

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.¹

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.^{1,2}

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.³

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.⁴

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.⁵

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.⁵

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

Facts

- The family caregiver's role in managing pain includes:⁷
 - 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.^{8,9}
- 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.⁹

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.¹⁰

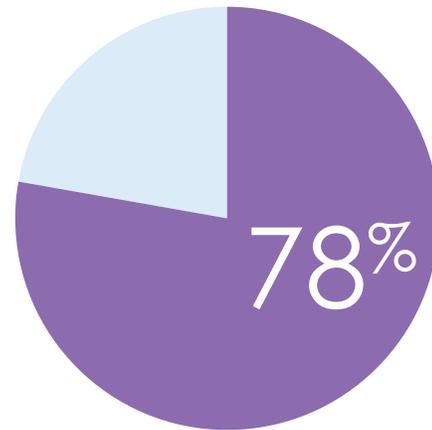
Although patients and caregivers show a willingness to be involved in pain management, it is identified as one of the most challenging aspects of care and many believe that they do not have control over cancer pain. The adverse effects of cancer pain on patients' quality of life have been well-documented.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

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.¹²

- Your loved one may be in pain if he/she:¹
 - 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:¹¹
 - 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%.⁸

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



Hours of Care a Week



13% of family caregivers provide 40 hours of care a week or more.⁹

Additional Resources

AARP

601 E Street, NW
Washington, DC 20049
Phone: (888) 687-2277
E-mail: Via website
Twitter: @AARP
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
Twitter: @ACLGov
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

Caregiver Action Network

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

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

Leading Age

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

Lotsa Helping Hands

34 Washington Street
Suite 310
Wellesley Hills, MA 02481
E-mail:
info@lotsahelpinghands.com
Twitter: @LotsaHelping
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

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
Twitter: @CancerAdvocacy
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
Twitter: @ConsumerVoices
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

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
Twitter: @NHPCO_news
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
Twitter: @NIH_NIAMS
www.niams.nih.gov

Resources verified April 2014.

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