



Keeping In Touch

Summer 2002

News For Family Caregivers

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For Your Information

Find Benefit Programs Online

The Internet continues to be a wonderful place to find new cake recipes, buy airline tickets and, now, help seniors identify federal and state assistance programs and learn who is eligible.

BenefitsCheckUp – www.benefitscheckup.org (sponsored by the National Council on Aging) – is a confidential and free web site with easy-to-access information. The site serves all states.

The web site has a database of more than 1,000 federal and state programs for which seniors may be eligible. After completing a confidential questionnaire, users get a report detailing the programs they may qualify for as well as information on where and how to apply for the benefits.

Before using this web resource, it may be helpful to compile the following information:

- Date of birth for self and spouse
- State and zip code
- Type of residence
- Length of time in current residence
- Employment history for self and spouse
- Current income and assets from all sources in the household
- Estimate of current expenses (such as mortgage/rent, utilities, out-of-pocket medical bills, etc.)

More comprehensive program information specific to Minnesota can be found at www.mnaging.org by clicking on "Public Benefits Counselor."

The Missing Good-byes

June was a caregiver for many years before her husband died from complications of Alzheimer's disease. She lived through the stresses and strains of the caregiving years but also enjoyed the heart-warming moments. When her husband got to the point where he didn't recognize her, June started to feel less and less like a wife and more like a nurse. She lost her role as wife. Thus, she decided to take off her wedding ring. After he died, she put it back on her ring finger and it felt right. Now she was a widow, not a widow waiting to happen. Before her husband died, June was experiencing "ambiguous loss."

A book called *Ambiguous Loss: Learning to Live with Unresolved Grief*, written by Pauline Boss, a psychotherapist and professor of family social science at the University of Minnesota, is the basis of this article. Boss describes ambiguous loss as the state families arrive at when one of two things occur: someone is physically present but emotionally absent – like June; or someone is physically gone but emotionally present – a husband missing in war or a father not present because of a divorce.

These losses are very different from the grief of death, which most of us can survive and move forward. Ambiguous losses are like "frozen sadnesses." They are confusing and present conflicting emotions that can lead to anxiety, depression, and a family's emotional destruction. The uncertainty prevents people from adjusting to the loss by reorganizing the roles and rules of their relationships. The couple or family freezes in place. They cannot problem solve because they don't know whether the loss is final or temporary.

Boss suggests these strategies to help handle sadness and regain one's life:

- Give the situation a label. Naming it acknowledges its existence and gives you a reason to feel this way.
- Gather the family or group and discuss the situation from everyone's perspective. Often, there are many different views and experiences.
- Seek information that empowers. Learn more about ambiguous loss through Boss' book, support groups, friends, and the Internet.
- Share your family's interpretations of what has been lost and what remains the same.
- Listen to each other's interpretation and stories and be ready for disagreements, because there may be some.
- Recognize the positive and sometimes unexpected changes that can result from the experience. (For June, caring for her husband brought

The Missing Good-byes – continued

her closer to her daughter, who was her primary support during that time.)

- Seek ways to find meaning in the loss. (June became a respite volunteer after her husband died.

She found she could be a great help to others who were walking in her old shoes.)

Our culture tells us that we need to be in control and that we can solve every problem. We feel terrible when we can't solve a problem. Ambiguous losses, by definition, can't be solved.

Boss acknowledges that even after we have taken all the steps she recommends, we are still left with unanswered questions and feelings of uncertainty. But, we can move on with our lives. In researching the Anishinabe tribe of Ojibwe Indians of northern Minnesota, she found that they are much better than most at coping with ambiguity. They believe that, in the circle of life, aging and illness are normal. They embrace the concept that life is a mystery to behold.

Boss' book is available in the DARTS Caregiver Library. Call Alicia at 651-234-2245 to request it.



You never see it coming.

Don't Miss This in October: PBS Documentary on Caregiving in America

I don't have three arms," says Lorraine Watson. "I only have two arms. And I can only take so many people on my arms." Watson is the sole caregiver for her aging parents and her blind, mentally disabled sister.

While most of America's caregivers are responsible for the well-being of fewer loved ones than Watson, her daily demonstrations of love and quiet heroism are typical of the estimated 30 million men and women who currently provide care for the elderly and the disabled.

Their stories are told in "And Thou Shalt Honor: Caring for Our Aging Parents, Spouses, and Friends," a groundbreaking two-hour documentary scheduled to air Wednesday, October 9, from 8 to 10 PM on PBS (check local listings in October). The film, with its accompanying nationwide outreach program, is the first major PBS initiative on caregiving, an emerging healthcare issue of staggering proportions.

Filmed all over America, the program makes it clear that today's longer life spans come at a cost, and that a disproportionate amount of that cost is borne by those who step up to assume responsibility for their loved ones. Not everything about long-term caregiving is dark, however. This commitment can be a spiritual journey that expands the boundaries of love. To learn more about the PBS program, visit www.thoushalthonor.org.

Contributing is Ageless

A colleague of mine who teaches in Kansas City told me about taking his grandmother to a long-term care facility and about filling out the forms. They asked about her special needs, about the state of her health, and so on. "Well, where's the place on the form for what she contributes?" he asked. They said, "What do you mean?" "Well," he said, "she has a great deal to contribute. She will contribute wherever she is." "Oh, that's nice," they replied. "Well," my friend said, "if you're going to write down her weaknesses, why don't you write down her strengths?"

Some places might do that, but the impression is probably that people going into a long-term care facility are measured by their weaknesses rather than by their potential gifts.

(Footnote: This is one of those jewels I filed away, but I neglected to include enough of the original to give credit to the source. So, thanks to the author!)

CaregiverMN.org

Don't forget to visit our DARTS web site for family caregivers of seniors. The site -- www.caregiverMN.org -- offers to-the-point information about common caregiving issues, confidential e-mail communication with a DARTS advisor, recommended resources and web sites, and a bulletin board to share experiences and questions.

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