

Coping With Alzheimer's Disease

PHILADELPHIA (Philadelphia, Co.) - Approximately four million Americans are living with a disease that robs them of their memories and their ability to take care of themselves. It is Alzheimer's disease, and there is no known cure.

According to a 1993 survey, 19 million Americans said they had a family member with Alzheimer's disease. These family members must not only take care of their loved one, who is no longer able to care for himself or herself, but must deal with the loss of the person they once knew. In addition there are financial strains placed on the family, and a series of hard decisions and sacrifices that affect the entire family.

More than 7 out of 10 people with Alzheimer's disease live at home. Almost 75% of the home care is provided by family and friends. The remainder is "paid" care costing an average of \$12,500 per year. Families pay almost all of the out-of-pocket, because Medicare does not cover the cost of chronic care. Meanwhile, the average cost for an Alzheimer's patient to live in a nursing home is \$42,000 per year, but can exceed \$70,000 per year in some areas of the country.

One of the biggest problems facing Alzheimer's families is what they feel they must face this trial alone. Many feel it is a private family matter that the family must deal with. Others feel they cannot afford the many services that are available to help Alzheimer's families such as respite care, adult day care, or in-home care. November is National Alzheimer's Awareness Month, supported by the

Alzheimer's Association of Southeastern Pennsylvania. The Alzheimer's Association of Southeastern Pennsylvania is here to help local families who are facing these difficult decisions, and are unsure of where to turn. One woman who has enlisted the help of the Alzheimer's Association of Southeastern Pennsylvania is Miriam Burnett.

By 1983, Miriam knew that there was something wrong with her mother, Mildred Harris. Mildred was no longer able to function as the clerk at her church. She had difficulty organizing and keeping track of the cookie sale for her Girl Scout Troop. Mildred's friends from church called Miriam to tell her that they worried about Mildred's driving ability. Suddenly one day, her employers suggest to her that she retire that day. Miriam decided it was time to take her 72-year old mother to the doctor. Like one out of every 10 persons over the age of 65, Mildred Harris has Alzheimer's disease.

For ten years, Miriam and her family were the primary caregivers for Mildred. They faced some difficult problems. Mildred was often frustrated by her inability to remember things, by her confusion. She often lashed out at her husband and began to beat him. Her husband was also elderly and frail and could not handle these bouts of frustration alone. Often Miriam had to travel at a moment's notice from her home in West Philadelphia to her mother's house in North Philadelphia to help calm her mother down. The disease progressed so quickly that for two years Miriam

was living with her mother while trying to maintain her own household as well.

But Mildred and Miriam were not alone during this time. Miriam notes that she contacted the Alzheimer's Association of Southeastern Pennsylvania less than a year after her mother's diagnosis.

"After calling the Alzheimer's Association back in 1984, I became aware of all the resources available to families caring for an Alzheimer's patient, particularly respite and day care. Those are the types of things that many folks do not realize are available," Miriam notes. The Alzheimer's Association of Southeastern Pennsylvania and Miriam began a partnership back in 1984 that is still going strong to this day.

As Mildred progressed through the stages of Alzheimer's, more help was needed to insure her safety and comfort. For Miriam this meant utilizing respite care, day care and in-home care for her mother. She admits that she was very hesitant in making the decision to let others care for her mother, but relied on the Alzheimer's Association of Southeastern Pennsylvania to help her through this difficult time.

"I was very concerned, because I wouldn't know what was happening while I was not with my mother. I wanted to insure that the caregivers were living up to my standards of care. The Alzheimer's Association helped me get in touch with very qualified people," Miriam said. Miriam continued to care for her mother at home until 1993, when Mildred entered an

Alzheimer's facility full-time.

With this step came more worries than Miriam had counted on. "Having my mother in a facility did not relieve the stress as much, because I still had serious concerns, but little control over my mother's care."

She enlisted the help of the Alzheimer's Association of Southeastern Pennsylvania support group she had been a part of for so long to help her vent her fears and frustrations. After a few years, Miriam became the co-facilitator of her support group. And her work with the Alzheimer's Association of Southeastern Pennsylvania, the people who helped her when she needed it most, did not end there.

Since she began calling the Alzheimer's Association of Southeastern Pennsylvania for help and information, Miriam has worked on the chapter's Helpline, its minority outreach program, and also has sat on the board of directors and acted as president of the chapter. She notes that she has

seen a lot of changes in the organization, mostly in regards to the growth of the chapter. "But the Alzheimer's Association of Southeastern Pennsylvania is still dedicated to bringing help and hope to area families coping with Alzheimer's, just as it was back in 1984 when I first called."

Miriam counted on the Alzheimer's Association of Southeastern Pennsylvania to help her through a potentially devastating time for her and her family. The Alzheimer's Association of Southeastern Pennsylvania realizes the huge impact Alzheimer's has not only on the patients, but their families and caregivers as well. If you would like more information about Alzheimer's Awareness Month, The Alzheimer's Association of Southeastern Pennsylvania's programs, including the Helpline, caregiver Education programs, Safe Return program, or the Support Group network, call the chapter office at (215) 925-3220 or (800) 559-0404.

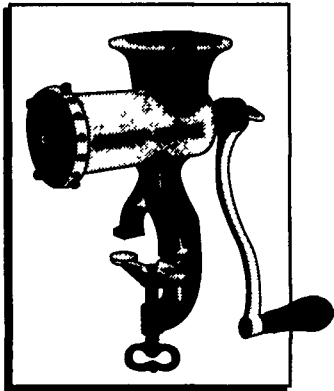


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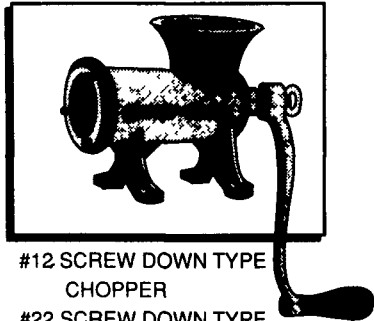
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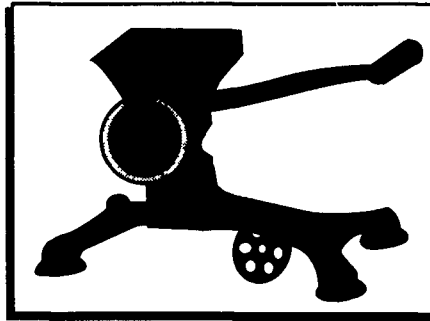
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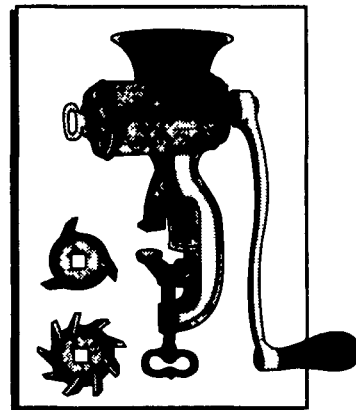
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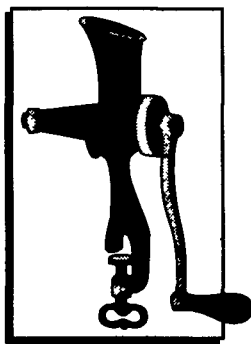
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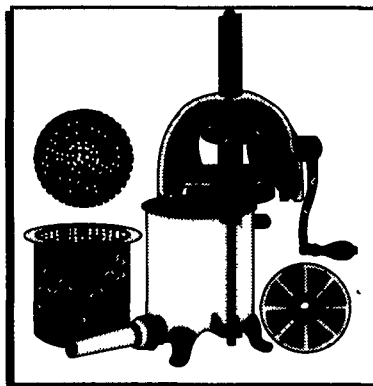
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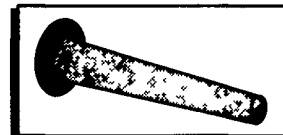
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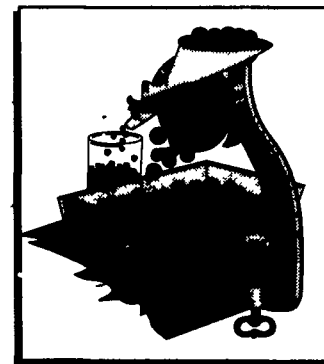
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