

Living With John: Caring for a Loved One with Alzheimer's Disease

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Alzheimer's disease has been called the "death of the mind." Sufferers not only forget their keys, but what keys are for; they get lost in familiar surroundings; they become suspicious and agitated as life becomes increasingly baffling. Over a period of three to twenty years they are reduced to the developmental stage of a newborn, totally dependent on their caregiver until death releases them.

John Madison was stricken with Alzheimer's at the premature age of fifty-three. His wife, Nellie, has been looking after him in their own home for the past fourteen years. After crying for three days because the husband she had known was gone forever, this self-described "eternal optimist" took on the challenge of being his caregiver, one problem at a time. From the distress of the first warning signs of the disease to the importance of brain autopsy after death, she shares what she has learned in matter-of-fact terms, neither dramatizing or sentimentalizing.

When John asked her what they were going to do about his Alzheimer's, Nellie told him not to worry because she would look after him. He went peacefully to sleep and never mentioned it again. She carried on for nine years without any professional respite care, until a heart attack forced her to rely on the assistance of nursing homes, where the staff often does not remember that John cannot sleep without his special bedtime rituals, or that he likes to chew up paper napkins.

How does a sixty-six-year old woman with a bad back cope with a restless, child-like adult who is still fit enough to race up the steps two at a time? With common sense, resourcefulness, and a sense of humor, Mrs. Madison describes how she manages to keep her husband clean, clothed, and healthy, even if it means chasing him around the bathroom with a toilet plunger. When she first faced the enormous challenge of being a round-the-clock caregiver, she needed specific, practical information and found very little. Now, she hopes to help others by passing on her hard-earned knowledge.

Four million Americans have been diagnosed with Alzheimer's including former President Reagan. Unless a cure is found, there will be fourteen million patients by 2050. Living with John puts a human face on these statistics, and offers information, advice and encouragement to friends, neighbors and families of the victims of this devastating illness.

CHRISTINE G. RICHARDSON (July / August 2000)

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