programs and add others to create a virtual Family Caregiver University, where family caregivers can develop skills and

knowledge in healthcare communication, financial management, decision-making, and more. NFCA's educational programs will be available in multiple formats for access by all.

Grow Caregiver Communities

- NFCA will develop a broad-based, interconnected network of caregiver communities nationwide:
 - CCAN, currently numbering nearly 100 volunteers, will grow exponentially to become a significant, active grass-roots movement.
 - Geographically specific e-communities, currently in a pilot phase, will thrive in big cities, small towns, and neighborhoods, forming collegial groups that share information and advice and provide members with reviews of products and resources.
 - The telephone help line, which currently operates 9 a.m. to 5 p.m. Eastern time, will be available longer hours and in more languages.
 - NFCA's Web site will continue to grow in both capabilities and traffic to reach an expanding caregiver population hungry for information and multiple ways to connect with others.

Advocate for Systemic Change

- NFCA will continue to build awareness of and create solutions for the problems faced by families living with chronic conditions.
- In collaboration with others, NFCA will build a vibrant and politically active community of family caregivers and supporters who recognize and act on their power to bring about healthcare reform that improves the quality and safety of chronic illness care and simultaneously lowers Medicare's costs.

We invite you to join with us as we continue on our journey to improve the health and well-being of America's family caregivers. ■

We're Looking for a Few Good Volunteers

The Caregiver Community Action Network (CCAN) is a unique and highly dedicated volunteer group made up of more than 90 NFCA members who advocate on behalf of all family caregivers.

CCANers regularly attend meetings, conferences, and conventions about family caregiving issues and they serve as presenters, speakers, panelists, and workshop directors. Some CCANers are professional caregivers while others are full-time family caregivers. CCANers have a wide variety of backgrounds and experiences, from healthcare professionals to homemakers to teachers and community activists. What they all have in common is a desire to make a difference in the lives of other family caregivers.

You can be a part of this growing grass-roots movement. More CCANers are needed all across the U.S., but especially in Kentucky, Alaska, Wyoming, Delaware, Kansas, and North and South Dakota.

For more information, contact Linda Jones at 248/358-1186 or linda_jones100@hotmail.com.



The NFCA teamed up with Intel and Ian Ziering to launch www.connectingforcare.com, a new online forum for professional and family caregivers. The launch took place in New York City on June 17, 2008. Pictured (l to r): Louis Burns, Intel Corporation; Suzanne Mintz, NFCA; MaryJean Schumann, American Nurses Association; and Ian Ziering, actor and family caregiver.



As a family caregiver, you belong to a very large community — about 50 million strong.

That's right. Fifty million people across our country are caring for a loved one with a chronic illness or disability.

For 15 years, we have provided services and support to family caregivers, like you, who have joined NFCA's Family Caregiver Community.

Our work would not be possible without the generosity of our corporate partners, who invest time and resources in support of NFCA's programs.

We are grateful to our Anniversary Circle Members:

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SpeakUp!

National Family Caregivers Month

Every year, we celebrate family caregivers during the month of November. National Family Caregivers Month is a time to thank, support, educate and empower one another. This year is particularly exciting because it's NFCA's 15th anniversary.

As part of the celebration, we are launching a FREE National TeleClass to teach family caregivers how to communicate more effectively with healthcare professionals.

When: Thursday, November 6 and 13, at 2 p.m. Eastern time.
How: By phone and Internet — the TeleClass will be FREE to all family caregivers.
Why: The TeleClass will empower family caregivers to be better healthcare advocates for themselves and their loved ones.

For more information on National Family Caregivers Month and the National TeleClass, visit www.thefamilycaregiver.org or call 800/896-3650.

Endorsing Organizations

Thanks to our endorsing organizations for their support and celebration of NFC Month. All of our endorsing organizations and institutions are working with us to Speak Up for family caregivers during NFC Month by sharing information about family caregiving and the FREE National TeleClass with their members, chapters and constituents. National Family Caregivers Association is grateful to the following for their support:

Administration on Aging	Christopher & Dana Reeve Foundation Paralysis Resource Center	MITSS (Medically Induced Trauma Support Services)	Paralyzed Veterans of America
AGS Foundation for Health in Aging	Consumer Consortium on Assisted Living (CCAL)	National Alliance for Caregiving	Pediatric Adolescent Gastroesophageal Reflux Association (PAGER)
Allergy & Asthma Network Mothers of Asthmatics	Consumers Advancing Patient Safety (CAPS)	National Association for Contingence (NAFC)	Private Duty Homecare Association
ALS Association	DMAA: The Care Continuum Alliance	National Association for Home Care & Hospice	Rosalynn Carter Institute for Caregiving
Alzheimer's Association	East Arkansas Area Agency on Aging	National Association of Social Workers	Rush University Medical Center
Alzheimer's Foundation of America	Families for Depression Awareness	National Council on Aging	Screening for Mental Health
American Academy of Nurse Practitioners	Family Caregiver Alliance/ National Center on Caregiving	National Health Council	Share the Care
American Academy of Physician Assistants	Generations United	National Hospice and Palliative Care Organization	The Transverse Myelitis Association
American Association for Geriatric Psychiatry	Greater Nashville Regional Council	National Lupus Foundation of America – Greater Washington Chapter	The Wellness Community
American Occupational Therapy Association	Huntington's Disease Society of America	National Multiple Sclerosis Society	United Cerebral Palsy
Amputee Coalition of America	Mississippi Department of Human Services	National Organization for Rare Disorders (NORD)	United Ostomy Association of America, Inc.
Association of Professional Chaplains		National Patient Safety Foundation	WE MOVE
Catholic Health Association		National Respite Coalition	Well Spouse Association
Central Plains Area Agency on Aging			Women's Institute for a Secure Retirement (WISER)

Transitions in Care

Continued from page 1

and shorter lengths of stay, planning for the patient's next stage of care must begin immediately," says Dr. Nay. Should your loved one need to transition to another facility such as a rehabilitation unit or a nursing home, make sure you seek the advice of the hospital's discharge planner to help locate quality facilities that fit your needs. You can also research nursing homes, home health agencies, and other healthcare services in your area by using Medicare's comparison tool on its Web site. (Go to www.medicare.gov and scroll down to Search Tools for links to a variety of comparison tools.)

But what do you do if your loved one is being discharged back home directly from the hospital? What if there's been a change in your loved one's medical condition that requires even more hands-on caregiving? It's crucial to find out if your loved one qualifies for home healthcare, which the hospital may be able to help you secure. If you are going to be responsible for performing new medical procedures (such as taking blood sugar levels or changing catheters), you need someone to teach you how. This is a time to be observant and to stand your ground. Don't let the hospital staff dismiss your concerns. You will need help; if your insurance company won't pay for home healthcare, hopefully you (or someone advocating on your behalf) can convince the hospital to extend your loved one's stay and/or to provide the training you need to provide safe, quality care at home.

Setting Realistic Goals

One important way you can help ease your loved one's transition out of the hospital is to help get him or her up and moving as quickly as possible. "As part of your advocacy role, get the physical therapist or another

member of the hospital team focused on getting your loved one out of bed," says Dr. Coleman. "It's also important to communicate to the team members who their patient was prior to his or her hospitalization. Your loved one may be weak or confused. The healthcare team needs to be reminded that this is not his or her normal physical or mental state."

In the same vein, everyone involved in the care team should have realistic expectations regarding your loved one's recovery. Dr. Coleman recommends asking three important questions of the members of the healthcare team:

1. What is the likelihood that Mom will be coming home and when?
2. Will she need to go to a rehabilitation unit or other facility first?
3. What are our treatment goals?

It's the job of the healthcare team to help you and your loved one establish concrete goals and a realistic timeline for achieving them. The team members need to understand that caring for your loved one may be only one of many responsibilities you shoulder. They aren't thinking

Did You Know?

In one study of ER visits in 2005, important information such as the medical history and laboratory results was missing in nearly one-third of the visits.

(Gandhi TK. "Fumbled Handoffs: One Dropped Ball after Another." *Annals of Internal Medicine*. 2005;142(5):352-358.)

Nearly half of the patients in a 2003 study experienced at least one medical error related to the discontinuity of care from the inpatient to the outpatient setting.

(Moore C., et al. "Medical Errors Related to Discontinuity of Care from an Inpatient to an Outpatient Setting." *Journal of General Internal Medicine*. 2003;18(8):646-651.)

about your life outside the hospital. It's your job to explain what you can and cannot do and to enlist their help to make the transition as smooth as possible. It's not easy, but it's critical that you try. ■

Sandy Padwo Rogers is the managing editor of TAKE CARE!

To Learn More

The Care Transitions Program This program was developed to educate healthcare professionals as well as patients and their caregivers on the many factors that can affect a smooth transition in care. By creating a model of care that includes a core set of care coordination self-management skills, the goal is to improve the quality and safety of all healthcare transitions. A large part of this effort involves educating the family caregiver. Downloadable tools for patients and their caregivers are available on the program's Web site. Go to www.caretransitions.org.

Next Step in Care: Family Caregivers and Health Care Professionals

Working Together This program was created by the United Hospital Fund's Families and Health Care Project to educate healthcare professionals and family caregivers on the myriad issues that complicate healthcare transitions. The program, which will officially launch in late fall 2008, will be a Web-based resource offering free guides about hospital admissions, planning for discharge, and the discharge process itself. The guides — which have been pilot tested in hospitals, nursing home rehabilitation units, and home care agencies — offer concrete, straightforward explanations, checklists, and "to do" lists that are designed to enhance the conversation between healthcare provider and family caregiver. More information is available at www.uhfnyc.org/nextstepincare; to be notified when the Next Step in Care Web site is online, send your e-mail address to nextstepincare@uhfnyc.org.

Keeping Your Loved One Safe

When dealing with any type of care transition, there are things you can do to help you maintain control and to help keep your loved one safe. These tips were compiled from information shared by Dr. Eric Coleman, Carol Levine, and Dr. Tricia Tomsco Nay and reflect their years of experience:

- Have multiple copies of all important forms and papers and be prepared to provide them at each different stage of care. Be prepared to repeat everything you tell the healthcare team about your loved one. Make sure that your loved one's treatment preferences are reinforced at each level of care and in each department, especially when it comes to advance directives. Be persistent and repeat often!
- Identify yourself as the primary family caregiver and the key person who needs to be involved in all decision making and planning. Don't assume that the healthcare team will know that it's you they need to speak with, especially if other family members or friends have been helping your loved one in the hospital. Make it clear what your role is and what you feel comfortable doing in the future. If there are limitations to what you can do for your loved one, make those limitations clear to everyone.
- Make sure you understand your loved one's entire medication regime, which can be very complicated. What's prescribed in the hospital may not be prescribed at home. On a similar note, routine medications may be discontinued during the hospital stay and then forgotten about after a transition. Make sure that you account for all missing medications and all newly prescribed medications and that you have a clear understanding of the entire medication plan — before, during and after any hospital admission.
- Find out who is responsible for each aspect of your loved one's care and what to expect in the future. Make sure you understand what follow up is needed and by whom. Upon your loved one's return home, be sure to contact his or her primary care physician to provide an update on everything that's taken place and to make sure that the proper information has been transferred appropriately. Don't assume that this communication has already occurred. (If your loved one was seen in the hospital by a hospitalist, this physician will be responsible for communicating with the primary care physician.)
- Try to identify an ally in the healthcare system early on in your loved one's stay. Be open to individuals you may not think about initially, such as a patient advocate, social worker, or chaplain.
- The majority of patients and their family caregivers have unrealistic expectations about everything from clinical goals to the financial costs of care. Asking for help in setting realistic goals will go a long way toward improving your relationship with your loved one's healthcare providers.
- Don't get overwhelmed by looking at the entire picture at once. Break it into its parts and deal with each part separately. Prioritize the pieces and address the most important points first. Think of it like a jigsaw puzzle: You have to put the borders together before you can fill the inside. ■

Communicating With The Healthcare Team

Any type of healthcare crisis can be extremely stressful; however, your communication with members of the healthcare team doesn't have to be. Dr. Nay offers a few simple tips for family caregivers:

1. **Be organized.** Write down the names and contact information for all the physicians who interact with your loved one. Keep a list of questions or concerns and find out who the best person is to ask. It may be more than one person. By organizing your thoughts, you can make the communication process more efficient.
2. **Be respectful** of the staff's time. There are appropriate times to ask questions.
3. **Don't wait** for the day of discharge to let someone know that you don't understand something or you are uncomfortable with new procedures or care plans. If you don't think you will be able to handle a task that you will be given upon your loved one's discharge, speak up immediately. Remember that the assumption always is: If you don't say you can't handle it, then you can.

For more on improving communication with healthcare professionals, be sure to check out NFCA's FREE Family Caregiver TeleClass, a two-part class to be held November 6 and 13, beginning at 2 p.m. Eastern time. For registration information, visit www.thefamilycaregiver.org. For questions, call 800/896-3650.

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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 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
Subject Line: What Can I Do?

Q My husband has had Alzheimer's for the past five years and much of that time I took care of him myself. Eventually, it became clear that it wasn't safe to have him at home. One night he wandered out of the house, leaving all the doors open, and walked 10 miles before the police picked him up in the middle of a road. I awoke to find the police in my bedroom; the open doors made them worried that something had happened to ME. Another time he almost drank a bottle of cleaning fluid. Finally, it became too much.

I have found that I constantly have to validate my decision to put my husband in an assisted living facility. I've had people tell me I'm a horrible person for putting him there. One woman commented on my having lost weight, and asked if it was because of all the guilt I felt for putting him away. How can people be so ignorant? Why can't they be more sensitive? What can I say to them?

A Research studies suggest that when family caregivers place a relative in an institutional setting, it brings them equal measures of relief and guilt. The cause of the relief is obvious: They no longer feel compelled to be on 24-hour-a-day alert, ever ready to avert disaster; they depend, instead, on the trained staff members and secure environments of assisted living facilities and nursing homes to ensure their loved ones' safety. The causes of guilt are more complex: Many caregivers feel that, by opting for placement, they are failing to honor implicit or explicit promises made to their family member. Many of them realize, though, that the intensity of care-demands reaches a point that their loved one

can't be tended to adequately in the home, no matter how skilled, stubborn or superhuman the caregiver. Then, as your letter depicts, there are external sources of guilt. Acquaintances, neighbors and distant relatives pass judgment. They cast stones with little restraint. They compound suffering, inadvertently or not.

Why do they do this? It's worth considering, if only to lessen the sting of their outright condemnations and snide asides. The primary reason is that many people have misconceptions about institutional facilities, likening them to human wastebaskets. They don't regard them as diverse communities in their own rights, with their own personalities and opportunities for new relationships. They don't appreciate that what they may lack in homey touches they make up for in security and comfort. They don't grasp the significant differences between nursing home and assisted living settings. They don't understand that such settings often enhance a resident's quality of life.

The second reason seems to me to be one of sheer emotion. The more vehemently critics of institutional placement rail against it, the more I suspect that they are reacting out of their own fears of being shunted aside and forgotten by their relatives. They project those fears onto you and other family members who've made this difficult decision. Then they attack you as unjust.

Thirdly, they generally are uninformed about what it's like to care for an agitated, demented patient in your home. They don't know the sacrifices involved or the dangers inherent. They often cling to images of the patient before he became ill

(Continued on page 14)

What Can I Do?

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and refuse to accept evidence to the contrary.

None of these reasons suggest that your critics are making the effort to consider the pros and cons of institutional placement thoughtfully and dispassionately. In short, they haven't a clue; their opinions lack credibility. I would respond to them with calmness but firmness, saying things like, "I appreciate your concern. I've given this difficult decision a great deal of thought in order to do the best I can for my loved one." They will likely back off. Then do trust your judgment that you did make the most loving choice possible at the time for your husband and that he and you are still better off for it — regardless of whatever grief anyone else gives you.

Q I am 58 years old and for the past eight months I've been the full-time caregiver for my 59-year-old husband. As the result of a stroke-induced motorcycle accident, he was left with massive injuries including a broken back and a broken neck. He is paralyzed from mid-chest down, with limited arm movement because of two broken shoulder blades. We get SS Disability, his VA pension, and I get paid by the VA for providing some of his medical care. I'm worried about what will happen to him without me. I'm also trying to get over being angry at him because our entire existence has changed. I've gone from being a career woman to being a full-time caregiver and it's been a difficult transition. I know that my anger is caused by depression over our situation. What can I do?

A It's unclear from your question whether you are seeking ad-

vice on changing your extremely difficult caregiving situation or just altering your emotional reactions to it. If the former, then I'd suggest assessing your caregiving plan to determine whether it's sustainable. Have you recruited sufficient support and marshaled all available resources, such as help from home health aides, support groups, church groups, etc.? Are you discovering means of pacing and replenishing yourself? Are you effectively grieving what you've lost but still savoring those small pleasures that remain? To help you with this assessment, there are many available caregiver Web sites (such as the National Family Caregivers Association site — www.thefamily-caregiver.org) and books (including my own), as well as knowledgeable healthcare professionals such as mental health therapists and geriatric care managers.

If your intention is to change your emotional reactions, then we should

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start by taking into account a broader perspective on anger toward family caregiving. Most caregivers feel ambivalently about what they have to do because it's hard, grinding work that they wish had never befallen them. It's therefore normal to feel anger, among other emotions, about having to sacrifice so much of oneself and one's old life. It is even appropriate for you to feel angry, to a degree, at your husband, especially if he put himself in harm's way or didn't take care of himself prior to the accident. In other words, your anger may not be a symptom of the pathological condition that we call major depression. It may be an understandable human response to a horrendous set of unbidden circumstances. Accepting that you are responding in a normal way may prevent you from harshly castigating yourself for your emotions and thereby making your predicament all the more arduous. Please do express

This NFC Month: Give Yourself a Gift

How do we tell others that we love and appreciate them? We may give them a unique gift, write them a note, or do a special favor for them. We express love and friendship to others in countless ways, but we sometimes find it hard to love ourselves. We need to develop the daily habit of telling ourselves that we are important. How? Start with some of our ideas and let your creativity take over!

- Write yourself encouraging notes and place them around your house.
- Memorize one encouraging saying every day or week.
- Listen to your favorite music.
- Treat yourself to a present once in a while, as your budget allows. It need not be big, but it should be something especially for you.
- Prepare your favorite meal or order out from your favorite restaurant.
- Buy or pick yourself flowers.

that anger to friends, family members, support group members or healthcare professionals. They shouldn't think less of you for it. You should feel better for having expressed it.

If you are having other symptoms of major depression — for example, changes in sleep or appetite, nagging

fatigue or diminished capacity to enjoy activities that usually give you pleasure — then, by all means, please ask your family physician to evaluate you. Treatment for depression may give you greater energy and an improved outlook on caregiving — but your anger about this tragedy will likely linger. ■

Join the League of Experienced Family Caregivers (LEFC): A Partnership Between NFCA and University of Wisconsin-Milwaukee

What is it?

- The League of Experienced Family Caregivers is a national registry of family caregivers who are sharing their experiences with a team of researchers at the University of Wisconsin-Milwaukee.
- Information gathered will be used as the basis for creating services family caregivers say they need and advocating for the funding needed to make them available.

Who is eligible?

- Any family caregiver providing assistance to a loved one over the age of 18. It could be your parent, your spouse/partner, your child, a sibling, etc.

What will I need to do?

- Complete one or more short questionnaires about your experiences as a family caregiver.
- Questionnaires take no more than 20 minutes to complete and can be done by U.S. mail, phone, or on the project Web site, www.familycaregivers.uwm.edu — whatever is easiest for you!

- Information gathered is kept confidential and caregivers may withdraw from the project at any time.

Why should I join?

By participating in the League you will be:

- Speaking Up for yourself and all of our nation's family caregivers.
- Educating local, state and federal officials about the obstacles you and other family caregivers face every day and the types of support services you need to take better care of yourself and your loved one.
- Educating service provider organizations so they can design programs based on your needs.
- Educating yourself and other family caregivers so you can all learn from each other.

How do I enroll?

It's simple:

- Call toll free 800/410-2586
 - E-mail lefc@uwm.edu
 - Visit the Web site at www.familycaregivers.uwm.edu
- We look forward to hearing from you!



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