



Fact Sheet

Caregivers & Pain

About

The biggest fear of chronically ill patients and their families is that the patient will suffer with unrelieved pain.¹ Many caregivers consider pain to be an indication of the patient's status and equate worsening pain with advancing disease and 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

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in terms of providing pain relief.²

Research shows that patients and caregivers benefit from structured pain management education, resulting in reports of caregivers feeling useful and patients having more strength, increased appetite, less worry, and greater sense of control.

Caregivers Serving as a Pain Management Advocate

Besides being the person experiencing pain, the next worst thing is for a caregiver to watch a loved one in pain. One way you can help is by acting as his/her advocate. A few ways you can do this are by:

- Believing your loved one's report of pain.
- Paying attention to the signs that indicate that your loved one might be in pain. These may include facial expressions, breathing and sighing heavily, unusual body movements, behavioral changes (such as not wanting to eat or sleep), or mental changes such as crying or irritability.
- Speaking up for your loved one when you go to the doctor, including insisting on managing his/her pain.

From the National Family Caregiver's Association
http://www.thefamilycaregiver.org/caregiving_resources/aapm.cfm

Facts

According to the Department of Pain Medicine and Palliative Care at Beth Israel Hospital in New York, 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 family caregiver’s role in managing pain includes:³

- 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

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

Family Caregivers are a critical support structure for Americans with chronic illnesses, and the U.S. Health System. In any given year, more than 50,000,000 Americans find themselves in a caregiving role.⁴



13% of family caregivers provide 40 hours of care a week or more.⁵



Family caregivers provide the vast majority (80%) of all long-term care services for those with a chronic illness or disability.⁴

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).⁵

Additional Resources

Administration on Aging- National Family Caregiver Support Program

One Massachusetts Avenue NW
Washington, DC 20001
Phone: (202) 619-0724
Fax: (202) 375-3555
E-mail: aoainfo@aoa.hhs.gov
www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Caregiver/index.aspx

AARP

601 E Street NW
Washington, DC 20049
Phone: (888) 687-2277
http://assets.aarp.org/external_sites/caregiving

American Nurses Association, Inc. Council on Gerontological Nursing

8515 Georgia Avenue, Suite 400
Silver Spring, MD 20910-3492
Phone: (800) 274-4262
Phone: (301) 628-5000
Fax: (301) 628-5001
www.nursingworld.org

Legal Services for the Elderly

350 Broadway, 6th Floor
New York, NY 10013
Phone: (212) 431-7200
Fax: (212) 966-9571
E-mail: info@LegalServicesNYC.org
www.lsnyc.org

National Center on Elder Abuse c/o Center for Community Research and Services

University of Delaware
297 Graham Hall
Newark, DE 19716
Phone: (302) 831-3525
Fax: (302) 831-4225
E-mail: ncea-info@aoa.hhs.gov
www.ncea.aoa.gov

Caregiving Tipsheets:

www.aoa.gov/AoARoot/Press_Room/Products_Materials/index.aspx

American Geriatrics Society

The Empire State Building
350 Fifth Avenue, Suite 801
New York, New York 10118
Phone: (800) 563-4916
Phone: (212) 755-6810
Fax: (212) 832-8646
www.healthinaging.org

Leading Age (formerly American Association of Homes for the Aging)

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

Lotsa Helping Hands

2 Clock Tower Place, Suite 610
Maynard, MA 01754
E-mail: info@lotsahelpinghands.com
www.lotsahelpinghands.com

National Citizens Coalition for Nursing Home Reform

1828 L Street, N.W., Suite 801
Washington, DC 20036
Phone: (202) 332-2275
Fax: (202) 332-2949
E-mail: info@theconsumervoice.org
www.nccnhr.org

National Coalition for Cancer Survivorship

1010 Wayne Avenue, Suite 770
Silver Spring, MD 20910
Phone: (888) 650-9127
Phone: (301) 650-9127
Fax: (301) 565-9670
E-mail: info@canceradvocacy.org
www.canceradvocacy.org

National Family Caregivers Association

10400 Connecticut Avenue, Suite 500
Kensington, MD 20895-3944
Phone: (800) 896-3650
Phone: (301) 942-6430
Fax: (301) 942-2302
E-mail: info@thefamilycaregiver.org
www.nfcacares.org

National Institute of Arthritis, Musculoskeletal and Skin Disease Information Clearinghouse

1 AMS Circle
Bethesda, MD 20892-3675
Phone: (877) 226-4267
Phone: (301) 495-4484
Fax: (301) 718-6366
E-mail: niamsinfo@mail.nih.gov
www.niams.nih.gov

National Council on the Aging, Inc.

1901 L Street, N.W.
4th Floor
Washington, DC 20036
Phone: (202) 479-1200
Fax: (202) 479-0735
E-mail: info@ncoa.org
www.ncoa.org

National Hospice & Palliative Care Organization

1731 King Street, Suite 100
Alexandria, Virginia 22314
Phone: (703) 837-1500
Fax: (703) 837-1233
E-mail: nhpco_info@nhpco.org
www.nhpco.org

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References

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<http://www.netofcare.org/content/default.asp>.
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. McCaffery M, Pasero C. *Pain: Clinical Manual*. Mosby, Inc.; 1999:685.
4. Thompson L., "Long-term care: Support for Family Caregivers [Issue Brief]." Washington, DC: Georgetown University, 2004 and U.S. Agency for Healthcare Research and Quality. Long-Term Care Financing Project, Long-term Care Users Range in Age and Most Do Not Live in Nursing Homes. November 8, 2000.
5. National Alliance for Caregiving. "Caregiving in the U.S. 2009." November 2009. page 5.
http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf Accessed May 24, 2011.