

## Family Caregivers: The Unsung Heroes of Alzheimer's Caregiving

*Except where noted, the selected highlights below are drawn from an ongoing, longitudinal survey conducted by Consumer Health Sciences every six months since March 1997. Janssen Pharmaceutica supported and provided input into the CHS survey. Sample size varies over time; however, in December 2001 – the date of the most recent analysis available to Janssen – there were 3,047 Alzheimer's caregivers participating. The purpose of the survey is to understand, explain and predict the healthcare attitudes and behaviors of caregivers of Alzheimer's patients.*

### **Relatives Shoulder Most Caregiving Responsibilities**

- Overall, 92% of Alzheimer's caregivers are family members.<sup>1</sup>
- 68% of Alzheimer's patients live with a caregiver.<sup>1</sup>
- 48% of caregivers are adult children.<sup>1</sup>
- 44% of caregivers are spouses.<sup>1</sup>
- 79% of caregivers are women.<sup>1</sup>
- The average age of caregivers is 60.<sup>1</sup>
- On average, caregivers have been playing this role for four years.<sup>2</sup>

### **Caregiving is Time-Consuming and Physically/Mentally Difficult<sup>3</sup>**

#### *Most time-consuming tasks:*

- Managing money and financial matters
- Running errands
- Performing household chores

#### *Most difficult tasks from caregiver perspective:*

- Managing behavioral disturbances, such as physical or verbal aggression
- Providing emotional support to the patient
- Assisting with personal hygiene (bathing, bladder/bowel functions)

### **Caregiving Affects Employment and is Costly to Society/Caregiver**

- 34% of respondents reported that caregiving affected their employment status; of those, 50% took early retirement and 39% changed jobs<sup>3</sup>
- Working caregivers lost an average of 18 days within the previous six months due to patient needs<sup>3</sup>
- 27% of caregivers devoted more than 40 hours per week to caring for an Alzheimer's patient<sup>2</sup>

### **Alzheimer's Caregivers Have Significant Physical and Mental Health Problems<sup>4</sup>**

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<sup>1</sup> Derived from CHS survey data gathered in December 2001

<sup>2</sup> Who Cares? Families Caring for Persons with Alzheimer's Disease (published by the Alzheimer's Association, 1999)

<sup>3</sup> Derived from CHS survey data gathered in April 1997

- **Percentage of caregivers who experience the following mental health problems due to caregiver stress:**  
46% sleep disturbances; 37% anxiety; 36% depression
- **Percentage of caregivers who are coping with their own health problems:**  
60% backaches/pain; 49% arthritis; 40% indigestion/ulcers; 32% high blood pressure; 31% high cholesterol

*To gain further insight into the needs of the Alzheimer's caregiver, Janssen Pharmaceutica conducted focus groups among adult children and spouses in six cities (Philadelphia, Chicago, Tampa, Minneapolis, Phoenix and Fort Lauderdale). Research revealed the following insights:*

### **Caregivers Have Unmet Needs**

- Alzheimer's caregivers often feel disconnected and isolated.
- Many caregivers do not access the wealth of information available to them for a variety of reasons, including lack of awareness and time.
- When they do obtain information, family caregivers are unlikely to access a single source.
- Caregivers' information needs are two-fold:
  1. **Medical** (diagnosis, treatment and prognosis), specifically:
    - Warning signs
    - Expectations for each stage
    - Treatment options
    - Managing combativeness and other behavioral disturbances
  2. **Non-Medical**, specifically:
    - Activities for persons with dementia
    - Eating/nutrition
    - Coping with caregiver stress
    - Understanding Medicaid
    - Safety precautions for the home
    - Planning/managing long-term care

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<sup>4</sup> Derived from CHS Survey data gathered in July-August 1999