



## HANDING OFF CRITICALLY ILL PATIENTS TO FAMILY CAREGIVERS WHAT ARE YOUR BEST PRACTICES?

One of the themes for this issue is supporting family members of acute and critically ill patients. In addition to more traditional meanings of *family* as the primary social unit of biological or adopted relatives, we are referring here to any type of close kinship or social ties that may exist between the patient and others. Davidson<sup>1</sup> considers various strategies that nurses may employ to optimize the family's adaptation to a loved one's critical condition. Sacco et al<sup>2</sup> describe how the institution of ongoing support groups facilitated by family members can create a more family-inclusive environment in a burn-trauma intensive care unit. Plost and Nelson<sup>3</sup> report on the steps they implemented to achieve family-centered care via creation of a new full-time nursing position of family care specialist. In addition to improving family and patient satisfaction with care received in an intensive care, critical care, or progressive care unit, programs that augment family support complement direct patient care and may relieve some of the burden experienced by nursing staff who are attempting to meet pressing patient and family needs simultaneously.

As mutually satisfying as partnering with the family during the acute phase of care may be, however, what about patients whose recuperation, rehabilitation, recovery, or remaining life necessitates a program of care no longer assigned to us, but one that will be assumed by a family caregiver? As Sacco et al<sup>2</sup> point out, family concerns regarding what to expect during the transition of care from hospital to home and coping

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with care requirements after the patient is discharged home are prominent concerns voiced by family members while the patient is still hospitalized. Can critical care nurses extend the care they render to include greater support for the family caregivers of discharged critical care patients?

Before identifying some resources available to assist family caregivers, we need to acknowledge that every patient's clinical case, family support system, and family attributes are unique and influence the nature and scope of his or her needs for care in the home setting. However, critical care nurses may improve their ability to lend support to family caregivers by first becoming better acquainted with who these caregivers are, who the recipients of care are, the types of care family members provide, the challenges they confront, and the needs they identify as most important.

### Family Caregivers

Three aspects of family caregivers are worth noting: a definition of who constitutes a family caregiver, the number of family members who serve in this capacity, and a profile of these care providers.

#### Definition

According to the Family Caregiver Alliance, the term caregiver refers to "anyone who provides assistance to someone else who is, in some degree, incapacitated and needs help."<sup>(4p1)</sup> A family caregiver may also be referred to as an informal caregiver because the term refers not only to members of the patient's family, but to anyone

Health care institutions ... discharge patients from critical care units every day, ... directly into the arms of the family members who will care for them at home.

with a significant personal relationship to the patient such as friends, partners, or neighbors.<sup>5</sup>

### Number

Different organizations have attempted at various times to estimate the number of family caregivers in the United States. Data from the late 1980s suggested that there were 29 million family caregivers for ill or disable persons aged 18 years or older.<sup>6</sup> A decade later, the US Department of Health and Human Services estimated that there were 52 million family caregivers providing care to someone 20 years or older with an illness or disability.<sup>7</sup> More recently, the National Alliance for Caregiving and American Association of Retired Persons (AARP) reported that 34 million adults, or 16% of the US population, provide care for adults aged 50 years and older.<sup>8</sup> When comparing these disparate estimates, the AARP admonishes that many of those who provide such care do not identify themselves as family caregivers; as a result, AARP projects that the number of caregivers is likely closer to 65 million, representing nearly one-third of the US population over the age of 18.<sup>9</sup>

A 2008 update of that earlier AARP reports an estimated 30 to 38 million individuals age 18 or older who provide caregiving to an adult with a limited activities of daily living (ADL); this figure does not include those caring for children under 18 years with disabilities, caregivers under age 18, grandparents caring for grandchildren, or caregivers assisting adults with chronic health conditions but without ADL limitations.<sup>10</sup> By whichever yardstick is used for measurement, the number of Americans serving as family caregivers is already substantial and anticipated to grow as the population ages.

### Profile

Most family caregivers are middle-age women who work outside the home while providing more than 12 hours of care each day for an adult who resides with them.<sup>11</sup> A more detailed description of attributes of the typical family caregiver is summarized in Table 1.

## Family Care Recipients

In its most recent survey of caregiver services, the California Caregiver Resource Center reported<sup>11</sup> that the recipients of family caregiving are typically older

**Table 1** Profile of recipients of family caregiving<sup>11</sup>

Care recipient attribute	Finding	Percentage/other measure
Gender	Female	59%
Age	18 to 103 77	Range Mean/average
Household income	\$20 000 to \$39 999 annually	Median/midpoint
Living arrangement	Lives with others Lives outside a nursing home	85% 98%
Duration of need for care	Fewer than 2 years More than 10 years	49% 10%
No. of care areas	10	Mean/average

women who live with family members and whose needs for care assistance have existed for fewer than 2 years. A more specific detailing of care receivers is provided in Table 2.

## Health Conditions That Precipitate Need for a Family Caregiver

The circumstances that may lead to someone serving in the role of a family caregiver are many and varied. Although these share in common some relative or absolute loss of one or more functional abilities and/or the need for management of one or more persisting health problems, the onset of these impairments may be slow (eg, Alzheimer's disease, other dementias, Parkinson's disease, amyotrophic lateral sclerosis, multiple sclerosis, rheumatoid arthritis)<sup>11</sup> or delayed (some brain tumors, sequelae following traumatic brain injury or blast injuries such as improvised explosive device detonation, or toxic complication associated with some chemotherapeutic agents such as 5-fluorouracil,<sup>12</sup> or immediate (eg, stroke, gunshot injury to the head, spinal cord injury).

Even patients who might be expected to recuperate from an initial major diagnosis—for example, those with acute myocardial infarction, acute respiratory failure, or acute renal failure—may later progress to a chronic and debilitating stage of the condition that demands assistance from others for maintaining many aspects of a normal life. For patients such as those with severe head injury or posttraumatic stress disorder, who appear to have maximally recovered from their physical trauma, the balance of their life and that of their family may be marked by the need for ongoing management of enduring behavioral and functional after-effects.

**Table 2** Characteristics of family caregivers<sup>4,11</sup>

Attribute	Caregiver	Comment
Gender	Female	59%-75% of all caregivers are women. <sup>4</sup> 77% of caregivers in California are women. <sup>11</sup> Women outnumber men by about 2 to 1. <sup>8</sup>
Age	≥ 60 y	Nearly 21% are 36-50 years old, 48% are 60 years or older, and 17% are ≥ 75 years old. <sup>11</sup> The typical caregiver in the United States is 46 years old. <sup>10</sup> Most caregivers are middle-aged (35-64 years old). <sup>8</sup>
Relationship to recipient	Adult child	47% are patient's children, 35% are spouses, and 9% are not family members. <sup>11</sup> Most are relatives of the person cared for, ie, children, spouses, siblings, grandchildren. <sup>8</sup> As recipients of care age, they are more likely to receive care from a spouse. <sup>11</sup>
Living arrangement	With recipient	71% live with the care recipient. <sup>11</sup>
Hours of caregiving/day	12.7	The average is nearly 13 hours per day. <sup>11</sup>
Hours of caregiving/week	Varies widely 89 h	21 hours per week on average <sup>10</sup> 90 hours per week on average <sup>11</sup> No. of hours spent caregiving increases with the caregiver's age and with the severity of the care recipient's cognitive impairment. <sup>4</sup> Nearly 50% provide fewer than 8 hours of care per week, but 20% provide more than 40 hours per week. <sup>8</sup>
Duration of caregiving		Ranges from less than 1 year to more than 40 years <sup>4</sup> 4.3 years on average <sup>8</sup>
Marital status	Married	Most are married. <sup>8</sup>
Work status	Work	49% work; 31% work full-time and 18% work part-time. <sup>11</sup> 48% work full-time. <sup>8</sup>
Ethnicity	White	69% are white. <sup>11</sup> About 21% of whites and 21% of blacks provide care, whereas 18% of Asians and 16% of Hispanics participate in care. <sup>8</sup>

## Types and Value of Care That Family Caregivers Provide

There are 3 broad categories of care that family caregivers provide: ADL, instrumental ADL, and ministrations considered as nursing care. These categories and some of the inclusions within each are summarized in Table 3. It is estimated that more than 40% of caregivers provide various types of nursing care.<sup>13</sup> Of the family caregivers who work with medical equipment and change dressings, however, 33% report receiving no instruction on how to perform these tasks from health care staff.<sup>16</sup>

Taken together, the value of these services that family caregivers provide is estimated to be \$306 billion per year, or virtually twice the amount spent per year on home care and nursing home care combined (\$158 billion).<sup>17</sup> Other organizations estimate the value of those services at figures of \$350 billion<sup>10</sup> to \$375 billion.<sup>5</sup>

## Challenges Experienced by Family Caregivers

The toll of caregiving is often heavy and, at times, protracted. Some of the psychological, physiologic, and

economic effects experienced by family caregivers include emotional impact, depression, declining physical health, higher mortality, reduced work hours and wages, direct out-of-pocket costs, and reduced retirement income.

### *Emotional Impact*

**Stress.** Regardless of the patient's medical diagnosis or specific needs for care, 61% of caregivers report high stress levels resulting from their caregiving circumstances.<sup>11</sup>

**Emotional Factors.** Although the specifics of individuals' caregiving situations may differ, the National Family Caregivers Association<sup>18</sup> found that the common bond among caregivers is the emotional impact that caregiving has on their lives. The emotional impact of caregiving encompasses the following:

- Intense sadness
- Frustration owing to altered family dynamics
- Stress from the enormous responsibilities
- Longing for a return to normalcy
- Isolation due to living outside normal life

**Table 3** Types of care that family caregivers provide<sup>13</sup>

Category of care	Inclusions
Activities of daily living <sup>14</sup>	Bathing, hygiene Continence Dressing Eating Transferring, mobility Toileting
Instrumental activities of daily living <sup>15</sup>	Food preparation Housekeeping Laundry Managing finances Medications Shopping for necessities Telephone use Transportation
Nursing care	Administration of medications Changing dressings Monitoring vital signs Working with medical equipment such as ventilators

- Depression over the losses caused by caregiving
- Disappointment over noncaregivers' lack of understanding

**Depression.** The most detrimental effects of caregiving appear to be waged on the caregiver's psychological health. Within this area, depression is the most commonly reported problem by 20% to 50% of caregivers, with the highest levels associated with those caring for individuals with dementia.<sup>4</sup>

- Family caregivers manifest symptoms of depression at more than twice the rate in the general population.<sup>19</sup>
- Forty-three percent of family caregivers show clinical manifestations of depression and 61% report feeling depressed.<sup>11</sup>

### Declining Physical Health

Twenty-eight percent of caregivers reveal that their own physical health has declined over the past 6 months; 31% report having hypertension; 27% complain of back and neck problems; and 21% have sleep disturbances.<sup>11</sup>

**Heart Failure Patients.** Nearly 90% of caregivers for patients with end-stage heart failure report sleep disturbances.<sup>18</sup>

**Chronic Conditions.** Caregivers report having chronic conditions at rates nearly twice (45% vs 24%) that of individuals who are not caregivers.<sup>21</sup>

**Impaired Immunity.** High levels of stress related to caregiving are associated with elevations of cytokine interleukin 6 at levels 4 times that of comparable individuals who are not caregivers.<sup>22</sup>

### Higher Mortality

**Caregiving as a Risk Factor.** In addition to elevated blood pressure, insulin levels, and incidence of cardiovascular risk factors, a widely-quoted study from 1999<sup>23</sup> reported that elderly spouses who experienced stress related to caregiving had a 63% higher mortality rate than counterparts at their same age who were not caregivers. Caregiving itself, then, appears to be a potentially lethal risk factor.

**Lifespan.** Family caregivers who experience extreme levels of stress associated with caregiving may have a lifespan 10 years shorter than adults of comparable ages who are not caregivers.<sup>24</sup> A wife's hospitalization increases her husband's likelihood of dying within a month by 35%, whereas a husband's hospitalization raises his wife's risk of dying by 44%.<sup>25</sup>

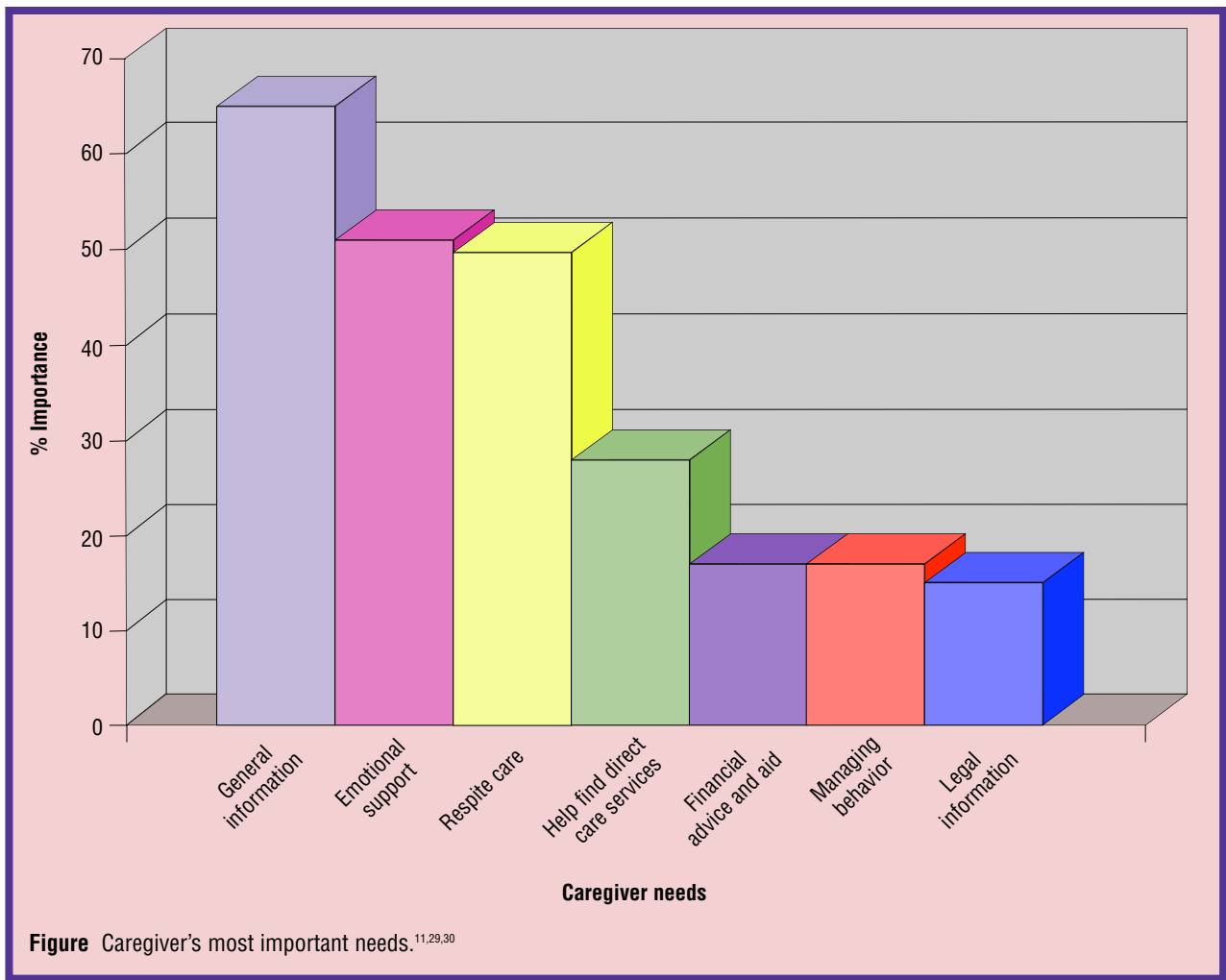
### Financial Implications of Caregiving

**Reduced Work Hours and Wages.** Most caregivers need to make adjustments to their work schedule, ranging from arriving to work late (83%), taking a leave of absence (41%), switching from full- to part-time work (37%), giving up work entirely (35%), losing work benefits (15%), and turning down a promotion (14%).<sup>8</sup> Seven percent of caregivers took a leave of absence, family leave, medical leave, or early retirement in order to provide caregiving.<sup>11</sup>

**Reduced Pay.** For middle-aged women, caregiving reduces paid work hours by about 41%.<sup>26</sup>

**Reduced Benefits.** Fifteen percent of family caregivers quit their jobs or reduced the number of their work hours because of the need to provide care, thereby also reducing their salary and paid benefits, including retirement and health insurance.<sup>11</sup>

**Reduced Profit.** US businesses can incur \$34 billion loss per year attributable to workers' needs to care for loved ones.<sup>27</sup>



**Out-of-Pocket Costs.** About 50% of family caregivers spend an average of \$200 per month for groceries, medicine, or other types of cash support. Caregivers who spend the most report spending \$324 per month (\$3888/year) in financially supporting the care recipient.<sup>10</sup>

**Financial Strain.** A study funded by the National Institute on Aging<sup>13</sup> reported that women who are family caregivers are 2.5 times more likely to live in poverty than women who are not caregivers.

**Benefit Losses.** Reports as far back as 20 years ago<sup>28</sup> estimated that family caregivers lose more than \$25 000 in Social Security benefits, nearly \$70 000 in pension benefits, and more than \$567 000 in wages because of their caregiving contributions.

**Reduced Retirement Income.** Reduction in work hours reduces Social Security benefits and job security, limits

or eliminates access to employer-sponsored retirement accounts, limits contributions to participatory pension plans, and limits or eliminates saving for emergencies or other retirement needs.<sup>26</sup>

## Needs of Family Caregivers

Considering the challenges faced by family caregivers, it is not difficult to anticipate that their most pressing and enduring needs will relate to identifying ways to lighten their considerable burden while affording some modicum of support in their efforts. According to the California Caregiver Resource Center<sup>11</sup> and the Family Caregiver Alliance,<sup>29</sup> the 3 greatest needs that caregivers report are as follows:

- General information, identified by 65% of caregivers
- Emotional support, identified by 51%
- Respite care, identified by 50%

Other priority needs that caregivers report are summarized in the Figure.



**Table 4** Sample of practical tools and resources for professionals from Family Caregiver Alliance<sup>31</sup>

Tools and Resources	Web site
<b>Training and Education</b>	
<b>Caregivers Count Too! A Toolkit to Help Practitioners Assess the Needs of Family Caregivers.</b> This toolkit equips professionals for developing and implementing an appropriate caregiver assessment process in practice settings.	www.caregiver.org
<b>Family Caregiving: State of the Art, Future Trends.</b> Proceedings from national conference hosted by National Center on Caregiving at Family Caregiver Alliance to discuss cutting-edge research, explore effective service interventions and identify emerging issues that affect family caregivers.	www.caregiver.org
<b>Caregiving Awareness Through Resources and Education for Professionals.</b> Web-based, multimedia, self-study curriculum to increase the skills and knowledge of professionals serving family caregivers. Also available on DVD from American Society on Aging.	www.asaging.org
<b>How to/Try This.</b> Translates the evidence-based geriatric and caregiver assessment tools in the Try This: Best Practices in Nursing Care to Older Adults series into cost-free, Web-based resources.	www.hartfordign.org
<b>Educational Guides, Training Programs, and Curricula for Caregivers</b>	
<b>Caring for You, Caring for Me: Education and Support for Family and Professional Caregivers.</b> Curriculum designed for professionals who lead groups and/or conduct educational programs for caregivers across disease/disability groups throughout the lifespan. Program guide helps professionals lead the 10-hour program (five 2-hour modules). Available from Rosalynn Carter Institute for Caregiving.	www.rosalynncarter.org
<b>Communicating Effectively Workshops.</b> Workshops that teach family caregivers to improve communication with health care professionals. The curriculum is available online from the National Family Caregivers Association.	www.nfcacares.org
<b>Maine Primary Partners in Caregiving.</b> Model education curricula for rural caregivers and primary care providers. A best-practice replication guidebook can be downloaded. Original study screened patients for caregiving burden in primary care practices in rural counties and provided expedited referral pathway to caregiver specialists at Area Agencies on Aging. Available from Maine Eastern Area Agency.	www.umaine.edu
<b>Family Caregiving Program.</b> Nine-module course for caregivers. Professionals in the community can take steps and obtain materials to teach the course. Call local chapter of American Red Cross for information.	www.redcross.org
<b>General Information and Research Related to Caregiving</b>	
<b>Caregiver Education and Support Programs: Best Practice Models.</b> A report that describes 5 widely used caregiver programs that have empirical evidence to support their effectiveness. Includes information about how to obtain materials for these programs.	www.caregiver.org
<b>Family Care Navigator.</b> A comprehensive online guide to help families in all 50 states and the District of Columbia locate government, nonprofit, and private caregiver support programs and resources for older or disabled adults in their communities. The guide includes eligibility criteria and contact information for each program.	caregiver.org/caregiver/jsp/fcn_content_node.jsp?nodeid=2083
<b>Caregiver Nursing Protocol: Integrating Nursing Intervention With Social Work Services.</b> Provides recommendations on successful interventions for nurses to use when working with informal caregivers.	www.pcacares.org
<b>eXtension: Family Caregiving Resource Area.</b> Educational partnership of 74 US universities providing objective and research-based information and learning opportunities on a range of issues, including family caregiving.	www.extension.org
<b>National Guideline Clearinghouse.</b> A comprehensive database of evidence-based clinical practice guidelines and related documents from the National Guideline Clearinghouse Agency for Healthcare Research and Quality. Some topics include caregiver assessment, caregiver depression, and discharge planning.	http://www.guideline.gov
<b>Retooling for an Aging America: Building the Health Care Workforce.</b> A report that examines the looming shortage of health care professionals and others trained to work with older adults. It includes a chapter focused on informal caregivers and the need to provide them with training opportunities and stress relief.	www.iom.edu

*Continued*

**Table 4** *Continued*

<b>Caring for the Caregiver</b>	
<b>Caregiver Assessment. Volume I: Principles, Guidelines and Strategies for Change. Volume II: Voices and Views From the Field.</b> Report from a National Consensus Development Conference on Caregiving. Explains key principles and guidelines for caregiver assessment and background information.	<a href="http://www.caregiver.org">www.caregiver.org</a>
<b>Caregivers Count Too! A Toolkit to Help Practitioners Assess the Needs of Family Caregivers.</b> Based on the work from a National Consensus Development Conference by the Family Caregiver Alliance's National Center on Caregiving. Toolkit equips professionals for developing and implementing an appropriate caregiver assessment process in practice settings.	<a href="http://www.caregiver.org">www.caregiver.org</a>
<b>National Family Caregivers Support Program.</b> Comprehensive information and resources for elders and caregivers. Topics include Help! Where to Find It, Taking Care of Others, Taking Care of You, Coping with Your Caregiver Role, Support Groups, Caregiver Voices.	<a href="http://home.nyc.gov/html/dfta/downloads/pdf/alz-nfcsp.pdf">home.nyc.gov/html/dfta/downloads/pdf/alz-nfcsp.pdf</a>
<b>Respite Services: Enhancing the Quality of Daily Life for Caregivers and Care Receivers.</b> Online booklet that helps family caregivers assess their abilities and circumstances, encourages caregivers to use respite services and provides suggestions to make respite most effective.	<a href="http://aging.utah.edu">aging.utah.edu</a>

**Table 5** National Family Caregivers Association resources for family caregivers<sup>32</sup>

<b>How-to guide topics</b>	<p>Speak Up</p> <p>10 Tips for Family Caregivers</p> <p>10 Tips for Family Caregivers Spanish</p> <p>A Home Healthcare Primer</p> <p>A Support Group Guide</p> <p>Caregiver Self-Advocacy: 4 Messages to Live by</p> <p>Care Management Techniques You Can Use</p> <p>Choosing a Nursing Home: A Caregiver's Guide</p> <p>Believe in Yourself: Take Charge of Your Life</p> <p>Reaching Out for the Help You Need</p> <p>Improving Doctor-Caregiver Communications</p> <p>Share the Caring: Action Checklists for Family Caregivers</p> <p>Telephone Techniques for Family Caregivers</p> <p>When Your Loved One Is Hospitalized</p> <p>When Your Loved One Isn't Very Lovable</p> <p>The Stress of Family Caregiving</p>
<b>Communication topics</b>	<p>Checklists for Healthcare Encounters</p> <p>Medical Record Form to Keep Track of All Medications From the SOS Rx Coalition</p> <p>How to Communicate Your Loved One's Symptoms in a Crisis</p> <p>How to Communicate With Insurance Personnel</p> <p>Questions to Ask Your Healthcare Provider</p> <p>How to Communicate Your Loved One's Needs About Well-being, Pain, and More</p>
<b>Suggested Web sites</b>	<p><b>Be Smart. Be Well. Caregiving.</b> <a href="http://besmartbewell.com/caregiving/index.htm">besmartbewell.com/caregiving/index.htm</a> This Web site is designed to raise awareness of largely preventable health and safety issues. Engaging video stories highlight the personal and profound struggles of caregivers and how they can also bring families together.</p> <p><b>CareCentral.</b> <a href="http://www.carecentral.com">www.carecentral.com</a> This personalized Web service enables users to create a free, private, secure online community to update friends and family, schedule offers to help, and provide support when it is most needed.</p> <p><b>CarePages.</b> <a href="http://www.carepages.com">www.carepages.com</a> CarePages are free, private Web pages that facilitate sending and receiving messages of support to stay connected to family, friends, coworkers, and others.</p> <p><b>Lotsa Helping Hands.</b> <a href="http://www.nfca.lotsahelpinghands.com">www.nfca.lotsahelpinghands.com</a> This free service creates private caregiving coordination communities in which family and friends can stay informed and more easily provide assistance and support to caregivers. Features many communication and social networking tools, including the ability to easily store and retrieve vital medical, financial, and contact information, convey medical updates, and post photos. The easy-to-use calendar is specifically designed for organizing helpers, where everyone can pitch in with meal deliveries, rides, visits, and other tasks.</p>

## Resources for Nurses to Assist Family Caregivers

A variety of resources are available to assist critical care nurses in supporting family caregivers for the transition and discharge of a critically ill patient to the home setting. Although there is an abundance of online resources directed at caregivers, this section focuses on information and materials developed for health care professionals to assist caregivers in their role.

The Family Caregiver Alliance is in the formative stages of designing what it refers to as “an Innovations Clearinghouse on Family Caregiving,” a repository of cutting edge public policies, procedures, programs, evidence-based practices, as well as educational opportunities and an online national community assembled to advance and advocate for the family caregiver role. Already available at their Web site<sup>31</sup> are 2 complementary sets of tools and resources, one for caregivers and one for health care professionals. For professionals, one section contains highlights of programs selected for their innovative approaches to program development for caregiver families and a second area contains a plethora of programs and tools selected for their value in augmenting professionals’ knowledge and ability to support family caregivers. A small preview of the contents available in this set of tools and resources can be found in Table 4.

Another compendium of useful tools, tips, guidelines, and informative Web sites is available at the National Family Caregivers Association Web site.<sup>32</sup> A summary of these resources is provided in Table 5.

## Strategies Your Facility Has Found Effective in Supporting Family Caregivers

Health care institutions across the United States and around the world discharge patients from critical care

**Critical Care Nurse** would like to hear about the strategies and approaches your organization has developed to support and lighten the burden of family caregivers. Please e-mail brief descriptions of your programs to us by August 15, 2009, at [GrifCCN@comcast.net](mailto:GrifCCN@comcast.net), using a Subject line of “Supporting Family Caregivers.” Tell us your success stories and we will compile these and communicate them to all CCN readers as soon as possible.

Help us help you to provide the best possible care to both critically ill patients and their families.

units every day, handing off these patients at times to other nurses in less acute care areas and, at other times, directly into the arms of the family members who will care for them at home. **CCN**

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