

# **At the Heart of Alzheimer's: CARING & COPING**

*by Carol Simpson*

All human hearts long for security, basic comforts, affection, and respect. Age and abilities make no difference. Infants who cannot intellectually "understand" their environment react positively to having these needs met, as do people with Alzheimer's who have lost the ability to respond in ways that are familiar to most caregivers. In fact, the challenge to parents of the very young and caregivers of people with Alzheimer's are often similar: to understand and fulfill the needs of someone who cannot easily communicate what those needs are.

At times this seems an impossible challenge. It's only normal for frustration to build when it's difficult to decipher the clues. But caregivers should always remember that what they give makes a difference. The language of the heart can be heard even when there are no words to express it.

## **The Keys to Quality Caregiving**

As the caregiver, you will find the challenges that lie ahead may be eased if you look for, appreciate, and reinforce the mental and physical strengths of your relative with Alzheimer's.

You will be well rewarded for the effort -- the person with Alzheimer's disease will remain at maximum levels of function, will express less anger and frustration, and may have fewer behavior problems. In turn, you will feel less overwhelmed by the caregiving tasks at hand ... and in the future.

It's understandable that many families seem to become preoccupied with the deterioration they see instead of taking comfort from and reinforcing what's still positive. However, if you emphasize the strengths, it will help you develop new ways of communicating and interacting effectively. This is not as difficult as it may sound at first. Through most of the course of the disease, a person with Alzheimer's can laugh, communicate, enjoy children, music and pets, and remain deeply spiritual.

Jean, who has had Alzheimer's for several years, finds great pleasure in her life, despite difficulty coping with many day-to-day tasks. "My general

advice to someone else with Alzheimer's," she says with a smile, "would be to find out what the rules are and be sure to have fun."

### Suggested Goals for Caregivers

Encourage maximum independence and social interaction, while providing security and comfort to the person with Alzheimer's.

Help your relative with daily personal care activities but don't do tasks for him or her if they can be done independently. This is important because even though those with Alzheimer's may seem childlike, they are adults and will feel angered or embarrassed if treated like a dependent infant.

Learn to accept compromise. Allow the person with Alzheimer's to perform tasks and responsibilities in whatever way he or she can, as long as it causes no physical harm or mental anguish even if the execution doesn't meet your standards.

Develop new ways of communicating and creative methods of sharing activities. For example, if your loved one enjoyed going to the symphony, you may not be able to go out to the theater, but you can listen to classical records together at home. Remind yourself of your loved one's previous interests and abilities and encourage him or her to talk about them or help continue to do them.

Establish a support network - don't isolate yourself. Rely on friends, family, and social service organizations to provide day-to-day assistance, counseling, and advice.

Educate yourself about Alzheimer's and its impact on the caregiver and family. The more you understand what is happening to your relative, the easier it is to be patient and to act appropriately in the face of often confusing and difficult behaviors.

### Challenges Facing the Caregiver

Finding your emotional equilibrium when your loved one has Alzheimer's can be difficult. You're mad. You're sad. You're trying to figure out how to act. Watching your loved one slowly fade is heartbreaking. Coping with erratic behaviors may be frightening or embarrassing. Eventually the disease makes *it* impossible for the person with Alzheimer's even to recognize you.

You don't need false encouragement. You don't want to be swamped with advice about how to provide care, and you surely don't want anyone telling

you that if you just buck up, you can sail through the process without hitting rough spots. Yet all of us need support and advice at one time or another.

"Caring for someone with Alzheimer's is a roller coaster. Sometimes you feel strong, sometimes helpless and bewildered," says Lisa Gwyther, MSW, Director of the Family Support Program at the Duke Center for Aging. "That's only to be expected." Gwyther's approach is gentle and effective. "You don't have to figure everything out immediately," she says. "You don't have to make all the decisions about how to cope with providing care all at once.

"In our research, the one thing that we recognized is most helpful to families is to stop assuming that it is a simple, straight forward process," says Gwyther. "In the best of all possible worlds, you wouldn't have to see your family member deteriorate, but you have limited choices, and nothing is going to make things the way they were."

Remember, above all, you're not alone, and, chances are, many other people in your situation feel the same way you do.

### Asking for Help

There are few rules about providing care, but one that you should take to heart is: *Ask for help.*

The first place to turn is friends and family. Arranging for two or three short breaks a week will help you restore your energy. If you can expand that time, do so. But don't rule out possible assistance simply because it is only for short periods of time.

Participating in support groups made up of other caregivers is also tremendously helpful. You will learn how normal your feelings are and gather tips and techniques for coping and caring.

Using social services, such as adult daycare or at-home nursing services that are provided by the local, state, or federal government at little or no cost, hiring an assistant, or spending money on caregiving programs, can help you cope with stress and fulfill the needs of your loved one. However, many caregivers are reluctant or unaware of how to use such resources. "Using social agencies or paid help can be difficult. Fear of spending money that might be needed later inhibits many people," says Gwyther.

"People are afraid that the future costs of the disease will be so great that they don't want to spend money on services that will help them cope better today."

In addition, caregivers see respite services or daycare, even when offered on a sliding scale so they aren't too expensive, as something they'd be doing for themselves instead of for their loved one. *They* don't want to spend money on themselves. But remember, a new friend or a new situation for your relative can be beneficial and fun.

Other obstacles to relying on social services or paid help include a mistrust of strangers, media stories of people being exploited or abused by home-care workers, and the feeling that, "No one can care for my loved one like I do." According to Gwyther, most people turn to outside help only after they become disappointed in the availability or reliability of assistance from friends and family or when they are so overwhelmed and can't cope anymore.

As a caregiver, you want to recognize that easing your stress does help your loved one, because it keeps you strong physically and emotionally. It lets you avoid burnout. You want to give yourself permission to ask for help before you reach such a crisis point. Relying on an ever-changing mix of family and friends, social services, and support groups is the most effective.

Signs of Burnout:

#### A Checklist for Caregivers

1. Are you curtailing visits and phone calls with close friends?
2. Have you given up hobbies or activities that you have enjoyed for years?
3. Are you developing stress-related problems such as back pain, headaches. Chronic feelings of fatigue, and depression?
4. Are you coming down with colds, flu, and other illnesses more than usual?
5. Do you have a short temper? Do you find you're getting mad in the checkout line at the grocery store? In traffic? With friends or family?
6. Do you have outbursts of anger at your loved one with Alzheimer's when he or she behaves erratically or becomes difficult?
7. Have you gained or lost weight unintentionally?

8. Do you have an unshakable feeling of despair or pessimism?

9. Are you crying "for no reason" or over minor problems?

10. Do you complain about lack of sleep or chronic insomnia?

*If you answered "yes" to two of these questions, you are probably developing burnout. "Yes" to three or more questions indicates the need for immediate help from friends, family, and social-service organizations to ease your stress.*