

## Caregivers & Pain

**A family caregiver is anyone who provides any type of physical and/or emotional care for an ill or disabled loved one at home. For this definition, “family” refers to a nonprofessional who is called “family” by the person who is sick. Sometimes, family is whoever shows up to help.<sup>1</sup>**

The biggest fear of chronically ill patients and their families is that the patient will suffer with unrelieved pain. Many caregivers consider pain to be an indication of the patient's status and equate worsening pain with advancing disease and, in the case of terminal illness, impending death. Some caregivers view death as a welcome relief from the pain, and others avoid thinking about death by denying both the pain and the progressing illness. Caregivers tend to perceive pain and associated distress as worse than the patients perceive it. Fears of addiction, tolerance, uncontrolled pain, and analgesic side effects are sources of constant worry for caregivers and present a conflict in terms of providing pain relief.<sup>1,2</sup>

Caregivers' attitudes toward pain also come into play when caring for a child with chronic pain. One study found that parent perceptions of greater child vulnerability were significantly associated with both lower child functioning and more pain-related health care utilization regardless of child age, sex, and duration of chronic pain.<sup>3</sup>

A separate study of caregivers of workers with low-back pain found that their significant others shared, and perhaps further reinforced, claimants' illness beliefs, including fear of pain/reinjury associated with certain types of work and activity, and pessimism about the likelihood of returning to work. In some cases, significant others appeared more resigned to the permanence and negative

inevitable consequences of the claimant's back pain condition on work participation, and were more skeptical about the availability of suitable work and sympathy from employers.<sup>4</sup>

Findings from the American Psychological Association's Stress in America survey show those who serve as caregivers – providing care to both the aging and chronically ill – for their family members report higher levels of stress, poorer health and a greater tendency to engage in unhealthy behaviors to alleviate that stress than the population at large.<sup>5</sup>

What's more, while lower stress levels are often associated with older adults, those older adults with caregiving responsibilities report more stress and poorer physical health than their peers.<sup>5</sup>

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**“One of the most frightening and stressful aspects of caregiving is not knowing what to do when your loved one is experiencing pain.”<sup>6</sup>**

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## Facts

- The family caregiver's role in managing pain includes:<sup>7</sup>
  - deciding what medications to give and when to give them
  - waking at night to assess pain and administer pain medications
  - reminding and encouraging reluctant patients to take pain medication
  - keeping complex records of multiple medications
  - guarding or limiting medications because of fear of addiction
  - taking responsibility for pain medications
- Family caregivers are a critical support structure for Americans with chronic illnesses, and the U.S. Health System. An estimated 65.7 million American adults find themselves in a caregiving role. They provide the vast majority (78%) of all long-term care services for those with a chronic illness or disability.<sup>8,9</sup>
- On average, caregivers spend 20.4 hours per week providing care. Caregiving is particularly time-intensive for those who live with their care recipient (39.3 hours/week), and those caring for a child under the age of 18 (29.7 hours/ week). Female caregivers spend more time providing care than men do, on average (21.9 vs. 17.4 hours/week); 13% of family caregivers provide 40 hours of care a week or more.<sup>9</sup>

### Caregiving at the End of Life

With 66% of the hospice patients dying in their place of residence, the day-to-day implementation of pain management plans is accomplished by informal family caregivers. These untrained caregivers are ill-prepared for the struggles associated with managing pain in the terminally ill and their former caregiving experiences influence their perception and management of their loved ones' pain experience.<sup>10</sup>

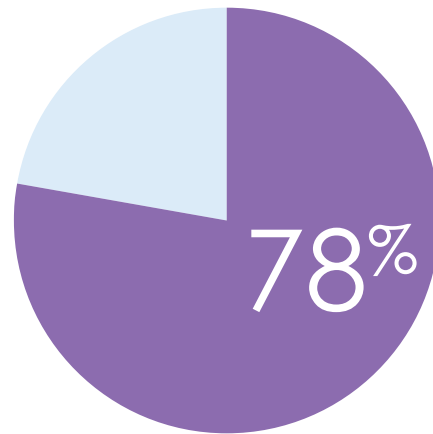
Although patients and caregivers show a willingness to be involved in pain management, it is identified as one of the most challenging aspects of care and many believe that they do not have control over cancer pain. The adverse effects of cancer pain on patients' quality of life have been well-documented. Witnessing a family member in pain can negatively affect the caregiver.<sup>11</sup>

Terminal illness affects not only the individual with the diagnosis but also the loved ones who surround him or her and, most of all, the caregiver who manages daily care needs. Research has found that all aspects of a caregiver's life are affected including physical, emotional, and social well-being. Caregivers have been found to experience anxiety, depression, physical symptoms, and strain in marital relationships. Caregivers of dying people have been identified as being at greater risk for depression, health problems, and increased mortality rates than the general population.<sup>12</sup>

- Your loved one may be in pain if he/she:<sup>1</sup>
  - has decreased appetite
  - has lost interest in regular activities
  - is crying and upset about discomfort
  - grimaces or winces when moving
  - stays in bed and doesn't get dressed
  - has difficulty sleeping
  - is tense and tries to avoid movement

- One study based on interviews with caregivers of older advanced cancer patients found that the pain for caregivers originated from witnessing and sharing in the experience. Some caregivers' responses to patients' pain indicated that they perceived themselves as experiencing more distress from the pain experience than did patients. The study found that caregivers describe three main themes surrounding the cancer pain experience:<sup>11</sup>
  - Feeling cancer pain
  - Reacting to cancer pain
  - Living with cancer pain
- In examining the evidence concerning the frequency of depression among caregivers in hospice, the reported range of frequency of depression is between 26-57%.<sup>8</sup>

Family caregivers provide the vast majority (78%) of all long-term care services for those with a chronic illness or disability.<sup>8</sup>



#### Hours of Care a Week



13% of family caregivers provide 40 hours of care a week or more.<sup>9</sup>

## Additional Resources

### **AARP**

601 E Street, NW  
Washington, DC 20049  
Phone: (888) 687-2277  
E-mail: Via website  
Twitter: @AARP  
[www.aarp.org](http://www.aarp.org)

### **Administration for Community Living**

One Massachusetts Avenue,  
NW  
Washington, DC 20001  
Phone: (202) 619-0724  
Fax: (202) 357-3555  
E-mail: [aclinfo@acl.hhs.gov](mailto:aclinfo@acl.hhs.gov)  
Twitter: @ACLGov  
[www.acl.gov](http://www.acl.gov)

### **American Nurses Association, Inc. Council on Gerontological Nursing**

8515 Georgia Avenue  
Suite 400  
Silver Spring, MD 20910-3492  
Phone: (800) 274-4262  
Fax: (301) 628-5001  
E-mail: Via website  
Twitter: @ANANursingWorld  
[www.nursingworld.org](http://www.nursingworld.org)

### **Caregiver Action Network**

2000 M Street NW,  
Suite 400  
Washington, DC 20036  
Phone: (202) 772-5050  
E-mail: [info@caregiveraction.org](mailto:info@caregiveraction.org)  
Twitter: @caregiveraction  
[www.caregiveraction.org](http://www.caregiveraction.org)

### **Gerontological Society of America**

1220 L Street, NW  
Suite 901  
Washington, DC 20005  
Phone: (202) 842-1275  
E-mail: Via website  
[www.geron.org](http://www.geron.org)

### **Health in Aging Foundation**

40 Fulton Street  
18th Floor  
New York, NY 10038  
Phone: (800) 563-4916  
Phone: (212) 308-1414  
E-mail: Via website  
Twitter: @AmerGeriatrics  
[www.healthinaging.org](http://www.healthinaging.org)

### **Leading Age**

2519 Connecticut Avenue, NW  
Washington, DC 20008-1520  
Phone: (202) 783-2242  
Fax: (202) 783-2255  
E-mail: [info@leadingage.org](mailto:info@leadingage.org)  
Twitter: @LeadingAge  
[www.leadingage.org](http://www.leadingage.org)

### **Lotsa Helping Hands**

34 Washington Street  
Suite 310  
Wellesley Hills, MA 02481  
E-mail:  
[info@lotsahelpinghands.com](mailto:info@lotsahelpinghands.com)  
Twitter: @LotsaHelping  
[www.lotsahelpinghands.com](http://www.lotsahelpinghands.com)

### **National Center on Elder Abuse**

c/o University of California –  
Irvine  
Program in Geriatric Medicine  
101 The City Drive South  
200 Building  
Orange, CA 92868  
Phone: (855) 500-3537 (ELDR)  
E-mail: Via website  
Twitter: @NCEAatUCI  
[www.ncea.aoa.gov](http://www.ncea.aoa.gov)

### **National Coalition for Cancer Survivorship**

1010 Wayne Avenue, Suite 315  
Silver Spring, MD 20910  
Phone: (877) NCCS.YES  
Phone: (877) 622-7937  
Fax: (301) 565-9670  
E-mail:  
[info@canceradvocacy.org](mailto:info@canceradvocacy.org)  
Twitter: @CancerAdvocacy  
[www.canceradvocacy.org](http://www.canceradvocacy.org)

### **The National Consumer Voice for Quality in Long-Term Care**

1001 Connecticut Avenue, NW  
Suite 425  
Washington, DC 20036  
Phone: (202) 332-2275  
E-mail:  
[info@theconsumervoice.org](mailto:info@theconsumervoice.org)  
Twitter: @ConsumerVoices  
[www.theconsumervoice.org](http://www.theconsumervoice.org)

## Additional Resources

### National Council on Aging

1901 L Street, NW  
4th Floor  
Washington, DC 20036  
Phone: (202) 479-1200  
E-mail: Via website  
Twitter: @NCOAging  
[www.ncoa.org](http://www.ncoa.org)

### National Hospice & Palliative Care Organization

1731 King Street  
Suite 100  
Alexandria, VA 22314  
Phone: (703) 837-1500  
Fax: (703) 837-1233  
E-mail: [nhpco\\_info@nhpco.org](mailto:nhpco_info@nhpco.org)  
Twitter: @NHPCO\_news  
[www.nhpco.org](http://www.nhpco.org)

### National Institute of Arthritis, Musculoskeletal and Skin Disease

Information Clearinghouse  
1 AMS Circle  
Bethesda, MD 20892  
Phone: (877) 226-4267  
Phone: (301) 495-4484  
Fax: (301) 718-6366  
E-mail: [niamsinfo@mail.nih.gov](mailto:niamsinfo@mail.nih.gov)  
Twitter: @NIH\_NIAMS  
[www.niams.nih.gov](http://www.niams.nih.gov)

Resources verified April 2014.

## References

1. Department of Pain Medicine and Palliative Care at Beth Israel Hospital, Caregiver Resource Directory <http://www.netofcare.org/content/default.asp>. Accessed April 18, 2014.
2. Ferrell BR, Rhiner M, Cohen MZ, Grant M. "Pain as a metaphor for illness. Part I: Impact of cancer pain on family caregivers." *Oncol Nurs Forum*. 1991;18(8):1303-9.
3. Connelly M, Anthony KK, Schanberg LE. "Parent Perceptions of Child Vulnerability Are Associated With Functioning and Health Care Use in Children with Chronic Pain." *J Pain Symptom Manage*. 2012 May; 43(5):953-960.
4. McCluskey S, Brooks J, King N, Burton K. "The influence of 'significant others' on persistent back pain and work participation: A qualitative exploration of illness perceptions." *BMC Musculoskeletal Disorders*. 2011;12:236.
5. American Psychological Association. "Our Health at Risk." <http://www.apa.org/news/press/releases/stress/2011/health-risk.aspx>. Accessed April 18, 2014.
6. Roberts J, "Caregivers Providing Pain Management." The Caregiver.com, [http://www.caregiver.com/channels/medication/articles/caregivers\\_providing\\_pain\\_management.htm](http://www.caregiver.com/channels/medication/articles/caregivers_providing_pain_management.htm). Accessed April 18, 2014.
7. McCaffery M, Pasero C. *Pain: Clinical Manual*. Mosby, Inc.; 1999:685
8. Thompson L., "Long-term care: Support for Family Caregivers." Washington, DC: Georgetown University, 2004.
9. National Alliance for Caregiving. "Caregiving in the U.S. 2009." November 2009. p 5. [http://www.caregiving.org/data/Caregiving\\_in\\_the\\_US\\_2009\\_full\\_report.pdf](http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf). Accessed April 18, 2014.
10. Albright DL, Kruse RL, Oliver DP, Washington K, Cagle J, Demiris G. Testing the Factorial Validity of Scores From the Caregiver Pain Medicine Questionnaire. *J Pain Symptom Manage*. 2014 Jul; 48(1):99-109.
11. McPherson CJ, Hadjistavropoulos T, Lobchuk MM, Kilgour KN. Cancer-related pain in older adults receiving palliative care: patient and family caregiver perspectives on the experience of pain. *Pain Res Manag*. 2013 Nov-Dec;18(6):293-300. Epub 2013 Aug 16.
12. Parker Oliver D, Albright DL, Washington K, Wittenberg-Lyles E, Gage A, Mooney M, Demiris G. Hospice caregiver depression: the evidence surrounding the greatest pain of all. *J Soc Work End Life Palliat Care*. 2013;9(4):256-71.