Institutional Approaches To The Care of Individuals With Dementia: Report of a National Facility Survey and The Hebrew Home for the Aged at Riverdale, as a Case Study

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I. INTRODUCTION

The provision of competent, compassionate and cost-effective care to individuals with dementing illnesses, and their families, has become a critical concern of Federal, State and local governments, the formal and informal care networks, service advocates and consumers (HHS, 1984, New York Academy of Medicine, 1985, New York City Department of Mental Health, Mental Retardation and Alcoholism, 1985). The 1985 initiative by Congress to the Office of Technology Assessment "to analyze the public policy implications of the large number of people who are affected..."represents an important step toward a cohesive, national, long-term care policy in this regard.

In contrast to this recent increased interest in care for the individual with dementia, it should be noted that institutional, long-term care facilities have always cared for individuals with serious cognitive impairments - whether it was under the rubric of "senility", "hardening of the arteries", "organic brain or mental syndrome", or more recently "dementia - probably of the Alzheimer's type." What has changed is not the existence of a population with dementing illnesses but, rather, their proportion within the total number of institutionalized aged has increased significantly.

Estimates of the presence of cognitive impairment among nursing home residents range from thirty to eighty percent. While these statistics vary with definition, four surveys are germane, beginning with the 1977 National Nursing Home Survey that found almost 60% of nursing home residents to have chronic brain syndrome or senility without psychosis (National Center for Health Statistics, 1979). Similarly, an assessment of a Washington, D.C. nursing home
(Rovner & Rabins, 1985) indicated that 70 to 80% of the residents had some form of cognitive disorder - of which Alzheimer's disease and multi-infarct dementia were the most common cause. These results are consistent with the 1984 survey of 42 skilled nursing facilities in upstate New York confirming that 64% of the population had moderate to severe behavioral problems ranging from impaired judgement to danger to oneself and others (Zimmer, et. al., 1984). Katzman (1985), in a recent evaluation of nursing home admissions (also) in New York State, noted that seventy-five percent had some form of dementia upon admission; these were not symptoms which developed following prolonged nursing home residency.

Perhaps the primary reason that nursing homes have become the major source of institutional care for the elderly mentally impaired population is the concomitant de-institutionalization of the State mental hospital system population and the quadrupling of nursing home beds in the United States over the past twenty years (U.S. National Center for Health Statistics, 1979, Johnson & Grant, 1985, Brody et. al., 1984). Changes in contemporary society from the demographic as well as nuclear family perspective have also increased the role of the nursing home. With the dramatic increase in the number of individuals 85+ years, was a decline in the availability of informal supports as a function of changes in the woman's role toward employment, fewer children, greater geographic diversity, and an increased divorce rate (Grossman, et. al., 1986, Brodv, et. al., 1984, Johnson & Grant, 1985).

It is estimated that one million people over age 65 suffer from severe dementia with an additional 2 to 3 million mildly affected (Ringler, 1984). Inasmuch as the prevalence rates of SDAT increase from approximately 2% in
those age 65-70 to 22% in those 80 years and over (Brody, et. al. 1984) the rapid growth of the old-old age cohort makes the issue of appropriate and effective institutional response critical to the needs of the demented population.

The notion of homogeneous versus heterogeneous placement of individuals with dementia in nursing homes has been intellectually debated in the literature. It has been suggested that patients with varying levels of clinical need should be integrated on the same nursing unit, i.e., "main-streaming" (Ablowitz, 1983). It is further postulated that such integration will result in a beneficial impact for all patients on the integrated unit. Those with lower levels of need may enjoy or benefit from helping the more impaired patients. Those patients who are more impaired may benefit from the companionship of a patient who functions at a higher cognitive level. Bergman (1983) specifically suggests that residents with different abilities compensate for fellow patients' lack of ability, seemingly without peer or staff pressure. Gurland (1985) further suggests that segregation is a reaction to staff and family who find disruptive behavior disconcerting.

In contrast, Bowker (1982) reported that mixing of patients with different levels of functioning may result in a strong sense of dehumanization. Specifically, such integration of patients may have a demoralizing impact upon those who need to demonstrate their own mental competency (Smithers, 1977). Wiltzius (et. al. 1981) noted negative changes in mental and emotional status in competent residents whose roommates were confused. Further, the severely impaired patient's response to a "typical" skilled nursing unit may be explosive or result in withdrawal from a setting which is too demanding. In contrast, an
oriented, rational individual may find the supportive, environmentally modified unit confining, too circumscribed and devoid of interest (Goldfarb, 1973).

An experiment on the effects of segregating and integrating the mentally impaired (Kahana, et. al., 1970) was inconclusive with regard to the patient population, but did suggest benefits, for staff, of related stimulation and attitude training. Hiatt (1985) also supports the notion of patient placement by functional level as a means to more effectively and efficiently pool resources.

Mace (1985) simply concludes that special units have shown that patients can benefit from a safe environment and planned activities.

Regardless of its philosophy or approach to patient placement, the long-term care facility has an important function within the continuum of services for persons with dementing illnesses. Haycox (1980) suggests that when the patient can no longer recognize the caregiver, institutional placement becomes appropriate. Clearly, the role and importance of the nursing home is increased when there are limited informal care networks (Oriol, 1985). Interestingly, it has been suggested that the nursing home is, in fact, the most appropriate and effective option for care of the moderately to severely demented individual (Brody, et. al., 1984). Yet, as the (1984) Report of The (HHS) Secretary's Task Force on Alzheimer's Disease emphasized, increased efforts are required to evaluate the:

"socio-environmental and organizational characteristics of long-term settings (i.e. size, type of institution, staff to patient ratios) which effect the functioning and well-being of Alzheimer's disease patients."
Similarly, a recent survey of American Association of Homes for the Aging facilities also indicated a desire for information regarding staffing, environment and design for programs for this population cohort (Webb, 1985).

This report documents long-term care facility response in the care of patients with dementia from two perspectives. The first component provides an overview of the approaches taken by facilities nationally that have identified themselves as providing "special programs for individuals with dementia." Part 3 utilizes the Hebrew Home for the Aged at Riverdale as a case example of a large, voluntary, long-term care facility's special care unit (SCU) approach.

It should be noted, at the outset, that in the context of this report, dementia refers to the DSM-III categories of: primary degenerative dementia, senile onset; primary degenerative dementia, pre-senile onset, and; multi-infarct dementia, each including the sub-types of delirium, delusions, depression, and uncomplicated (American Psychiatric Association, 1980).

II. NATIONAL FACILITY SURVEY

With the support of the Brookdale Foundation, and in the context of The Hebrew Home for the Aged at Riverdale's (HHAR) own institutional planning, an in-depth mail survey of facilities (see Appendices A and B) identified as having special programs for individuals with Alzheimer's disease and other dementias was conducted. These 48 facilities were identified as a result of earlier American Association of Homes for the Aging and National Association of Jewish Homes for the Aged surveys, a computerized literature review,
grass-roots research and collegial correspondence. Of these, thirty-eight (80%) responded to the more in-depth questionnaire as detailed in this paper. These facilities represent the diversity of geographic locations, religious and secular affiliations, and agency size. Thirty-three (86%) are voluntary, non-profits; 5 (14%) are proprietary facilities. While more than 10,250 beds are represented by these facilities, this information is presented as descriptive with the caveat that these are self-selected facilities and programs.

Development of Special Care Units

An indication of the provision of special programs does not defacto indicate the existence of special care units (SCUs) for individuals with dementia. Of the thirty-eight facilities, twenty-five (66%) have developed such designated units. (See Table 1)

The majority of SCUs are at the SNF level of care or within facilities with only one level of care. The number of beds allocated to special care units ranges from 8 beds to 200 beds and 6% to 51% of institutional bed complement. Further, the average designation is 12% of bed complement and 1.5 such units in the facility. The contrast between the 12% complement designation (for patients with dementia) and the probable number of patients with dementia (exceeding 50%) is noteworthy.

The establishment of such SCUs is not a new phenomena within practice realms; the "average" unit having been established 5.4 years ago. While the "age" of the oldest unit exceeds 24 years, both OTA and HHAR learn of new SCUs
### Table 1

**Organization of Patients with Dementing Illnesses**

(N=38)

<table>
<thead>
<tr>
<th>Approach</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discrete, planned &amp; designated</td>
<td>25</td>
<td>63</td>
</tr>
<tr>
<td>Special Care Unit</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Progressive, functional placement</td>
<td>5</td>
<td>14</td>
</tr>
<tr>
<td>without SCU designation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Considering SCU development;</td>
<td>5</td>
<td>14</td>
</tr>
<tr>
<td>currently have special activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cluster approach on one unit</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Closed a SCU in favor of</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>heterogeneous placement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Special activities, are not</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>considering a SCU</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
seemingly on a daily basis. SCU development is almost equally divided between new construction and conversion of traditional ICF/SNF units.

It should be noted that one-third of the respondents indicated increased costs associated with SCU programs. Private rates vary from $40 to $120 per day.

Reported Objectives of a Special or Designated Unit

Special care unit objectives provide an operational framework, and context for further decision-making and program development. Program objectives or goals articulated most frequently by those facilities surveyed, are summarized in Table 2.

In addition, some facilities specifically indicate clinical goals including: the elimination of restraints; the elimination of diapers and catheters for the incontinent patient, and; the minimization of psychotropic drugs.

The determination of objectives, is usually followed by the development of admission and discharge criteria, including age, behavioral and functional criteria, and a decision regarding priority admissions (i.e. transfers) for in-house residents. It should be noted that only 5 of the facilities responding waive their 60/65 year minimum age requirement and 51% give priority for admission to the SCU to the current facility patient population (via transfers).
Table 2

Reported Special Unit Objectives

1. To provide a safe, and secure environment which is supportive from both a nursing as well as socialization perspective.

2. To reduce feelings of anxiety and confusion through both environmental and communication supports.

3. To "rehabilitate" or maintain the patient at their optimal level of physical and cognitive function.

4. To provide care to the patient in a holistic manner.

5. To recognize that these patients have come to facilities to live, rather than merely exist, and provide experiences and activities which will add to the quality of their lives.

6. To recognize that patients are autonomous human beings who can expect that their special needs and those of their families will be met with sensitivity and appropriateness.

7. To provide each patient with opportunities to succeed which will build their sense of self esteem, dignity and hope.

8. To improve the quality of life/living environment of mentally intact patients, residing on traditional SNF units.

9. To support the caretakers (staff, families and significant others) through understanding, training, education, and the minimization of stress (AAHA, 1985; Weissman, 1984; Peppard, 1984; Clark, 1982; and Weiner, 1985).
From the survey, twenty-six facilities indicated that patients were placed according to their level of cognitive/behavioral function. Of these, two facilities indicated that this was but one component of a more comprehensive system of patient placement based upon functional assessment. These facilities did not create an Alzheimer's Special Care Unit.

Table 3 categorizes the approach within thirty-one facilities with operational (or planned) SCUs or clusters. Of the five facilities identifying diagnosis as a criteria, it is not an automatic criteria for placement, but rather linked to other behavioral and functional measures. Only four report use of validated assessment tools including the MSQ.

Of these facilities, six identified their programs as serving individuals with "mild to moderate" dementia without being part of a larger, progressive institutional system of placement. It should be noted that there was no relationship between this definition and the level (i.e. SNF or ICF) of care.

Unit Designation

Approximately seventy percent of the facilities utilize their existing institutional nomenclature in referring to these units, for example "E" Floor, Barnhard Unit. In addition,

* Two facilities call their special units - "Life Enrichment Units".
* Two facilities do refer to these floors as "Alzheimer's Unit" or "Alzheimer's Division".
Table 3

Overview - Special Care Unit Role Within The Long-Term Care Facility

(N=31)

<table>
<thead>
<tr>
<th>Definition</th>
<th>Number of Facilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;Short-term&quot; placement, discharged to traditional SNF</td>
<td>24</td>
</tr>
<tr>
<td>when:</td>
<td></td>
</tr>
<tr>
<td>* The patient is not able to respond to and</td>
<td>11</td>
</tr>
<tr>
<td>benefit from the structured approach</td>
<td></td>
</tr>
<tr>
<td>* Physical care needs increased</td>
<td>8</td>
</tr>
<tr>
<td>* The patient becomes non-ambulatory</td>
<td>8</td>
</tr>
<tr>
<td>* Behavior becomes extremely disruptive</td>
<td>4</td>
</tr>
<tr>
<td>Multiple units, progressive intra-unit placement</td>
<td>3</td>
</tr>
<tr>
<td>Long-term or permanent placement</td>
<td>4</td>
</tr>
</tbody>
</table>

Note: If patient was misdiagnosed, or improves, transfer to traditional SNF is affected, regardless of other admission/discharge criteria.
One facility had a staff contest to name their unit and now utilize the acronym "MIND" which means "maintaining independence in neuro-circulatory disorders" (Fishkill Health Related Center, Beacon, New York).

Environment

Fifty-eight percent of the facilities with special care units developed these through conversion from more traditional ICF or SNF units. Regardless of the SCU/cluster or special program approach, there was, a consensus about the importance of the environment for safety and security, orientation, organization and structure, and the minimization of agitation and other behavior problems as detailed in Table 4.

In addition:

- Two facilities utilize private rooms only.
- Two facilities are designed around a cluster (6-8) of patient rooms that open onto a communal day area.
- One facility indicates the addition of considerable texture for noise control and sensory stimulation.

The value of an SCU on the ground floor with the possibility of an adjacent and secure "wandering garden" was specifically reported as beneficial to patients, family and staff (the latter for reduction of burnout).
Table 4
Environmental Modifications/Supports
(N=33)

<table>
<thead>
<tr>
<th>Increased Security/Visual Access</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>* Alarming, coding, securing exits</td>
<td>28</td>
<td>(84%)</td>
</tr>
<tr>
<td>* Modification of nurse's station</td>
<td>5</td>
<td>(15%)</td>
</tr>
<tr>
<td>* Coding, securing, camouflaging elevators</td>
<td>5</td>
<td>(15%)</td>
</tr>
<tr>
<td>* Securing patio/garden areas</td>
<td>10</td>
<td>(30%)</td>
</tr>
<tr>
<td>* Use of wide angle mirrors</td>
<td>3</td>
<td>(9%)</td>
</tr>
<tr>
<td>* T.V. monitors</td>
<td>1</td>
<td>(3%)</td>
</tr>
</tbody>
</table>

2. Increased Orientation

<table>
<thead>
<tr>
<th>Increased Orientation</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>* R 0 boards, large calendars, daily schedules</td>
<td>12</td>
<td>(36%)</td>
</tr>
<tr>
<td>* Color coding - corridors, furniture, etc.</td>
<td>7</td>
<td>(21%)</td>
</tr>
<tr>
<td>* Large letter/number/object room identification</td>
<td>8</td>
<td>(24%)</td>
</tr>
<tr>
<td>* Directional signs</td>
<td>1</td>
<td>(3%)</td>
</tr>
<tr>
<td>* Remove poisonous plants, electric wires</td>
<td>1</td>
<td>(3%)</td>
</tr>
</tbody>
</table>

3. Modification of Communal Spaces

<table>
<thead>
<tr>
<th>Modification of Communal Spaces</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>* Increased square footage</td>
<td>7</td>
<td>(21%)</td>
</tr>
<tr>
<td>* Garden, walkway created</td>
<td>5</td>
<td>(15%)</td>
</tr>
<tr>
<td>* Space modified to provide smaller areas</td>
<td>3</td>
<td>(9%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>for small group activities</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4. Noise Control

<table>
<thead>
<tr>
<th>Noise Control</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>* Carpet tiles</td>
<td>5</td>
<td>(15%)</td>
</tr>
<tr>
<td>* Elimination of intercom or PA system</td>
<td>2</td>
<td>(6%)</td>
</tr>
</tbody>
</table>

*Note: Many facilities utilize more than one technique to secure the environment, etc.
Staffing

Twenty-six skilled nursing facilities provided adequate information for staffing comparisons as noted in Table 5. Within these, facility size ranged from 120-784 beds, the number of "dementia unit beds" from 8-200. Existing staffing patterns were calculated and adjusted to a forty-bed SNF unit for ease of comparison.

It should be noted that staffing intensity was related to reported severity of patient condition, within the framework of SCU goals.

Indications of social work or recreational staff allocations were not consistent. However, where these were included, there was a range from .3 FTE to 1 FTE for both social work and activities staff, based on that illustrative 40-bed unit.

There are several approaches to staffing that merit note:

1. Activity workers assigned to a 10 a.m. to 6 p.m. shift, more reflective of available program hours.

2. Social work and activity workers' offices located on the special care units.

3. The use of part-time feeders, assistants or nurse's aide staff on the evening shift for feeding, and assistance at bedtime.

4. The use of "lounge aides" in addition to nursing assistants to supervise patients within lounge areas.
### Table 5

**Comparison of SCU Staffing Within SNF Facilities** *(N=25)*

<table>
<thead>
<tr>
<th>SNF Facility</th>
<th>Nurses</th>
<th></th>
<th></th>
<th>Aides</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>RN+LPN</td>
<td>Day</td>
<td>Evening</td>
<td>Night</td>
<td>Day</td>
<td>Evening</td>
</tr>
<tr>
<td>1.</td>
<td>4.7</td>
<td>4.</td>
<td></td>
<td>4.</td>
<td>8.</td>
<td>8.</td>
</tr>
<tr>
<td>2.</td>
<td>3.9</td>
<td>1.3</td>
<td>1.3</td>
<td></td>
<td>5.2</td>
<td>5.2</td>
</tr>
<tr>
<td>3.</td>
<td>3.9</td>
<td>1.3</td>
<td>0</td>
<td></td>
<td>3.9</td>
<td>2.6</td>
</tr>
<tr>
<td>4.</td>
<td>3.5</td>
<td>-</td>
<td>-</td>
<td></td>
<td>9.8</td>
<td>-</td>
</tr>
<tr>
<td>5.</td>
<td>3.2</td>
<td>1.6</td>
<td>1.6</td>
<td></td>
<td>6.8</td>
<td>4.</td>
</tr>
<tr>
<td>6.</td>
<td>3.</td>
<td>1.5</td>
<td></td>
<td>7</td>
<td>4.5</td>
<td>3.</td>
</tr>
<tr>
<td>7.</td>
<td>3.</td>
<td>1.4</td>
<td>1.4</td>
<td></td>
<td>4.9</td>
<td>4.9</td>
</tr>
<tr>
<td>8.</td>
<td>2.7</td>
<td>1.8</td>
<td>.9</td>
<td></td>
<td>5.4</td>
<td>4.5</td>
</tr>
<tr>
<td>9.</td>
<td>2.6</td>
<td>1.9</td>
<td>1.3</td>
<td></td>
<td>5.7</td>
<td>4.3</td>
</tr>
<tr>
<td>10.</td>
<td>2.6</td>
<td>1.3</td>
<td>1.3</td>
<td></td>
<td>5.2</td>
<td>3.9</td>
</tr>
<tr>
<td>11.</td>
<td>2.5</td>
<td>1.7</td>
<td>.8</td>
<td></td>
<td>6.6</td>
<td>3.3</td>
</tr>
<tr>
<td>12.</td>
<td>2.4</td>
<td>1.6</td>
<td>1.6</td>
<td></td>
<td>5.7</td>
<td>3.2</td>
</tr>
<tr>
<td>13.</td>
<td>2.4</td>
<td>2.4</td>
<td>1.6</td>
<td></td>
<td>6.4</td>
<td>4.8</td>
</tr>
<tr>
<td>14.</td>
<td>2.2</td>
<td>1.5</td>
<td>.7</td>
<td></td>
<td>4.2</td>
<td>4.</td>
</tr>
<tr>
<td>15.</td>
<td>2.1</td>
<td>1.</td>
<td>1.</td>
<td></td>
<td>5.2</td>
<td>4.2</td>
</tr>
<tr>
<td>16.</td>
<td>1.8</td>
<td>1.8</td>
<td>1.8</td>
<td></td>
<td>7.4</td>
<td>5.4</td>
</tr>
<tr>
<td>17.</td>
<td>1.8</td>
<td>1.2</td>
<td>.6</td>
<td></td>
<td>4.8</td>
<td>4.2</td>
</tr>
<tr>
<td>18.</td>
<td>1.6</td>
<td>1.6</td>
<td>.8</td>
<td></td>
<td>7.</td>
<td>5.2</td>
</tr>
<tr>
<td>19.</td>
<td>1.5</td>
<td>.5</td>
<td>.5</td>
<td></td>
<td>6.0</td>
<td>6.0</td>
</tr>
<tr>
<td>20.</td>
<td>1.4</td>
<td>1.4</td>
<td>.3</td>
<td></td>
<td>5.2</td>
<td>5.2</td>
</tr>
<tr>
<td>21.</td>
<td>1.3</td>
<td>-</td>
<td>-</td>
<td></td>
<td>6.5</td>
<td>6.5</td>
</tr>
<tr>
<td>22.</td>
<td>1.2</td>
<td>1.</td>
<td>0</td>
<td></td>
<td>5.</td>
<td>5.</td>
</tr>
<tr>
<td>23.</td>
<td>1.2</td>
<td>1.2</td>
<td>.9</td>
<td></td>
<td>3.5</td>
<td>3.5</td>
</tr>
<tr>
<td>24.</td>
<td>1.</td>
<td>1.</td>
<td>1.</td>
<td>5-6</td>
<td>3-4</td>
<td>1</td>
</tr>
<tr>
<td>25.</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td></td>
<td>6.5</td>
<td>4.5</td>
</tr>
</tbody>
</table>

**Average by Category**
- Nurses: 2.4 1.5 1.0 5.8 4.5 2.9
- Aides: 2.4 1.4 .9 5.6 4.3 2.7

**Notes:**
1. Based upon extrapolation to a forty bed SNF unit
2. "-" reflects omission in data.
5. The modification of traditional specific discipline or departmental responsibilities for tasks and activities. For example:

* In three facilities, nurse’s aides conduct reality orientation, remotivation, grooming and activity programs. Two other facilities have plans to utilize this approach.
* Within three facilities, nurse’s aide assignments are based on patient functional levels, allowing staff to conduct small group programs for persons at similar levels.

6. In twenty facilities (15 non-profit and 5 proprietary) there are "coordinators" for their special care unit. Their time commitment ranges from .5 FTE to full time with no relationship between either their existence, time allocation, or the number of designated special care beds. Most typically, this individual is a registered nurse (55%) or social worker (15%). In three facilities (15%) the responsibility is shared between nursing and social work. These individuals usually have the title of "Clinical Coordinator" with responsibility for program innovation, staff education, problem solving, and within, the proprietary facilities, program marketing. In one case, the coordinator is also responsible for actual programming on the unit.

**Training**

Twenty-eight of the facilities completed information regarding the type and level of training, education and staff supports provided within the context of "special programs" as detailed in Table 6. Facilities with regular staff and
Table 6

Staff Supports and Education

(N=28)

<table>
<thead>
<tr>
<th>Response</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Staff/team meetings (most usually weekly)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>distinct from actual care planning sessions</td>
<td>21</td>
<td>(75%)</td>
</tr>
<tr>
<td>2. Continued inservice</td>
<td>21</td>
<td>(75%)</td>
</tr>
<tr>
<td>3. Training prior to the development of the unit; and/or special training for new staff who will work on the special care unit</td>
<td>17</td>
<td>(60%)</td>
</tr>
<tr>
<td>4. Use of psychogeriatric hospital teams or other consultants for clinical input, rounds and education</td>
<td>4</td>
<td>(14%)</td>
</tr>
<tr>
<td>5. Team rounds</td>
<td>1</td>
<td>(3%)</td>
</tr>
</tbody>
</table>
team meetings underscored their importance from the perspectives of "ventilation" and the discussion of specific clinical issues. Initial training ranged from four to sixty hours addressing the clinical course of dementia, its cause, changes in behavior, communication patterns, and useful strategies in relationships with patients and family members.

The survey also indicated a clear understanding and integration of the importance of support for family members, as 81% of the facilities reported use of family group programs for emotional support and education.

Activities

Facility approaches to activities on dementia units vary from the highly structured, purposeful approach akin to The Burke Rehabilitation Model (Pannela, 1984) reported within five facilities, to a more flexible adaptation of institutional programs and weekly variety.

Table 7 provides an overview of activities utilized in rank order.

Research/Community Services

Sixteen (34%) of the facilities noted the existence of research activities. Of these slightly more than half relate to the impact of the SCU.
Table 7
Activities Utilized Most Frequently Within Special Programs for Dementia Patients

(in rank order)

(N=30)

<table>
<thead>
<tr>
<th>Program</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical exercise (walks, adaptive sports, dance exercise, movement, wheelchair exercise)</td>
<td>22</td>
<td>(73%)</td>
</tr>
<tr>
<td>Music (singing, active/passive listening, &quot;Mozart and wine&quot;)</td>
<td>19</td>
<td>(63%)</td>
</tr>
<tr>
<td>Cognitive stimulation (e.g. word games, communication, reminiscence)</td>
<td>11</td>
<td>(36%)</td>
</tr>
<tr>
<td>Crafts</td>
<td>9</td>
<td>(30%)</td>
</tr>
<tr>
<td>Reality orientation, remotivation</td>
<td>9</td>
<td>(30%)</td>
</tr>
<tr>
<td>Sensory stimulation, awareness (conducted by Occupational Therapy Department)</td>
<td>8</td>
<td>(26%)</td>
</tr>
<tr>
<td>Grooming, basic skills classes</td>
<td>8</td>
<td>(26%)</td>
</tr>
<tr>
<td>Cooking</td>
<td>7</td>
<td>(23%)</td>
</tr>
<tr>
<td>Bingo</td>
<td>5</td>
<td>(16%)</td>
</tr>
<tr>
<td>Ice cream and cocktail parties</td>
<td>5</td>
<td>(16%)</td>
</tr>
<tr>
<td>Horticulture</td>
<td>2</td>
<td>(6%)</td>
</tr>
<tr>
<td>Pet Therapy</td>
<td>2</td>
<td>(6%)</td>
</tr>
<tr>
<td>Sheltered workshop</td>
<td>1</td>
<td>(5%)</td>
</tr>
</tbody>
</table>
Thirteen (34%) of the facilities responding noted extension of services to community-residing elders. Most "typical" was the provision of adult day care services (8), outreach (3), and information and referral (2).

While neither this descriptive survey nor other reports within the literature draw conclusions regarding an ideal or model approach to caring for the institutionalized dementia patient, the diversity of organizational and programmatic options are of interest and value. The survey suggests that the SCU approach is viewed as an increasingly viable and popular approach within the nursing home sector. Clearly, research is required to evaluate its differential impact upon patients (both mentally intact and demented); staff, families, volunteers as well as the institution itself. Further, while the survey indicates a sharp contrast between the "typical" 12% bed designation for SCUs and the average 50% facility incidence of patients with dementia, we remain unsure of the "appropriate" institutional balance.

It is clear that SCU and/or special program development requires both substantive as well as process steps to succeed. Yet, until "success" is defined according to standards or outcomes of care, we must rely on intuitive clinical judgements to determine what is effective and/or valuable. Yet this descriptive material is useful in outlining existing approaches to care of the patient with dementia. Its lacking in depth, is related to the current state of the art, i.e. we do not yet know what goals are realistic, appropriate, valid, achievable nor which approaches (including programmatic, staffing, environment, family supports, etc.) are most successful in reaching these goals.
The HHAR, recognizing this paucity of knowledge, utilized its clinical expertise and administrative perspective to develop its Special Care Unit approach. Part 3 describes the process, substance, and outcome of this endeavor.

III. THE HEBREW HOME FOR THE AGED AT RIVERDALE

**Historical Perspective**

The Hebrew Home for the Aged at Riverdale, (HHAR) incorporated in 1917, is a voluntary, non-profit, non-sectarian, long-term, residential health care facility, in the Bronx, New York. Its origins, 68 years ago, were in a Harlem brownstone which functioned as an overnight shelter for 39 older adults. To accommodate the increasing need for shelter and care of older adults in the New York metropolitan area, the 18 3/4 acre campus on the Hudson River where the main campus is presently located, was purchased in 1948.

In the last four decades, the Home's planned institutional growth resulted in construction of three RHCF pavilions (the Infirmary building - 1958; the Goldfine building - 1965, and; the Palisade Nursing Home - 1975); renovation of the original main campus building (Stolz Pavilion - 1979); construction of a HUD/202, 137 unit apartment facility (River House West - 1980), and; purchase of a nearby 167-bed SNF to become a satellite facility (Fairfield Division - 1980).

In early 1985 ground was broken for the Henry Kaufmann Pavilion/Alzheimer's Comprehensive Care Center, which will replace the bed capacity of the Infirmary
Building as well as include an additional 49 licensed but presently non-operational HRF/ICF beds. The total number of aged individuals residing within these facilities exceeds 1100 persons.

A planning grant from the Brookdale Foundation to "Develop a Continuum of Care for Individuals With Dementia and Their Families" complemented facility construction eleemosynary support and provided the resources to complete the national facility survey detailed in Part Two of this report.

In addition, HHAR provides more than 330 "Meals on Wheels" daily and is anticipating approval in January, 1986 to open an adult day care program in which individuals with dementing illnesses will be served. Research and training activities complement core patient care services.

**Special Care Unit Development**

HHAR has had a long tradition of program and training innovation with regard to caring for a population with dementia, beginning with the establishment, in 1961, of an NIMH-supported workshop for the cognitively impaired. The remarkable nature of the 1973 lecture series by Dr. Alvin Goldfarb on working with the confused elderly was underscored by its fourth printing as a Monograph in 1982 (also with NIMH funding). Appendix C includes the Monograph resulting from the 1983 regional professional symposium sponsored by HHAR on "Alzheimer's disease and Related Disorders."
In 1983, HHAR had six ICF/HRF living areas and ten SNF units. Included within these SNF units were two "intensive units" (B and C floors) developed some 25 years ago, as "infirmary units" for patients identified as management concerns, and/or those acutely ill patients requiring very substantial nursing care. The primary difference between these and the other SNF units was the higher level of nursing staffing. In more recent years these units were used for permanent placement of patients who were "difficult to manage" from the medical and/or behavioral perspective.

A long waiting list for transfer and admission to these units as well as the expressed concern of alert patients and institutional staff about the patient mix on the other eight SNF units prompted an evaluation of the patient profile and institutional need (Grossman, et. al., 1986).

With the support of the Gerontological Society of America post-doctoral fellowship program in 1983, HHAR was able to re-evaluate its institutional preference (and actualization thereof) of homogeneous placement of patients with irreversible dementing illnesses. A three-pronged approach solicited input from patients and staff and documented changes in the Home's patient profile.

Forty percent of the clinical care staff, including social workers, doctors, nurses, aides and physical and occupational therapists on the ten SNF units were randomly selected and asked to respond to a questionnaire addressing two basic issues:

1. Could better care be provided to the patients if the units were segregated by behavior and function?
2. Would the patients be more comfortable if they were so segregated?
As Table 8 indicates, 76% of the clinical care staff felt that they could perform a better job in providing more direct service if the units were segregated. Eighty-three percent of the clinical care staff felt that patients would feel more comfortable if they were segregated by level of care. In addition, in response to expressed concerns by HHAR’s Resident Council, 48 (10%) of all SNF patients were randomly selected for interview. Of these individuals, only 24 could take part in the interview due to severe cognitive impairment. Those who were interviewed, however, were almost unanimous in stating their preference for homogeneity of placement. Only one of the 24 patients stated a preference for being on a unit where others had different clinical care needs (Salamon, 1983).

In addition to the patient and staff interviews, actual and perceived patient care needs were also assessed. This third component of the process included a retrospective analysis of DMS-1 scores*, for all HHAR’s patients for 1978-1983. Additionally, a survey of patient care staff was performed to determine their perception of the extent of the “changed patient profile” at the Home (Salamon, 1983). This was followed by an assessment of functional levels of all patients using Katz’s ADL Scale (Katz, et.al., 1963). This provided a measure of convergent validity and helped to determine current levels of need for special care, as a result of functional deterioration.

When presented with the documented changed needs of patients, the preferences of the more alert and oriented patients, as well as staff’s perception of their ability to provide better care, the Administration of the

*The New York State tool which measures appropriateness of nursing home placement and placement level as a condition of Medicaid reimbursement.
### Table 8

**Staff Responses to Questions Regarding Ability to Better Provide Care if Units were Segregated by Patient Functional Levels**

<table>
<thead>
<tr>
<th>SNF Unit</th>
<th>Better Care Could Be Provided</th>
<th>Patients Would Be More Comfortable</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>64%</td>
<td>88%</td>
</tr>
<tr>
<td>2</td>
<td>86%</td>
<td>100%</td>
</tr>
<tr>
<td>3</td>
<td>83%</td>
<td>67%</td>
</tr>
<tr>
<td>4</td>
<td>60%</td>
<td>60%</td>
</tr>
<tr>
<td>5</td>
<td>60%</td>
<td>80%</td>
</tr>
<tr>
<td>6</td>
<td>75%</td>
<td>75%</td>
</tr>
<tr>
<td>7</td>
<td>60%</td>
<td>80%</td>
</tr>
<tr>
<td>8</td>
<td>60%</td>
<td>80%</td>
</tr>
<tr>
<td>9</td>
<td>83%</td>
<td>80%</td>
</tr>
<tr>
<td>10</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

Overall 76% 83%
HHAR supported the initiative to develop a "SCU" for patients with dementia. A related goal of this initiative was to examine the effectiveness and viability of the model of care (to ultimately be developed on Goldfine-1 [GP-1]) with potential expansion onto the two already existing special units (i.e. B and C floors).

The development of this SCU required the concurrent operation of two planning processes. The first, a Task Force chaired by the facility's Associate Executive Director, was comprised of relevant Patient Care Department Directors (medicine, psychiatry, psychology, social services, nursing, therapeutic and recreational therapies) and two Assistant Administrators and was responsible for basic decision making and implementation regarding unit organization and therapeutic approach. A second group of direct care staff, whose efforts were coordinated by the Director of Social Services (also the designated Admission and Discharge Coordinator), was responsible for the identification of eligible patients and appropriate transfer protocols. It should be noted that this Task Force originally viewed as an ad hoc staff committee, has met periodically to re-evaluate approaches and discuss the pragmatic issues of implementing the GP-1-SCU therapeutic milieu onto B and C floors.

The initial planning process required approximately six months and resulted in a series of sequential decisions which defined the goals, framework and program focus and directed the actual implementation steps.

1. **Admission criteria** were developed to encompass a combination of behavioral and functional criteria as defined in Appendix D. Although the "model" program was to be developed and implemented first on GP-1, and subsequently on B and C Floors, admission criteria
for each of these three designated special care units were determined
to be consistent with the exception of placement of individuals who
wandered onto the more protected GP-1 and C floors. During this
planning process, the Task Force determined that placement decisions
would be "permanent", with the exception of those persons whose
condition improved. This decision is currently being re-evaluated in
light of the existing waiting list for placement on the SCU's and a
small number of patients currently residing on the SCU's whose
"ability to benefit from the developed structured therapeutic
approach" has been significantly reduced. This decision is a
difficult one especially as it requires value judgements regarding
allocation of limited resources.

It should be noted that the Home does not have a minimum age requirement
for either the SCU or any of the HRF/ICF/SNF units.

2. **Philosophy** - In developing this unit, the issues attendant to social
components of care, dignity, respect, and maximization of potential,
were articulated; Table 2 includes the framework defining HHAR's
approach to caring for this population. Specific outcome objectives
were not identified.

3. **A milieu therapeutic approach** (Sekais, 1985, Grossman, et. al.,
1986) was defined in the context of HHAR to include the role of both
the physical and programmatic environments. While there are very few
models for the development of such units within traditional nursing
homes (Benedict, 1983) literature does exist on making the nursing
home environment more comfortable for patients (Hiatt, 1980).
Conceptually:

A. The physical environment should be active, not passive, in its ability to protect, orient and provide space for safe wandering.

B. Throughout the day, activities should be offered that are at appropriate physical and cognitive levels, stimulate all of the senses, offer both physical and intellectual exercise, build upon earlier adult interest, involve all therapeutic disciplines and allow for small group activities within specific levels of cognitive function. In addition, activities should be scheduled to support the natural, individual energy cycles and patterns. It should be noted that this definition reflected clinical judgements regarding competent sensitive programming, with the recognition that there is little research to support (or refute) these perspectives within the SCU context.

4. **Staff supports**, including education, case discussions and opportunities for ventilation were viewed as critical for SCU success.

5. **Location** - As a result of individual patient assessments, GP-1 was determined to be the most appropriate unit for conversion; only 11 patients were determined ineligible for a SCU given their (higher) level of cognitive function. Patient transfers were affected to minimize location trauma for the patients, families and staff members (Borup, 1982, Grossman, et. al., 1986).
6. A geographic or unit-based family group program was already in existence on the unit, co-led by the unit social worker and head nurse, providing an ideal opportunity and setting to discuss the "SCU" approach to care. It was clear that this monthly family group meeting would continue to provide both emotional support and basic education.

7. Continued use of the geographic location name, i.e. GP-1, was deemed preferable to either "psychogeriatric" or a "Alzheimer's unit," to avoid stigmatization of the population from the family and staff perspectives.

Actual Implementation Steps

Environment

Environmental modifications on GP-1 were nominal in time and cost. This unit is 24,339 square feet, designed essentially as a square with a core, central nursing station. There are 12 double and 18 single rooms, consistent with New York State facility requirements. The congregate dining area is adjacent to but separated from a larger lounge area by glassed walls. Terraces, and one larger garden area, extend the communal spaces.

Initial environment changes related to security and orientation and included: alarming of the exits; color coding of doors and hallways; erecting double-view mirrors; lowering the height of the nurse's station; installation of addition terrace guard rails to prevent accidents; installation of additional reality orientation boards, and; development of large daily
schedules of patient activities. Several weeks following the establishment of this Special Care Unit, family members, staff and patients worked together to personalize patient room doors with memorabilia or other items that would enhance individual orientation, e.g. barber pole (barber), a notebook (elementry school teacher), and G-cleat (pianist). This was consistent with the belief that orientation is important for individuals with irreversible organic impairments (Parker & Sommers, 1983).

Subsequently, a "wandering garden" was created in an outdoor area adjacent to the unit, secured and camouflaged by movable garden boxes (these also provided an opportunity for horticulture programs), and art hung in the corridors consistent with the color-code design. Consideration is now being given to the elimination of the P.A. system in the unit dining room (noise control), modification of the elevator to minimize and/or eliminate patient egress, installation of a canopy for shade in the garden area and installation of an air lock system to minimize air conditioning loks from the unit onto the garden area.

The Involvement of Families

In working closely with the families, the social workers built upon institutional philosophy and commitment to families as both partners in care and clients in need of social work intervention. Acknowledgement was given to the view that within institutional long-term care a move to a more intensive level of care is a crisis step for the family (Solomon, 1983). An existing Family Group on Goldfine-1, (the then designated SCU) co-led by the unit head nurse and social worker helped to ease the anxieties surrounding the transfer
and re-location processes. Consistent with this approach, the plan to develop a SCU on Goldfine-1 was first introduced at a Family Group meeting. Representatives of administration, nursing and social services explained the goals of the SCU and the process of transfer. These monthly Family Group Meetings (on all SCUs) continue to be an important forum for education, support and problem solving.

Family acceptance of the Special Care Unit can be measured by the lack of resistance to transfer of patients to this unit, when indicated, and increased participation in the Family Group, unit activities, and planning for the care of their relatives. Current plans for increased family participation include joining patients for lunch/dinner on-the-unit, while simultaneously assisting in feeding.

Staff Meetings

Prior to the patient transfer process a series of staff meetings (nursing - all shifts) and community meetings (all patient care and support staff) on GP-1 were conducted to discuss unit goals, approaches and resultant staff concerns. With this introduction, daily 15 minute team meetings and twice monthly community meetings (day shift) were complemented by regular evening and night team meetings for the first year. At present, team meetings are conducted three times a week by the unit head nurse and Assistant Director of Social Work (there is currently a unit social worker vacancy).
Potential Improvements in the Planning Process

In retrospect, there were two ways in which the planning and implementation phase could have been improved. The first, is earlier involvement of the nurse’s aides to obtain their insight into pragmatic caregiving problems and issues and also to simply improve the "process" of the actual planning.

Secondly, despite the seriousness of the planning endeavor and clear administrative support, responsibility and authority for project implementation and followup required greater specificity. Therefore, a Project Management team, consisting of the Assistant Director of Social Services (a clinical social worker) and psychiatric nurse clinician (supervisory level) were appointed to this role. While this has provided better coordination and implementation, as the special care unit model has been extended to B and C floors, additional time demands have been difficult for these individuals. HHAR is evaluating a series of possible responses including the development of a "SCU Coordinator" position, increased psychiatric and/or psychology consultation, and additional opportunities for staff education.

Unit Staffing

Staffing on this unit (Table 9) was increased minimally during the planning phase and once again during the first 6 months of the unit's function in response to SCU staff's expressed needs. It should be noted that nurse staffing increases represented an adjustment, rather than an increase in overall staffing allocations within the (total) HHAR approved nurse staffing positions (in excess of 395).
Table 9

Staffing Patterns, GP-1, Prior to SCU
Development and Present

<table>
<thead>
<tr>
<th>Department</th>
<th>Pre-SCU</th>
<th>Interim Changes with SCU Development</th>
<th>Present Nursing</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Days</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurses</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Aides</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td><strong>Evening</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurses</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Aides</td>
<td>3</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td><strong>Nights</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurses</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Aides</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Physician</td>
<td>.6</td>
<td>.6</td>
<td>.6</td>
</tr>
<tr>
<td>Social Work</td>
<td>.3</td>
<td>.3</td>
<td>.3</td>
</tr>
<tr>
<td>Leisure Time Activities</td>
<td>.5</td>
<td>.5</td>
<td>.5</td>
</tr>
</tbody>
</table>

(office moved onto the SCU)
Staff assignments remained essentially intact. While HHAR offers no salary differential for SCU assignment, attempts have been made for the staff to feel "special". However, despite initial GP-1 staff preparation for conversion to this SCU and their indication of positive feelings about being part of "something special", the actual effect of a 25% increase in the number of demented patients, following the patient transfer process, did create stress and frustration, leading to a temporary decline in staff morale and confidence.

**Training**

Inasmuch as HHAR has given significant attention to training relevant to the special care needs of patients with dementia since 1981, no special pre-SCU education program was developed. Interdisciplinary staff training programs on all shifts, have previously addressed diagnosis, etiology, clinical course of the disease, management and communication techniques, family response and concerns, and psychopharmacological approaches. Resources for this continuing education have drawn upon Hunter College-Brookdale Center on Aging (specific training grants); Albert Einstein College of Medicine Teaching Nursing Home staff (HHAR is one of the three nursing home sites); College of Mt. St. Vincents nursing program (this college borders HHAR, and has a long-standing relationship for student placements and faculty teaching) and Home staff. These educational efforts are complemented by daily (rotating by unit), (Medical) Teaching - Management Rounds; and on-unit team meetings. Ongoing training now responds to specific articulated needs, e.g. the recent two part program "Differentiating Communication Problems Caused by Aphasia versus Dementia" for nursing, social services and therapy staff.
Other current, identified training needs include additional basic information for the nurse's aide regarding SDAT, group management techniques, and approaches to caring for the physically aggressive male patient. (The latter is indicative of a recent problem noted within the three special care units.) Currently, the HHAR SCU - Task Force is addressing the possibility of staff replacement through staff volunteering rather than assignment and a pre-service orientation and training module for new staff on the three SCU's.

**Activities**

Establishment of the activities program required significant cooperation and negotiation between the involved disciplines including Leisure Time Activities, Occupational Therapy, Physical Therapy, and Speech/Audiology. The regularity with which OT/PT participate in daily exercise programs reflects the demands of the rehabilitation therapy programs, posing difficulties for unit scheduling.

To the degree possible, on GP-1, daily on the unit programing is consistent. Activity times are fixed to enhance the time orientation for the patient (Pannala, 1984), staff and families.

A typical day might include:

**GP-1**

7:00 am - 10:30 am  Breakfast, activities of daily living
                    Medical and Clinic appointments.

10:30 am - 11:15 am  Sensory integration group - Occupational Therapy (OT)

11:15 am - 12:00 noon  Adaptive sports activities - Leisure Time Activities (LTA).
12:00 noon - 1:30 pm  Lunch, toileting, rest time.

1:30 pm - 2:15 pm  Exercise programming including dance therapy, music and movement - LTA, OT/PT (as available)

2:15 pm - 3:00 pm  Cognitive activities (e.g. Verbal games, crafts and reminiscence). - LTA

3:00 pm - 3:45 pm  Communication and/or social activities groups - (e.g., Discourse and Dialogue.) Rotation by LTA, Audiology/Speech Pathology

3:45 pm - 4:30 pm  (Tuesday/Thursday) Music and Wine

5:30 pm -  Dinner

6:00 pm - 7:00 pm  (Monday/Wednesday) After Dinner Music
To the extent possible, programs are brought to the unit, rather than patients brought to the activity. We have found that this reduces anxiety about leaving the familiarity of the unit and maximizes staff resources. The addition of late afternoon music and wine programming has, according to anecdotal report, improved the unit ambiance during the dinner hour. More significant evaluation studies of its impact are in process.

Several unusual programs within the SCU context include Friday afternoon Jewish poetry reading, use of "Walkman-like" radios to reduce verbal disruptive behaviors and "Discourse and Dialogue", conducted weekly by the Director, Audiology/Speech Pathology. Within this 45-60 minute program, "Discourse and Dialogue" combines the underlying principles of communication-cognition programs, and the techniques usually associated with aphasia therapy, reality orientation and group therapy dynamics. Specifically, 6-8 women categorized into stages 5-6 (Global Deterioration Scale, Reisberg, 1985), meet and discuss items of interest ranging from gardening, Israel and child-raising - to maintain their language pragmatics and the ability to adult dialogue.

As had been indicated earlier, the serious knowledge void of both defining the success of an activity (in concrete terms) and predicting differential success by activity, functional patient level and staff leader, marks a very critical next step for RHAR (and hopefully others in the field).

As the program and care model on GP-1 continues to be refined, efforts have also been made to extend this approach to the "original" special infirmary units, i.e. B and C floors. Regular team meeting were instituted on these units, in late 1985 to provide the ground work for the conversion to the more
comprehensive therapeutic model. It should be noted that these units suffer from an "environmental stigma"; it is the Infirmary Building whose replacement is imminent due to physical plant obsolescence. Additionally, B and C floors are also staffed by aides of long tenure, creating an expected "tug" between resistance to change and excitement. In addition to complete extension of the model program activities to B and C floors, future goals include continued programmatic and management innovation including: the training of nurse's aides to conduct sensory integration groups; weekend programs; smaller and more innovative group programs; the implementation and evaluation of a generic health care worker (or nurse aide centered) approach to care, introduction of finger foods to improve nourishment; evaluation of homogeneous versus heterogeneous placement of patients with dementia, increased utilization of family members as volunteers and; evaluation of specific therapeutic approaches on patients, family and staff.

SCU Overview

The actual preparation of this report provided an opportunity and motivation for retrospective patient data analysis.

Demographically, as indicated in Tables 10 and 11, the three special care units have a slightly higher proportion of male patients than the overall HHAR SNF ratios, i.e. 21% male versus 18% male respectively. Similarly, while the average age of HHAR's - SNF population is 88 years, the average age of its SCU population is 84.6 years. Staff reports and concerns regarding the increased numbers of younger males with aggressive behaviors, are consistent with these data reports and require considerable thought regarding therapeutic
Table 10

Gender Comparison Between SCU Patients and All SNF Patients, 1985

<table>
<thead>
<tr>
<th></th>
<th>Male</th>
<th></th>
<th>Female</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>%</td>
<td>Number</td>
<td>%</td>
</tr>
<tr>
<td><strong>SNF-Special Care Unit</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GP-1</td>
<td>10</td>
<td>24%</td>
<td>32</td>
<td>75%</td>
</tr>
<tr>
<td>B</td>
<td>10</td>
<td>20%</td>
<td>39</td>
<td>80%</td>
</tr>
<tr>
<td>C</td>
<td>9</td>
<td>18%</td>
<td>40</td>
<td>72%</td>
</tr>
<tr>
<td><strong>SNF-Excluding SCU Patients</strong></td>
<td>59</td>
<td>17%</td>
<td>285</td>
<td>83%</td>
</tr>
<tr>
<td><strong>All SNF</strong></td>
<td>88</td>
<td>18%</td>
<td>396</td>
<td>82%</td>
</tr>
</tbody>
</table>
### Table 11

Age Comparison of SCU Patients and Other HHAR SNF Patients

<table>
<thead>
<tr>
<th>Special Care Unit</th>
<th>Average Age (years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP-1</td>
<td>83.7</td>
</tr>
<tr>
<td>B</td>
<td>84.3</td>
</tr>
<tr>
<td>C</td>
<td>85.7</td>
</tr>
</tbody>
</table>

Two traditional SNF units, selected for comparison:

| GP-2 | 87.3 |
| P6   | 87.0 |

All SNF patients regardless of diagnosis: 88.0

**Note:** GP-2, P-6 patients include those with psychiatric diagnoses only.
interventions and supportive environmental strategies. It is anticipated that this problem will increase, in light of community needs and limited resources.

Consistent with initial planning, priority has been given for SCU admissions to HHAR intra-institutional transfers; 49% of the current SCU population was so admitted. (see Table 12) Within HHAR's traditional SNF units, only 35% of the admissions were intra-institutional transfers in November, 1985. Currently, there are 18 HHAR SNF patients awaiting SCU placement. Differences in sources of admission between the three SCU's are a function of environmental differences and, as noted earlier, in the unit's relative ability to prevent wandering. (B floor is the most open; C floor exits are alarmed but offer little wandering space; GP-1 is protected and offers wandering paths).

While admissions criteria to the three HHAR-SCUs, were to have been consistent, assessment of the Case Mix Index* for December 1985 and a recent functional assessment do suggest a greater impairment level on B and C floors. (Table 13)

This, in combination with sources of admission, indicates that GP-1 has been utilized primarily for in-house transfers (wherein patient/family expectations are high regarding the environment), while B and C floors accept more direct admissions for whom there are no such expectations (the reader is reminded of the new building construction to replace B and C floors).

*Note: Case mix indices (CMI) are calculated in New York State in accordance with recently developed RUGs II assessment and reimbursement criteria. Theoretically a CMI of 1 is the state-wide SNF norm.
TABLE 12

Comparison of Admission Source of SCU Patients with All HHAR-SNF Admissions

<table>
<thead>
<tr>
<th>Admission Source</th>
<th>SCU-CURRENT PATIENT POPULATION</th>
<th>TOTAL SNF-1984, and SAMPL MONTH</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>GP - 1  B  C</td>
<td>N = 42  N = 49  N = 49  N = 140</td>
</tr>
<tr>
<td></td>
<td>N  $   % $  N  $   % $  N  $   % $  N  $   % $</td>
<td>N  $   % $  N  $   % $  N  $   % $  N  $   % $</td>
</tr>
<tr>
<td>Intra Instit. Transfer</td>
<td>31  74  9  18  28  57  68  49</td>
<td>74 (49) 9 (31)</td>
</tr>
<tr>
<td>Community (own home)</td>
<td>7  17  20  41  10  20  37  26</td>
<td>39 (25) 9 (31)</td>
</tr>
<tr>
<td>Hospital</td>
<td>3  7  13  27  9  18  25  18</td>
<td>28 (18) 6 (23)</td>
</tr>
<tr>
<td>(Other) Nursing Home</td>
<td>1  2  6  12  2  4  9  6</td>
<td>10 (6) 2 (7)</td>
</tr>
<tr>
<td>Adult Home - HRF</td>
<td>0  0  1  2  0  0  1  1</td>
<td>0  0</td>
</tr>
</tbody>
</table>

42
<table>
<thead>
<tr>
<th>Case Mix Index</th>
<th>Patients Requiring Total Assistance*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Transfer</td>
</tr>
<tr>
<td>GP-1** 1.09</td>
<td>6 (14%)</td>
</tr>
<tr>
<td>B 1.19</td>
<td>48 (98%)</td>
</tr>
<tr>
<td>C 1.30</td>
<td>45 (94%)</td>
</tr>
</tbody>
</table>

**Notes:** *All others require partial assistance.  
**Based upon census of 42, 49, 48 respectively.
Length of stay (LOS) information is also important for facility planning, as (Table 14) as it suggests "turnover" rates for SCUs/SNFs. Further, such data provides indications for specific facility SCU bed need.

**Diagnosis and Management**

An overview of the psychiatric disorders (organic and functional) of SCU patients are presented in Table 16, with two "traditional" SNF units presented for comparison. As was anticipated based upon the epidemiological literature (Larson et. al., 1984, Larson, et. al., 1985) 89% of the patients with dementia are diagnosed as "probable SDAT," and 10% with "mixed dementia." Also expected was the 50% proportion of non-SCU patients with psychiatric diagnoses.

Management approaches on the SCU include, as indicated previously, environmental supports, creation of a therapeutic milieu, activity programs, etc. Psychotropic drugs are also viewed as an effective and important component of patient management when appropriately titrated and not utilized to replace human interventions (Marletta, 1985). Table 17 details psychotropic drug orders in effect on 1/12/86 on the three SCU's and compares these to the two other "typical" SNF units. While studies are not available to establish norms or standards for prescribing patterns within institutional SCU's, we believe the proportion of patients not on psychotropic drugs (60%) is appropriate to the delicate balance between under/appropriate/over medication. Overall drug utilization is also low on the SCU's; the average number of drugs is 4.3 versus 5.6 for all HHAR SNF units.*

*Note: This includes all prescription, controlled substances, over the counter and prn medications, calculated for quarter 3, 1985.
<table>
<thead>
<tr>
<th>Length of Stay Category</th>
<th># of Individuals</th>
<th>Years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Institutional LOS (HRF + SNF)</td>
<td>188</td>
<td>4.5</td>
</tr>
<tr>
<td>For all residents residing within</td>
<td></td>
<td></td>
</tr>
<tr>
<td>the HRF</td>
<td>19</td>
<td>2.6</td>
</tr>
<tr>
<td>For all patients expiring within</td>
<td></td>
<td></td>
</tr>
<tr>
<td>the SCU</td>
<td>56</td>
<td>5.4</td>
</tr>
<tr>
<td>LOS on the SCU only, for patients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>expiring in 1985</td>
<td>56</td>
<td>2.9</td>
</tr>
<tr>
<td>For all patients expiring within</td>
<td></td>
<td></td>
</tr>
<tr>
<td>the &quot;traditional&quot; SNF</td>
<td>113</td>
<td>4.3</td>
</tr>
</tbody>
</table>

Note: LOS calculations are based upon the 188 HHAR patients expiring in 1985.
Table 15

Transfer Patterns of Patients Expiring Within HHAR - SCUs, 1985

<table>
<thead>
<tr>
<th>Unit</th>
<th>Total #</th>
<th>Transfer Pattern</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>HRF—SNF—SCU</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients Expiring</td>
<td></td>
<td></td>
</tr>
<tr>
<td>B</td>
<td>23</td>
<td>7 (30%)</td>
</tr>
<tr>
<td>C</td>
<td>19</td>
<td>3 (16%)</td>
</tr>
<tr>
<td>GP-1</td>
<td>14</td>
<td>9 (64%)</td>
</tr>
<tr>
<td>Total</td>
<td>56</td>
<td>19 (34%)</td>
</tr>
</tbody>
</table>

Note: No patient placed on the GP-1, SCU directly from the community from May 1984 to December 1985 has yet expired.
### TABLE 16

Comparison of Psychiatric Diagnostic Categories of SCU Patients With "Traditional" SNF Patients

<table>
<thead>
<tr>
<th></th>
<th>Special Care Units</th>
<th>Total SCU(N=140)</th>
<th>Traditional SNF</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>GP1(N=42)</td>
<td>B (N=49)</td>
<td>C(N=49)</td>
</tr>
<tr>
<td>Prob. SDAT</td>
<td>41 (98%)</td>
<td>40 (82%)</td>
<td>44 (90%)</td>
</tr>
<tr>
<td>Prob. SDAT With MID</td>
<td>0 0 9 (18%)</td>
<td>5 (10%)</td>
<td>14 (10%)</td>
</tr>
<tr>
<td>Depression</td>
<td>0 0 0 0 0 0 0 0 0 9 (23%)</td>
<td>7 (13%)</td>
<td></td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>1 ( 2%)</td>
<td>0 0 0 0 0 0</td>
<td>1 (.1%)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>0 0 0 0 0 0 0 0 0 0 0 1 ( 2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>42 49 49 140</td>
<td>23 (57%)</td>
<td>27 (51%)</td>
</tr>
</tbody>
</table>

Note: The diagnosis utilized is the primary psychiatric diagnosis noted by the physician.
TABLE 17
Comparison of Psychotropic Drug Orders for Patients with Psychiatric Diagnoses on SCUs & "Traditional" SNF Units

<table>
<thead>
<tr>
<th></th>
<th>Special Care Units</th>
<th></th>
<th>Traditional SNF Units</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>GP 1(N=42)</td>
<td>B(N=49)</td>
<td>C(N=49)</td>
<td>Total (N=140)</td>
</tr>
<tr>
<td></td>
<td>#</td>
<td>%</td>
<td>#</td>
<td>%</td>
</tr>
<tr>
<td>Anti Psychotics</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Standing</td>
<td>8 (19%)</td>
<td>11 (22%)</td>
<td>10 (20%)</td>
<td>29 (21%)</td>
</tr>
<tr>
<td>PRN</td>
<td>1 ( 2%)</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Anti Depressants</td>
<td>1 ( 2%)</td>
<td>5 (10%)</td>
<td>4 ( 8%)</td>
<td>10 ( 7%)</td>
</tr>
<tr>
<td>Tranquilizers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Standing</td>
<td>6 (15%)</td>
<td>2 ( 5%)</td>
<td>4 ( 8%)</td>
<td>12 ( 9%)</td>
</tr>
<tr>
<td>PRN</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Sleep</td>
<td>1 ( 2%)</td>
<td>3 ( 6%)</td>
<td>2 ( 4%)</td>
<td>6 ( 4%)</td>
</tr>
<tr>
<td>Standing</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1 ( 2%)</td>
</tr>
<tr>
<td>PRN</td>
<td>17 (40%)</td>
<td>21 (43%)</td>
<td>21 (42%)</td>
<td>59 (42%)</td>
</tr>
<tr>
<td>Total # Psych. Drugs</td>
<td>17 (40%)</td>
<td>18 (37%)</td>
<td>19 (39%)</td>
<td>54 (39%)</td>
</tr>
<tr>
<td>Total # Pts. on Psych. Drugs</td>
<td>17 (40%)</td>
<td>18 (37%)</td>
<td>19 (39%)</td>
<td>54 (39%)</td>
</tr>
<tr>
<td>Total # Pts. Not on Psych. Drugs with psychiatric diagnoses</td>
<td>25 (60%)</td>
<td>31 (63%)</td>
<td>30 (61%)</td>
<td>86 (61%)</td>
</tr>
</tbody>
</table>
It should be noted that two physicians are responsible for SCU care and utilize psychiatric consultation for evaluation, medication, titration and review. Psychiatric consultation use on the SCU's is stable and divided between bi-monthly medication reviews, recalls and (minimally) consultation requests. The rate of psychiatric consultation is consistent between HHAR's traditional SNF units and the SCU's - i.e. 10% /month. This requires approximately four hours per month per SCU by the HHAR psychiatrist.

Restraint use also requires that balance between individual protection and undue personal restriction. Table 18 documents HHAR's restraint order patterns. While the proportion of individuals with standing restraint orders exceeds 56%, we suggest it to be a function of end-stage dysfunctions as a result of the disease. Again while there are no standards for restraint use this data analysis has prompted HHAR SCU staff to more critically review such orders.

As has been emphasized throughout this document, there are not yet standards or outcome measures relative to the impact of therapeutic interventions for patients with dementia. From the inception of GP-1 as a SCU, data reports of patient screams, number of patients requesting assistance and accidents and incidents were maintained with the potential to establish HHAR - base line reports. The first two measures reflect disorientation and agitating behaviors, amenable we believe, to intervention and clearly detrimental to the creation of a therapeutic environment.

Screaming behavior has declined substantially on GP-1 since the creation of the SCU. (Table 19, Chart 1) To measure this, an observer, usually the HHAR
TABLE 18
Comparison of Restraint Orders for Patients with Psychiatric Diagnosis on SCUs & "Traditional" SNF Units

<table>
<thead>
<tr>
<th></th>
<th>Special Care Units</th>
<th></th>
<th>Traditional SNF Units</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>GP 1</td>
<td>B</td>
<td>C</td>
<td>Total</td>
</tr>
<tr>
<td></td>
<td>N=42</td>
<td>N=49</td>
<td>N=49</td>
<td>N=140</td>
</tr>
<tr>
<td># %</td>
<td># %</td>
<td># %</td>
<td># %</td>
<td># %</td>
</tr>
<tr>
<td>Standing Orders</td>
<td>13-(31%)</td>
<td>30-(61%)</td>
<td>35-(71%)</td>
<td>78-(56%)</td>
</tr>
<tr>
<td>PRN Orders</td>
<td>16-(38%)</td>
<td>12-(24%)</td>
<td>12-(24%)</td>
<td>30-(21%)</td>
</tr>
<tr>
<td>Total # Restr. Orders</td>
<td>29-(69%)</td>
<td>42-(86%)</td>
<td>49-(1.2%)</td>
<td>120-(86%)</td>
</tr>
<tr>
<td>Total # Pts. Restr.</td>
<td>29-(69%)</td>
<td>42-(86%)</td>
<td>47-(96%)</td>
<td>118-(84%)</td>
</tr>
<tr>
<td># Pts. with Psychiatric Diag. without Standing Restr. orders.</td>
<td>13-(31%)</td>
<td>7-(14%)</td>
<td>2-(4%)</td>
<td>22-(16%)</td>
</tr>
</tbody>
</table>

*Patients with Psychiatric Diagnosis
<table>
<thead>
<tr>
<th>Month</th>
<th># Days Of Observation</th>
<th>Screams</th>
<th>People Screaming</th>
<th>Patients Asking For Help</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>#</td>
<td>X</td>
<td>#</td>
</tr>
<tr>
<td>May '84</td>
<td>6</td>
<td>125</td>
<td>20.8</td>
<td>6</td>
</tr>
<tr>
<td>June '84</td>
<td>11</td>
<td>244</td>
<td>22.2</td>
<td>43</td>
</tr>
<tr>
<td>July '84</td>
<td>17</td>
<td>97</td>
<td>5.7</td>
<td>27</td>
</tr>
<tr>
<td>Aug. '84</td>
<td>13</td>
<td>17</td>
<td>1.3</td>
<td>10</td>
</tr>
<tr>
<td>Sept. '84</td>
<td>13</td>
<td>6</td>
<td>.3</td>
<td>5</td>
</tr>
<tr>
<td>Oct. '84</td>
<td>14</td>
<td>25</td>
<td>1.7</td>
<td>11</td>
</tr>
<tr>
<td>Nov. '84</td>
<td>14</td>
<td>27</td>
<td>1.9</td>
<td>16</td>
</tr>
<tr>
<td>Dec. '84</td>
<td>13</td>
<td>10</td>
<td>.8</td>
<td>11</td>
</tr>
<tr>
<td>Jan. '85</td>
<td>15</td>
<td>3</td>
<td>.2</td>
<td>1</td>
</tr>
<tr>
<td>Feb. '85</td>
<td>18</td>
<td>13</td>
<td>2.6</td>
<td>7</td>
</tr>
<tr>
<td>Mar. '85</td>
<td>15</td>
<td>38</td>
<td>2.5</td>
<td>21</td>
</tr>
<tr>
<td>Apr. '85</td>
<td>11</td>
<td>24</td>
<td>2.1</td>
<td>8</td>
</tr>
<tr>
<td>May '85</td>
<td>11</td>
<td>12</td>
<td>1.0</td>
<td>5</td>
</tr>
<tr>
<td>June '85</td>
<td>10</td>
<td>92</td>
<td>9.2</td>
<td>14</td>
</tr>
<tr>
<td>July '85</td>
<td>11</td>
<td>93</td>
<td>8.5</td>
<td>21</td>
</tr>
<tr>
<td>Aug. '85</td>
<td>6</td>
<td>20</td>
<td>3.3</td>
<td>5</td>
</tr>
<tr>
<td>Sept. '85</td>
<td>9</td>
<td>37</td>
<td>4.1</td>
<td>8</td>
</tr>
<tr>
<td>Oct. '85</td>
<td>8</td>
<td>72</td>
<td>8.</td>
<td>18</td>
</tr>
<tr>
<td>Jan. '86</td>
<td>2</td>
<td>6</td>
<td>3.</td>
<td>3</td>
</tr>
</tbody>
</table>

Note: Measures were taken at least 7 (random) days/month, by an observer located on the unit, for 5 minutes, at 3 p.m. (shift change). This individual walked the periphery of the unit, at least once, and stayed in the lounge area the remainder of the time.
CHART 1

SCREAMS AND ACCIDENTS/INCIDENTS - GP-1, 1984-85

ACCIDENTS/INCIDENTS - "TRADITIONAL" SNF UNITS, 1984-85
Research Director or a research student, was placed on the SCU for 5 minutes, at shift change (i.e. 3 p.m.). Their routine included walking the unit's perimeter, standing in the day room, and counting.

Variations from the lower plateau coincide with peak vacation periods (notable also for number of accidents) suggestive of the impact of vacation staff coverage for this disoriented population.

Accident and incident rates have not shown similar dramatic declines. We interpret this data to be a function of our reluctance to overmedicate and overrestrain this population, its increased frailty, (Brody, et, al, 1984) and the Home's policy to report as accidents and incidents, any occurrence regardless if injury has been sustained.

IV. CONCLUSION

The special care unit approach to care for the institutionalized patient with dementia is becoming recognized as a viable, perhaps even cost effective approach to caring for this population. While specific program and organizational components must reflect an institution's own style, the essential core of SCU development includes: delineation of objectives; admission and discharge criteria; use of an assessment instrument; environmental supports; special programs; staff training, and; family supports. However, even with this core, and anecdotal reports of clinical success, the differential benefits of programming and staffing approaches have not been evaluated. Further,
standards or outcomes of positive care have not been established for this population. These represent obvious, sequential steps to follow given the now existing, articulated organizational options for the care of individuals with dementia.

As long as programs or units for the care of this population are viewed as "special" there is a serious facility responsibility for diligent planning, continuous monitoring, re-evaluation, innovation, compassion and sensitivity.
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New York Academy of Medicine (1984) *Alzheimer's Disease-Implications for Public Policy In New York State, NY.*

New York City Department of Mental Health, Mental Retardation and Alcoholism (1985) *Local Government Plan for Mental Health Services, 1986-1987, NY, NY.*


Appendices

A - Facilities Participating in National Survey

B - Survey Tools

C - Monograph-1983 HHAR Symposium on Alzheimer's Disease and Related Disorders

D - HHAR Criteria for Admission to the SCU
APPENDIX A

Facilities Self-Identifying Through Hebrew Home for the Aged at Riverdale-Brookdale Study as Having Special Units or Special Programs for Individuals With Alzheimer's Disease

Non-Profit Facilities, Designated Special Units for Individuals With Dementia

Daughters of Israel Geriatric Center
1155 Pleasant Valley Way
West Orange, New Jersey 07052 201-721-5100

Greenwood House - Home for the Jewish Aged
53 Walter Street
Trenton, New Jersey 08628 609-883-5391

The Hebrew Home for the Aged at Riverdale
5901 Palisade Avenue
Bronx, New York 10471 212-549-8700

Morningside House
1000 Pelham Parkway
Bronx, New York 10461 212-863-5800

New York Medical College
Ruth Taylor Institute
25 Bradhurst Avenue
Hawthorne, New York 10532 914-347-7728

Rosa Coplon Jewish Home & Infirmary
10 Symphony Circle
Buffalo, New York 14201 716-885-3311

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Milwaukee, WI 53202 414-276-2627

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Los Angeles, California 90018 213-731-0641

Motion Picture & Television Hospital
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Woodland Hill, CA 91364 818-347-1591
Non-Profit Facilities Indicating Special Programs for Individuals With Dementia

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Courtland Gardens Retirement Residence
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Fairfield Manor Health Care Center
23 Prospect Avenue
Norwalk, CT 06850
(in planning stages)

Fishkill Health Related Center, Inc.
Route 9D and Dogwood Lane
Beacon, New York 12508  914-831-8704
Hillhaven Corporation has 12 to 15 active special units scattered about the country. Their "models" include, Newton-Wesley, Kansas City, Phoenix, Denver, Portland, and San Francisco.

The Hebrew Home for the Aged at Riverdale notes with gratitude the cooperation and assistance of these facilities in completing this survey.
Facility Name: __________________________
Address: ________________________________
Telephone Number: _______________________
Contact Person: _________________________

1. A. In total, how many beds are in your facility?
   ____ SNF
   ____ ICF/HRF

   B. In total, how many units are in your facility?
   ____ SNF
   ____ ICF/HRF

   C. Is your facility - non-profit, __________ proprietary? __________

2. How many units do you have for patients with dementia? ____

3. How is your special care unit(s) for individuals with dementia organized?
   A. Number of beds/unit ____
   B. Level of Care
      ____ SNF
      ____ ICF/HRF

4. When were your unit(s) opened? __________

5. What are your criteria for admission/discharge to and from the Special Care Unit? (Please specify functional/behavioral, age, source of payment, and if priority is given to in-house transfers.)
   A. Admission

   B. Discharge

6. If you have more than one Special Care Unit, are the criteria for admission/discharge the same for each unit? (If different, please specify.)
7. Did you convert a traditional SNF/ICF unit to create this Special Care Unit?
   YES ____  NO ____

   If yes, what environmental changes did you make?

8. Please describe any unusual aspects of the environment (not noted in #7 above) related to security, noise control, orientation, sensory stimulation, etc.

9. Please describe a typical day's activity schedule.

10. What is the unit's staffing pattern? (Please include all patient care disciplines.)

    Day: __________________________________________
       __________________________________________
       __________________________________________

    Evening: ____________________________________
      __________________________________________
      __________________________________________

    Night: ______________________________________
        _________________________________________
        _________________________________________

11. Do you provide any supports or education for families? (If yes, please specify.)

12. Do you provide any special training or supports for unit staff?
    If yes, please specify.
13. Do you have a special name for the unit?

14. A. What is your daily charge/rate for this unit? __________

   B. Is the rate the same as "traditional ICF/SNF" daily rate?

      YES    NO
      If no, please indicate the differential.

   C. Are your costs equivalent to your rate?

      YES    NO
      If no, please indicate actual (or approximate actual) costs.

15. Are you presently conducting any research about this unit?
   If yes, please describe briefly.

16. Do you provide any community-based services for this population?
   (If yes, please specify)

17. Please specify your age criteria for admission to the facility at large, as well as special care unit for dementia.

18. Do you have an individual in your facility who has administrative or clinical responsibility for the special care units? If you, please indicate their title, other responsibilities, training. If this individual was employed after the development of special care units, time allocation for special care unit programs, etc.

19. Other comments.

Thank you for your cooperation and assistance. A stamped, self-addressed envelope is included for your convenience.
Questionnaire A
Facilities with Discrete or Special Units
for Patients with Dementia

Facility Name: ________________________________

Address: ________________________________

Telephone Number: __________________________

Contact Person: _____________________________

1. A. In total, how many beds are in your facility?
   ______ SNF
   ______ ICF/HRF

   B. In total, how many units are in your facility?
   ______ SNF
   ______ ICF/HRF

   C. Is your facility - non-profit, ______ proprietary? ______

2. How many units do you have for patients with dementia? ______

3. How is your special care unit(s) for individuals with dementia organized?
   A. Number of beds/unit ______
   B. Level of Care
      ______ SNF
      ______ ICF/HRF

4. When were your unit(s) opened? ________________

5. What are your criteria for admission/discharge to and from the Special Care Unit? (Please specify functional/behavioral, age, source of payment, and if priority is given to in-house transfers.)
   A. Admission

   B. Discharge

6. If you have more than one Special Care Unit, are the criteria for admission/discharge the same for each unit? (If different, please specify.)
7. Did you convert a traditional SNF/ICF unit to create this Special Care Unit?

YES  NO

If yes, what environmental changes did you make?

8. Please describe any unusual aspects of the environment (not noted in #7 above) related to security, noise control, orientation, sensory stimulation, etc.

9. Please describe a typical day's activity schedule.

10. What is the unit's staffing pattern? (Please include all patient care disciplines.)

Day: __________________________________________

_________________________________________

_________________________________________

Evening: __________________________________________

_________________________________________

_________________________________________

Night: __________________________________________

_________________________________________

11. Do you provide any supports or education for families? (If yes, please specify.)
12. Do you provide any special training or supports for staff working with patients with dementia? If yes, please specify.

13. Do you have a special name for the unit?

14. A. What is your daily charge/rate for this unit? ___________

B. Is the rate the same as "traditional ICF/SNF" daily rate? __YES __NO
   If no, please indicate the differential.

C. Are your costs equivalent to your rate? __YES __NO
   If no, please indicate actual (or approximate actual) costs.

15. Are you presently conducting any research about patients with dementia?
   If yes, please describe briefly.

16. Do you provide any community-based services for this population?
   (If yes, please specify)

17. Other comments.

18. Do you have any questions about the Hebrew Home for the Aged at Riverdale's Special Care Unit?

Thank you for your cooperation and assistance. A stamped, self-addressed envelope is included for your convenience.
Questionnaire B
Facilities with Special Programs
(Not Special Units) for Patients with Dementia

Facility Name: ________________________________

Address: ________________________________

Telephone Number: ________________________________

Contact Person: ________________________________

1. A. In total, how many beds are in your facility?
   _____ SNF
   _____ ICF/HRF

   B. In total, how many units are in your facility?
   _____ SNF
   _____ ICF/HRF

   C. Is your facility - non-profit, ______ proprietary? ______

2. How many individuals in your facility have a diagnosis of dementia?
   _____ SNF
   _____ ICF/HRF

3. Please describe your special programs including goal, schedules, staffing, costs, etc.

4. Do you provide any supports or education for families? (If yes, please specify.)

5. Do you provide any special training or supports for staff working with patients with dementia? If yes, please specify.

6. Are you presently conducting any research about patients with dementia?
   If yes, please describe briefly.
7. Do you provide any community-based services for this population?  
(If yes, please specify)

8. Have you considered establishing a special unit for patients with dementia?  
   ______YES  ______NO
   
   If yes, why did you not choose this option?

9. Other comments.

10. Do you have any questions about the Hebrew Home for the Aged at  
    Riverdale's Special Care Unit?

Thank you for your cooperation and assistance. A stamped, self-addressed  
envelope is included for your convenience.
The Martin Steinberg Inaugural Memorial Symposium on Alzheimer's Disease and Related Disorders

A Monograph
The Hebrew Home for the Aged in Riverdale
November 5, 1983
This monograph is dedicated to the memory of Mr. Martin Steinberg
The Hebrew Home for the Aged in Riverdale

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The papers that follow were presented at
The Martin Steinberg Inaugural Memorial Symposium on Alzheimer's Disease and Related Disorders
held on September 21, 1983 at the Hebrew Home for the Aged in Riverdale.

# Welcoming Remarks

**Jacob Reingold, M.S.**
Executive Vice President
The Hebrew Home for the Aged in Riverdale
Panelist

Welcome distinguished guests, colleagues, members of the press, to the first Martin Steinberg Memorial Symposium on Alzheimer's Disease and Related Disorders. I am proud that the Hebrew Home for the Aged in Riverdale is the first institution for long-term care to direct its efforts towards informing the professional community and the general public about the threat of this little known disease that ravages more than ½ million Americans yearly.

Only a short time ago, as you know, a discussion of senility would never make newspaper headlines or claim valuable, saleable TV time. Everyone thought that becoming senile was something all elderly persons had the misfortune to look forward to as they advanced in age. It was not until the discovery and subsequent years of research into senile dementia that Alzheimer's Disease was isolated as a disease, which can strike at any age, but strikes the elderly most frequently of all. Alzheimer's Disease is attracting media attention. Research and treatment has become a national priority because the disease is perceived by our leaders and our medical profession as a potential threat to each of us as we age and a very real threat to our economy because of an anticipated increased need for institutional care for Alzheimer's victims.

We have come a long way since the forgetfulness, confusion and irritability of an elderly person would be swept aside with a single remark—he's just getting senile. Everyone ages, but no one has to get senile. That's what today's conference is all about. You will hear respected professionals tell you what they know and what remains a mystery about Alzheimer's Disease. They will discuss different treatments and methodologies, and they will explore social, ethical, political and economic problems of treating the Alzheimer's victim as well as dealing with the confused and care-ridden families. You will also learn what we at The Hebrew Home for the Aged in Riverdale are doing to unravel the mystery of Alzheimer's Disease, and to eliminate senility from the medical lexicon.

Thank you for coming.
Alzheimer's Disease—Ancient Problem, Recent Discoveries
by Carl Eis dorfer, Ph.D., M.D.
President, Montefiore Medical Center
Professor, Department of Psychiatry and Neuroscience
Albert Einstein College of Medicine

The title of this seminar on Alzheimer's Disease, "Ancient Problem, Recent Discoveries," is, I think, beautifully articulated. My role is to introduce this concept, to give you a flavor of what it is we're dealing with, but not to say too much and cut into the important talks that are to follow. I'll start with a comment that I've made several times because I think it needs to be understood. We have for centuries accepted the inevitability of profound intellectual and cognitive decline.

Basically, we talk about a demented state. In Man's and Mother Earth, that important volume by Arnold Toynbee, he tells us that man has a choice between death and senility. The first point to be made—perhaps the most important point—is that this is nonsense. We have not understood that dementia is not a normal process, that the choice is simply not between death and dementia. Any more cancer or heart disease, or high levels of infant mortality are inevitable. We need to change our mind-set.

The term senility implies two things, neither of which is true. It implies the inevitability of dementia, and it implies that if a person is demented there is nothing we can do for that individual. In most instances there are many things we can do.

There are a whole variety of dementing disorders. We're discussing just the non-reversible ones. The major non-reversible form of dementia is the Alzheimer's type. We use the term 'type' advisedly. We're still not sure of what happens in later life when the brain appears for the moment to be identical with an Alzheimer's brain. The disease process may be a quite accelerated rate of aging. It's still a disease; these are merely descriptive terms. In aging, what we really have is the loss of neuronal tissue for reasons unknown.

If we accept that senility is inevitable, nothing needs to be done. Why bother examining the patient? Health care costs are too high in the United States. Costs for hospital beds are too high: psychiatrists, neurologists, even neuropathologists are too expensive; so why bother? Why not just put these patients away and not worry about them? Well, for a variety of reasons, most of which I've already alluded to. Every patient with a cognitive disorder deserves a comprehensive medical evaluation, with the appropriate laboratory measures, appropriate neurological evaluation, and I would add a psycho-social component.

Can we do anything about dementia? Well, if in fact the dementia is caused by a reversible condition, whether it's a side effect of medication, too many medications, the wrong medication, or a disease, surely you can reverse dementia. Let me tell you what my concern is. With the help of the ADRDA, the Alzheimer's Disease and Related Disorders Association, I think we have seen a very significant shift from the use of the term senility to the use of the term Alzheimer's Disease. All to the good. Except I'm beginning to hear people use Alzheimer's Disease in the same way we used senility. And that would be a tragedy. It is not just a substitution of words we're talking about; it's the substitution of a concept. And unless we substitute the concept, the word is meaningless. So the first thing is, the cause of dementia may be reversible; not all dementia is Alzheimer's Disease. Secondly, one of the things that we see is the concur-rencce of disorders. Most of the patients with Alzheimer's Disease, even the early onset, tend to be older in life, and often have concurrent diseases. These diseases include the flu, pneumonia, or having a fever that's not readily detectable because older people have unreliable thermoregulation system. All of these in the face of a true or non-reversible dementia will make the dementia much worse. So a patient with Alzheimer's Disease who's depressed is a much more cognitively impaired patient than someone with Alzheimer's Disease who's not depressed. Do you treat the depression or not? Do you ignore the depression just because the patient has Alzheimer's Disease; do you ignore the pneumonia because the patient has Alzheimer's Disease; do you throw away your prescription pad and take a random guess at how much medication the patient should have because the patient has Alzheimer's Disease? Quite the opposite is true.

Because we know that the patient has brain impairment, we have to be more sensitive about the psychological, social, familial, medical and medicinal aspects of their care. And then finally we have an important responsibility. The obligation is not only to find out more about the disease, but to find out more about the clinical management of the patient. And that obligation is one that the country has only recently undertaken.

Can we do anything with these patients? By now we have data from Einstein, we have data from NYU, we have data from Seattle, we have data from San Francisco. We're beginning to recognize that if we try to make a difference we can make a difference. And that therapy works. Family therapy works because the family becomes the center of support. Institution-based therapy works. And medications may work, though they've got to be administered carefully. If you say somebody has Alzheimer's Disease does that mean you withhold treatment? No, It means your obligation to provide quality care increases.

What do we know about the disease? The one thing we do know is that the probability of getting the disease, if you live long enough, gets to be higher and higher as you get older. Inevitable? No. Increasing? Yes. We know that probably about half the patients in long-term care in the United States have a significantly dementing illness and probably the majority of that group has Alzheimer's Disease. We also know that for the first time since the 1950s, we now have more long-term care patients in the United States, there are more long-term care beds, than there are general hospitals. There are about 1.3 million Americans in long-term care. About 1.2 of them are over the age of 65, and, as I've said, the majority of that group have a dementing illness, complicating whatever else they have. There are hopes. Only a few years ago the Alzheimer's Disease and Related Disorders Society was founded nationally, and has become a rapidly growing program. The National Institute on Aging and the National Institute of Neurologic Diseases have begun to invest money in this disorder; the National Institute of Mental Health has shown some concern. And finally the Secretary of Health and Human Services has recognized that this is a disorder meriting national attention. So we are now taking an old problem, and saying it's important enough to warrant our attention.
Current Research
by Robert Terry, M.D.
Professor and Chairman
Department of Pathology
Albert Einstein College of Medicine
Panelist

My predecessors this morning have spoken to you about the frequency of Alzheimer’s Disease, its diagnosis, and something about its cost, but no one has yet mentioned its therapy. The question still remains: what can we do about this disease? Well, until recently we essentially ignored it, and I guess we could continue to do that. We could continue to do what we are doing now; that is, caring for patients; and we can improve that care in many ways. We can continue to observe these patients with ever-increasing detail. But we will still watch their numbers increase, and we will watch the cost—both emotional and economic cost—increase. Or, we can take the third alternative, and that is, to make a significant investment in laboratory research. This was the choice that faced the country not too long ago in regard to infantile paralysis, when great numbers of physicians and lay people were wrapped up (no pun intended) in the Salk Kenny treatments, in which hot packs were applied and physiotherapy was used. But the numbers of polio cases just increased until, ultimately, laboratory workers isolated the virus and made a vaccine against it, so that polio has disappeared as a problem. Now, Alzheimer’s Disease is proving to be a somewhat more difficult problem to solve, but I suggest to you that research is our only hope, because watching those numbers and those costs increase will only allow us to be overwhelmed, and in the not too distant future.

Well, what are the general areas where progress has been made in the last couple of decades? About half the patients with dementia who come to autopsy (and autopsy is still the only ultimate proof) have Alzheimer’s Disease; another twenty or so percent have multiple infarcts in the brain, and another ten or fifteen percent have a mixture. Those left over have a variety of organic causes of dementia, and a small but significant number have dementias based on some unknown or undetermined cause. To Alzheimer’s Disease in particular, I would remind you that more people die of, or at least with, severe Alzheimer’s Disease than die of carcinoma of the lung—the most common fatal cancer in the country today. Alzheimer’s is about ten times as common as multiple sclerosis, about a hundred times more common than amyotrophic lateral sclerosis or Huntington’s disease. It’s a disaster, and it’s a major one.

One of the two major microscopic features of Alzheimer’s Disease is the neurofibrillary tangle. This is a lesion or abnormality that lies within the cell body of the large and medium-sized neurons of certain parts of the brain. Not all parts of the brain are affected. The tangle is made up of abnormal fibers which are in fact paired helical filaments. It is incumbent upon us in the laboratories to determine the nature of these neurofibrillary tangles, and we’ve been working at it for twenty years. Some progress is being made. We want to find out what it’s made of, because if it is a new kind of protein, it would mean that there is new genetic information. That is the only way a cell can make an entirely new kind of protein. Now the genetic information may actually have been there all the time, but it was repressed, and then it becomes uncovered or de-repressed. We would like to know why and how it becomes uncovered. Or we would like to know how this new genetic information gets inserted into the cell—perhaps by a virus. Now if, on the other hand, this is a normal protein which has been modified in the process of its synthesis, then we would have to look in another direction for the reasons for its becoming modified, becoming insoluble, and becoming detrimental to the normal functions of those nerve cells that are affected. Alzheimer’s Disease concerns primarily tissues and cells, and this leads to disordered chemistry, and that leads to the clinical symptoms described by the preceding speakers.

Now one of the ways to get at the nature of these fibers is to homogenize the brain tissue and analyze it chemically, but this has been progressing slowly. That is because these fibers turn out to be very insoluble. They are very resistant to the usual solvents which can dissolve normal fibrous proteins. Another way of getting at it is to use specific antibodies as markers. Many such antibodies have been made which react with the neurofibrillary tangle to help us to identify its protein. So far, although we are making very real progress in identifying this protein, we still cannot answer the question which we posed about fifteen years ago: Is it a normal modified protein, or is it an abnormal protein?

The neuritic or senile plaque is the second marker, described even before Alzheimer, but recognized by Alzheimer as being a major component of the changes which occur in this disease. This plaque has a center made up of amyloid, which is an abnormal fibrous protein in the form of very delicate filaments in between the cells. We are looking for the nature of that amyloid. We would like to know where it comes from, and how it gets there. Surrounding the central amyloid of the plaque are abnormal branches of nerve cells which we can call, in general, neurites. In fact, most of them are the axonal endings, that is, the transmitter ending of the cell. These terminals are balloononed and they contain abnormal mitochondria and structures called lysosomes, which hold a certain group of enzymes, and the neurites also contain paired helical filaments identical to those of the tangle. So there is also a great deal to be done in regard to understanding the plaque.

But we do know that the concentration of the plaques, or for that matter of the tangles, per unit area in the brain parallels very closely the degree of severity of the dementia as measured by the clinicians. That doesn’t prove a causal relationship. Even after seventy-five years of this disease having been known, one cannot say that the tangles and the plaques cause the symptoms. It is also possible that the cause of the disease produces symptoms on the one hand, and tangles and plaques on the other, simply as markers of the disease.

A third change in the brain tissue of patients with Alzheimer’s Disease is a major loss of large neurons from the cerebral cortex. In normal aging, while there is no loss from several cranial nerve nuclei, there are decrements in other parts of the brain such as the basal ganglia, cerebellum, cortex and substantia nigra. In Alzheimer’s Disease there is an additional loss of thirty-five to forty-five percent of the large neurons in the cortex. Why we lose neurons in this disease, or for that matter in normal aging, is a major question; because this disease is caused by the loss or degeneration of cells. It is not caused by losing one’s memory: that is the confusion.

There seem to be seven possible general causes for cell loss. One suggestion is genetics, and we know that there is a genetic factor involved in many of the Alzheimer patients: there are some familial cases, and there are Down’s patients, those with the extra twenty-first chromosome. There might be a missing trophic factor. That is a factor, a chemical, which is made by one part of the brain and is essential to the survival of another part of the brain. Its being missing is not really a cause, though, because then one would ask what goes wrong with the first part of the brain. Then there is the possibility of the brain becoming immune to some part of itself or some other part of the body, a process called auto-immunity. This is a popular idea, but there is no real evidence for it in regard to Alzheimer’s Disease. A fourth possibility is a continuing process of peroxidation goes on as we age. It results in the yellow pigmentation we call lipofuscin, and this has been suggested as a major cause of Alzheimer’s Disease and various other problems—even of aging itself. But since trees age, and they don’t have lipofuscin, and since parts of the brain without lipofuscin also age, and since in Alzheimer’s Disease there is no more of this pigment than in normal aged controls. I can’t believe that it is important. How about an endogenous toxin (a toxin which is made by the body itself)? Well, it’s not impossible that the cost of our having become multi-cellular organisms eons ago causes us to age. Single-celled organisms don’t get old, they simply divide and go on. However, as soon as two cell types get together, each cell type having its own metabolism, it becomes conceivable that the normal products of metabolism from one cell type are detrimental to the long term survival of the other cell type. It is an interesting idea, but I don’t have
any evidence for it. In terms of an exogenous toxin, several people have suggested aluminum. It became very popular following our chance discovery of the model in rabbits. It was then found that aluminum is increased in the brain tissue of some patients with Alzheimer's Disease. But, in Lexington, Kentucky, where the aluminum levels in water are very low because they don't use alum to purify the water, the patients with Alzheimer's Disease come to autopsy and their aluminum concentrations are normal. And so, very possibly, up in Toronto, where the original high levels were found, or in Burlington, Vermont, where they were confirmed, and where they use alum to purify the water, the aluminum is aggregated in the brain simply as a secondary phenomenon rather than as a causal factor. Virus has been blamed for a great many things. We don't know that there is a virus involved; we haven't seen it, nor have we been able to demonstrate any other direct evidence of it at all.

However, a major series of breakthroughs in Alzheimer's Disease in regard to neurotransmitters, the chemicals which send the messages, began in about 1976. Curiously enough, it began almost simultaneously in three laboratories in Great Britain. One finding is a decrease in somatostatin, which is a neuro-modulator peptide. An ever more important discovery was that there is a major deficiency of acetylcholine, which is a very important transmitter. This was first published by Peter Davies, who is now working with us in the Bronx. The point of this is that having demonstrated the deficiency of this particular chemical transmitter, there are possible ways of correcting it. The ways are somewhat analogous to those of correcting Parkinson's disease, and they offer the same partial, not total, hope.

I want to close by emphasizing that in the last ten or twenty years there has been very real and significant progress in regard to understanding the nature of Alzheimer's Disease, especially in terms of its mechanism. This gives us real hope and real expectation that within the quite near future we will be able to interrupt the course, to alleviate and to stabilize the disease to some extent. In terms of getting at the ultimate cause of this disease, we've made a lot less progress. On the other hand, the curve of our progress is such that I can't help but be optimistic; and, by nature, pathologists are not optimistic. In Alzheimer's Disease, this one is.
The Clinical Syndrome
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Panelist

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The earliest recognized association of the clinical symptomatology associated with what we now term senile dementia of the Alzheimer's type (SDAT), or in the modern psychiatric nomenclature, primary degenerative dementia, appears to have come not from the medical profession, but rather from the legal profession. Solon, in circa 500 B.C., listed impaired judgment resulting from old age as one condition in which a will might be found to be invalid. 2 Plato (428/427-348/347 B.C.), in a work completed toward the end of a long and productive life, also recognized the syndrome in stating that, "the combination of certain crimes (sacrilege, treachery, treason) is excusable in a state of madness or when affected by disease or under the influence of extreme old age or in a fit of childish wantonness." 3-5

Hippocrates, a contemporary of Plato, did not include either dementia, nor the specific dementia associated with the aging process, in his list of mental disorders. The earliest recognition of dementia as a medical entity appears to come to us from a work known as "De Medicina," published by Aurelius Cornelius Celsus, a Roman writer, in the first century A.D. 6-8 Cicero, a contemporary of Celsus, noted in a famous oratorical composition known as "De Senectute" that, "as wantonness and licentiousness are faults of the young rather than of the old, yet not of all young men but only of the depraved, so the senile folly called dotage is characteristic not of all old men but only of the frivolous." 9 However, the first physician to have clearly recognized old age as a cause of dementia was probably Galen (c.A.D. 130-c.A.D. 200). He defined morosis (dementia) as "some in whom the knowledge of letters and other arts are totally obliterated, indeed they can't even remember their own names... Even now it is seen that on account of extreme debility in old age, some are afflicted with similar symptoms." 10

The clinical description of SDAT does not appear to have advanced for more than 15 centuries after Galen, although Galenic traditions were maintained throughout the centuries. In 1793, Benjamin Rush, the founder of American psychiatry and a signer of the American Declaration of Independence, published the first accurate case history of what was to subsequently become known as Alzheimer's Disease or SDAT. He noted that:

"It would be sufficiently humiliating to human nature if our bodies exhibited in old age the marks only of a second childhood, but human weakness descends still lower. I met with an instance of a woman between 80 and 90 who exhibited the marks of a second infancy, by such a total decay of her mental faculties as to lose all consciousness in discharging her alvine and urinary excretions. In this state of the body, a disposition to sleep succeeds the wakefulness of the first stages of old age." 11

Esquirol, in Paris, defined "démence senile" in an 1838 textbook of psychiatry, in terms with which present day investigators would not quarrel. He stated correctly that this was a condition in which there occurs a weakening of the memory for recent experiences and a loss of drive and willpower. Accurately, he noted that the condition appears gradually and may be accompanied by emotional disturbances. 12

At the same time that clinical descriptions of SDAT were being advanced, the pathologic syndrome was being elucidated for the first time. Baulé described dilatation of the cerebral ventricles in 1795, and Wilks described cortical atrophy and sulcal dilatation in 1864. The so-called pathologic hallmarks of the illness, senile plaques, neurofibrillary tangles, and granulovascular degeneration, were described by Redlich in 1898, 13 Alzheimer in 1907, 14 and Simchowitz in 1911, 15 respectively.

Alzheimer: described neurofibrillary changes, consisting of tangles of thick argentophilic fibrils within the cytoplasm of neurons. in a woman who first manifested signs of disease at 51 years of age. The term "presenile dementia" had been introduced by Binswanger in 1898. Alzheimer mistakenly believed the neuropathologic changes which he described occurred exclusively in dementia with onset in the presenium (i.e., before 65 years of age). Alois Alzheimer was a faculty member in the department of the eminent German psychiatrist, Emil Kraepelin. Indeed, in 1903, when Kraepelin left Heidelberg to take the chair of the Department of Psychiatry in Munich, Alzheimer accompanied him. It was Kraepelin who began the tradition of applying Alzheimer's name to the presenile form of the disease, 16 a tradition which continued until the 1970's. In a certain sense, Alois Alzheimer set back scientific knowledge of dementing illness of later life, at the same time that he advanced conceptualizations in other areas with respect to this disease. He mistakenly believed all dementia with onset after age 65 was characterized by the absence of senile plaques or neurofibrillary changes. He also mistakenly attributed the origins of the great majority of cases of dementia with senile onset to cerebrovascular disease. Finally, he mistakenly believed that neurofibrillary changes and senile plaques would not be found to be present in the brains of normal elderly persons 17-18.

Gradually, over the next sixty years, these misconceptions were remedied. Subsequent investigations demonstrated that the neurofibrillary tangles first described by Alois Alzheimer, occurred in dementia of senile onset as well as in elderly individuals without dementia. 19-21 Other studies demonstrated the same degree of arteriosclerotic brain changes in elderly persons who were not demented at the time of their demise as in those who were. 22-23 Finally, some revolutionary investigations demonstrated that the presence of senile plaques and of neurofibrillary changes in the brain of elderly persons correlated strongly with dementing illness in later life. 24 These findings led to the realization that Alzheimer's Disease, whether it occurs in the presenium or in later life, was a single illness and that this illness, not arteriosclerosis, was the major cause of late life dementia. 25 Epidemiologic studies had revealed that the dimensions of this illness in terms of morbidity and mortality were such as to make the condition a major area for medical concern, comparable to such other major illnesses as heart disease, cancer, and stroke. 26-28 Although the medical research community recognized the medical and social implications of these findings in the 1970s, and a series of edited volumes 29-41 and one single authored text 42 were published consolidating knowledge in the field, the condition continued to be neglected in general medical texts. For example, a standardized American textbook of medicine in 1982 devoted only one of its 2,354 pages to Alzheimer's Disease, which it accurately described as "a major public health problem...approximately 5% of the population at 65 and up to 20% of the population over 80 are affected" 43 (emphasis added). Neglect in specialty textbooks, specifically psychiatry and neurology, has been equally egregious. 44,45 Hence, the lay community came to learn about Alzheimer's Disease at approximately the same time as the general medical community. 46 Lay recognition was rapidly followed by political recognition of what seems to be a major health problem. 47

Until very recently these increases in medical and lay understanding with respect to the pathophysiologic nature of Alzheimer's Disease were not accompanied by improved clinical understanding of the disorder. Indeed, a consensus conference, the proceedings of which were published in 1981, 48 demonstrated that medical and scientific understanding of the clinical syndrome, in terms of phenomenology, progression, and prognosis, had not advanced notably since the descriptions of Rush 11 and Esquirol. 12 In this decade, however, the clinical manifestations of the illness have begun to be described in
suffer from complaints of cognitive decline. Kral has proposed the terminology Benign Senescent Forgetfulness, to designate this condition. In Kral's nomenclature, it is the hypothesis that the great majority of persons with these symptoms do not suffer any further decline in cognitive capacities. Results from follow-up studies support this hypothesis. In one study, Reisberg, et al.44 followed 16 community residing persons (mean age 68.70 ± 4.05 years) with subjective and psychometrically verified cognitive symptomatology as described above, for a mean interval of 27.18 ± 3.71 months (see Table 2). At the time of follow-up, the investigators found that none of the individuals had measurably worsened cognitively and all continued to be alive and well and community residing (see Tables 2 and 3).

Analogous results have been reported by Kral in a somewhat older patient group. He followed 94 subjects with a mean age of 80.5 years of whom 40 subjects had clinically preserved memory function and 20 had Senescent Forgetfulness over a four-year observation period. He found no significant difference in the death rate between the subjects with preserved memory and those with Senescent Forgetfulness. However, both groups survived significantly longer than the 34 subjects from the more severely impaired cohort. Furthermore, over the 4-year observation period, only one of Kral's 20 Senescent Forgetfulness patients became more severely cognitively impaired and required subsequent institutionalization.

Early Alzheimer's Disease
In a minority of individuals, Forgetfulness symptomatology does presage a more overt phase of cognitive deterioration, which has been termed the Confusional Phase. This phase begins at the point at which cognitive deficit becomes identifiable in the course of a detailed clinical interview. Individuals in this phase can no longer function as well in demanding employment or social situations as formerly. The deficit in recalling names becomes more manifest, such that familiar clients' and students' names are not easily recalled. The increased deficit in locating where objects have been placed results in the loss or temporary misplacement of valuables. Other cognitive deficits also become notable, particularly deficits in the recall of personal events and activities which the patient performed. Deficits in the recall of personal history and past events also occur, but are more difficult to demonstrate clinically. Concentration deficits, however, are frequently readily elicited utilizing such common clinical assessments as serial subtractions. Deficits in daily functioning also become manifest in this phase. The earliest clear-cut symptom recalled by family members is frequently an episode in which the patient had gotten hopelessly lost when traveling to a location which should have been reached without undue difficulty. As deficits become more manifest, Confusional Phase patients become less capable in managing their financial affairs.

A sense of helplessness on the part of both patients and those closest to them develops in this phase. Their sense of helplessness appears to replace the slight irritability and “shame” and increased familial strain which had accompanied the onset of symptomatology in the earlier phase. Persons in the Confusional Phase also develop what psychiatrists term a “flattening of affect.” That is to say, persons in this phase become emotionally less responsive than previously. In part, this occurs as a result of the increased feelings of helplessness. However, the decreased emotional responsivity is also a product of the confused patient’s decreased ability to process or understand incoming stimuli. The adaptive response to these decremental abilities is a partial withdrawal from stimuli input, and a lower level of cognitive and emotional responsiveness to events around them.

Surveys have indicated that the prevalence of Confusional Phase symptomatology (also referred to as mild dementia) is 10 to 12 percent of all persons aged 65 and greater.44 On the basis of these figures, we might expect that in the United States, approximately 3 million persons suffer from Confusional Phase symptomatology. Although the natural history of Confusional Phase symptomatology has not been extensively studied, in most Confusional patients these symptoms do appear to herald more malignant symptomatology, with further decline, institutionalization, and not infrequently, death within the subsequent two to five-year period. Of 11 patients (mean age 72.82 ± 5.95 years) with Late Confusional Phase (stage 4) symptomatology followed by Reisberg, et al.44 over a period of 27.54 ± 5.18 months, three were deceased or institutionalized at the time.
<table>
<thead>
<tr>
<th>GDS stage</th>
<th>Clinical phase</th>
<th>Clinical characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 No cognitive decline</td>
<td>Normal</td>
<td>No subjective complaints of memory deficit. No memory deficit evident on clinical interview.</td>
</tr>
<tr>
<td>2 Very mild cognitive</td>
<td>Forgetfulness</td>
<td>Subjective complaints of memory deficit, most frequently in following areas: (a) forgetting where one has placed familiar objects; (b) forgetting names one formerly knew well. No objective evidence of memory deficit on clinical interview. No objective deficits in employment or social situations. Appropriate concern with respect to symptomatology.</td>
</tr>
<tr>
<td>3 Mild cognitive</td>
<td>Early Confusional</td>
<td>Earliest clear-cut deficits. Manifestations in more than one of the following areas: (a) patient may have gotten lost when traveling to an unfamiliar location; (b) co-workers become aware of patient's relatively poor performance; (c) word and name finding deficit become evident to intimates; (d) patient may read a passage or a book and retain relatively little material; (e) patient may demonstrate decreased facility in remembering names upon introduction to new people; (f) patient may have lost or misplaced an object of value; (g) concentration deficit may be evident on clinical testing. Objective evidence of memory deficit obtained only with an intensive interview conducted by a trained geriatric psychiatrist. Decreased performance in demanding employment and social settings. Denial begins to become manifest in patient. Mild to moderate anxiety accompanies symptoms.</td>
</tr>
<tr>
<td>4 Moderate cognitive</td>
<td>Late Confusional</td>
<td>Clear-cut deficit on careful clinical interview. Deficit manifest in following areas: (a) decreased knowledge of current and recent events; (b) may exhibit some deficit in memory of one's personal history; (c) concentration deficit elicited on serial substractions; (d) decreased ability to travel, handle finances, etc. Frequently no deficit in following areas: (a) orientation to time and person; (b) recognition of familiar persons and faces; (c) ability to travel to familiar locations. Inability to perform complex tasks. Denial is dominant defense mechanism. Flattening of affect and withdrawal from challenging situations occur.</td>
</tr>
<tr>
<td>5 Moderately severe</td>
<td>Early dementia</td>
<td>Patient can no longer survive without some assistance. Patient is unable during interview to recall a major relevant aspect of their current lives: e.g., their address or telephone number of many years, the names of close members of their family (such as grandchildren), the name of the high school or college from which they graduated. Frequently some disorientation to time (date, day of week, season, etc.) or to place. An educated person may have difficulty counting back from 40 by 4s or from 20 by 2s. Persons at this stage retain knowledge of many major facts regarding themselves and others. They invariably know their own names and generally know their spouses and children's names. They require no assistance with toileting or eating, but may have some difficulty choosing the proper clothing to wear and may occasionally clothe themselves improperly (e.g., put shoes on the wrong feet, etc.).</td>
</tr>
<tr>
<td>6 Severe cognitive</td>
<td>Middle dementia</td>
<td>May occasionally forget the name of the spouse upon whom they are entirely dependent for survival. Will be largely unaware of all recent events and experiences in their lives. Retain some knowledge of their past lives but this is very sketchy. Generally unaware of their surroundings, the year, the season, etc. May have difficulty counting from 10, both backward and sometimes, forward. Will require some assistance with activities of daily living, e.g., may become incontinent, will require travel assistance but occasionally will display ability to travel to familiar locations. Diurnal rhythm frequently disturbed. Almost always recall their own name. Frequently continue to be able to distinguish familiar from unfamiliar persons in their environment. Personality and emotional changes occur. These are quite variable and include: (a) delusional behavior, e.g., patients may accuse their spouse of being an impostor; may talk to imaginary figures in the environment, or to their own reflection in the mirror; (b) obsessive symptoms, e.g., person may continually repeat simple cleaning activities; (c) anxiety symptoms, agitation, and even previously nonexistent violent behavior may occur; (d) cognitive abulia, i.e., loss of willpower because an individual cannot carry a thought long enough to determine a purposeful course of action.</td>
</tr>
<tr>
<td>7 Very severe cognitive</td>
<td>Late dementia</td>
<td>All verbal abilities are lost. Frequently there is no speech at all—only grunting. Incontinent of urine; requires assistance toileting and feeding. Lose basic psychomotor skills, e.g., ability to walk. The brain appears to no longer be able to tell the body what to do. Generalized and cortical neurologic signs and symptoms are frequently present.</td>
</tr>
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Table 2
Follow-Up Intervals, Residential Status at Follow-Up, and Mortality Differentiated by Initial GDS Scores*

<table>
<thead>
<tr>
<th>GDS (Initial Assessment)</th>
<th>Follow-Up Interval (months)</th>
<th>Residential Status at Follow-Up and Mortality</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean ± S.D.</td>
<td>Range</td>
</tr>
<tr>
<td>2</td>
<td>27.18 ± 3.71</td>
<td>23–33</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>27.36 ± 5.46</td>
<td>18–34</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>27.54 ± 5.18</td>
<td>21–37</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
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<tr>
<td>5</td>
<td>23.17 ± 5.78</td>
<td>16–32</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>26.81 ± 4.94</td>
<td>16–37</td>
</tr>
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</table>

†In nursing homes.

Table 3
Initial and Follow-Up Scores on Assessment Parameters (Mean ± S.D.) for Community Residing Survivors¹

<table>
<thead>
<tr>
<th>GDS</th>
<th>N</th>
<th>MSQ Score</th>
<th>Clinical Cognition Assessment Scores</th>
<th>Functional Assessment Inventory Scores</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pre</td>
<td>Post</td>
<td>Pre</td>
<td>Post</td>
</tr>
<tr>
<td>2</td>
<td>16</td>
<td>.25 ± .45</td>
<td>.13 ± .34</td>
<td>12.94 ± 1.44</td>
</tr>
<tr>
<td>3</td>
<td>14</td>
<td>.64 ± 1.08</td>
<td>1.36 ± 1.08</td>
<td>14.71 ± 2.64</td>
</tr>
<tr>
<td>4</td>
<td>8†</td>
<td>3.00 ± 2.20</td>
<td>5.87 ± 1.73 *</td>
<td>16.50 ± 3.21</td>
</tr>
<tr>
<td>5</td>
<td>3†</td>
<td>7.33 ± 2.08</td>
<td>8.33 ± 0.58</td>
<td>18.66 ± 3.79</td>
</tr>
<tr>
<td>Total</td>
<td>41†</td>
<td>1.41 ± 2.31</td>
<td>2.27 ± 2.98**</td>
<td>14.63 ± 2.96</td>
</tr>
</tbody>
</table>

*P<0.05 Significance of Baseline vs. Follow-Up Differences on Assessment Measures: Wilcoxon Matched Pairs Signed Rank Test (from Colton, *Statistics in Medicine*, 1974). Non-parametric, two-tailed probabilities.
**P<0.01
***P<0.001
† Community residing survivors only.
of follow-up (Table 2). Of the remaining eight individuals, all continued to function in a community setting. Of these, 50% evidenced significant decline over the follow-up period, and 50% were not notably worse in either cognitive or functional capacity (Table 3). Each of the 11 patients followed in the Late Confusional Phase demonstrated at least some decline, however (even if not overtly manifest decline), on detailed cognizance parameters. Hence, this phase (stage 4) can be said to represent the earliest stage of true Alzheimer’s Disease, in which, by definition, gradual cognitive decline is a concomitant of the illness process.

The Early Confusional Phase (stage 3) actually represents a borderland between normal aging, with characteristic Forgetfulness Phase symptomatology of normal aging, and true Alzheimer’s Disease. Fourteen patients (mean age 68.71 ± 5.25 years) with Early Confusional Phase symptomatology followed by Reisberg et al.43 over a period of 27.36 ± 5.46 months, showed significantly greater decline as a group than the Forgetfulness Phase subjects over the same time period (Table 3). However, only about half of these 14 subjects demonstrated any decline whatever over the follow-up period, and all 14 Early Confusional Phase subjects remained alive and well and community-residing at the time of follow-up (Table 2).

Middle and Late Stage Alzheimer’s Disease

The Dementia Phase can be defined as beginning at the point at which patients can no longer survive if left on their own. Difficulties in functioning and in carrying out basic activities of daily living are the hallmark of this phase of cognitive impairment. Early in this phase (stage 5), patients frequently have difficulty in choosing the proper clothing. At this point, individuals are forced to severely circumscribe their commitments and activities. Travel, even to familiar neighborhood locations, becomes difficult, if not impossible. Financial affairs are taken over by the spouse, caretaker or other family members. Memory suffers to the extent that patients have difficulty recalling the name of the current President, the year, their address, or their current location. Patients also forget the names of schools which they have attended, and towns and cities in which they have lived.

As the Dementia Phase progresses (stages 6 and 7), deficits develop in all cognitive and functional areas. The ability to cut food for oneself is lost, and, ultimately, the ability to manipulate silverware disappears in entirety. Patients lose the ability to wash and bathe themselves, even with adequate assistance. Patients become incontinent, and, ultimately, require assistance in toileting themselves. Patients become unsteady in their movements and, ultimately, psychomotor abilities are lost to the extent that individuals can no longer ambulate. All recent and remote memories and cognitive capacities gradually disappear. Patients forget the names of the spouse upon whom they are entirely dependent for survival, and, subsequently, lose the ability to even recognize their own name. All self-identity is lost. The previous profession of a lifetime is entirely forgotten as are all events from one’s past. Calculating and concentration ability is lost to the extent to which individuals cannot count from one to five consecutively. Ultimately, all ability to speak is lost; patients can only stare blankly and gurgle.

The loss of one’s cognitive and intellectual capacities is too overwhelming a deficit for conscious contemplation. Consequently, individuals in the Dementia Phase deny much of their deficit. For instance, a patient may aver that he cannot recall the current President’s name because he “doesn’t follow politics;” or his residence of twenty years because “I’ve only recently moved.” Emotional difficulties, which become manifest in this phase, are also frequently denied. The onset of symptomatology in this phase is met by an acute sense of shame. This is replaced by marked irritability and agitation as the condition progresses. Psychiatric manifestations with suspiciousness, overt paranoia, delusions, and visual, or other hallucinatory experiences, frequently occur in the middle to late Dementia Phase. These symptoms make caring for the patient particularly difficult and force even the most heroically concerned family to confront the necessity of institutionalization.

Estimates have indicated that Dementia Phase cognitive deficit occurs in approximately 5% of persons aged 65 and greater.14 Hence, more than one million Americans are probably afflicted with this condition. Government studies indicate that chronic cognitive deficits, probably synonymous in most cases with the condition which we are describing, occur in 38% of the more than one million Americans in nursing homes.44 Many such patients are also housed in other institutional facilities such as state mental hospitals and veterans hospitals. More than half of the patients over 65 in state and county mental hospitals carry diagnoses compatible with chronic cognitive decline. Despite these dramatic statistics, it is thought that at least half of all patients in the Dementia Phase remain within the community where they are assisted by their spouses, siblings, children, or others.

The Dementia symptoms described are associated with a marked decrease in life expectancy. In one study, the mean survival period was 2.6 years for men and 2.3 years for women, in comparison with 8.7 years and 10.9 years, respectively, for age-matched, nondemented controls.23 Of 6 community residing individuals with early Dementia Phase symptomatology (mean age 74.2 ± 4.7 years) who Reisberg, et al.44 followed for a mean interval of 23.17 ± 5.78 months, 1 was deceased at follow-up, 2 were institutionalized at the time of follow-up, and 3 remained community residing and performed only slightly, and not significantly worse on a brief Mental Status Questionnaire Assessment (Tables 2 and 3).

It is important for clinicians to recognize that the prognostic concomitants of the stages in the evolution of progressive cognitive decline vary. However, if the patient has been correctly diagnosed, then the presence of a particular stage of cognitive impairment does imply that the patient must have previously experienced the preceding stages and symptoms. In all cases, the progress of the condition is gradual, and all patients who are correctly diagnosed and who are not the victims of secondary disease processes spend periods of several months to years in each global stage.

Multi-Axial Clinical Assessments

More recent work has indicated that these global stages can also be clinically subdivided into five clinical axes: (I) Concentration; (II) Recent Memory; (III) Past Memory; (IV) Orientation; and (V) Functioning and Self-Care. When properly defined, decline on each of these clinical parameters tends to proceed at a rate consistent with the global stage of cognitive functioning.25 Definitions of these clinical parameters, or “axes,” corresponding to the successive stages of global cognitive deterioration can be seen in the Brief Cognitive Rating Scale described in Table 4.

Since scores on each of the clinical axes described in Table 4 correlate strongly not only with each other, but also with the corresponding Global Deterioration Scale (GDS) scores (Table 1), the Brief Cognitive Rating Scale (BCRS) axes (Table 4) provide a brief clinical sketch of the corresponding clinical stage of cognitive functioning. Hence, a patient with moderate cognitive decline in the Late Confusional Phase (GDS 4), as described in Table 1, is likely to show a corresponding degree of impairment on each of the BCRS axes. Specifically, this patient is likely to demonstrate “definite concentration deficit for persons of their background” (Table 2, Axis 1, a score of “4”). This concentration deficit can frequently be manifested by asking the patient to subtract serial 7’s from 100. Not only will the Late Confusional Phase patients frequently demonstrate marked deficits of subtraction of serial 7’s, but frequently deficits in subtraction of serial 4’s from 40 as well. As can be seen in Table 2, these same patients are, however, likely to be capable of subtracting serial 2’s from 20 without difficulty.

Patients in the Late Confusional Phase are also likely to be unable to recall certain major events from the previous weekend or week and to have a “scanty knowledge of current events” (Axis II, rating score “4”). However, Late Confusional Phase patients are likely to be able to recall the name of the current President or Head of State of the country in which they reside, and to recall correctly their current address.

As can be seen in Table 4, the Late Confusional Phase patient is likely to show corresponding deficits in past memory (Axis III), as well. A common statement is: “I always foolishly comment on how well he remembers past events.” As a result, the patient is usually able to recall, whether instructed or not, important personal life events. This perception is, in part, a product of the PDD patient’s continued necessity to recall events from his recent past, whereas he is rarely
Table 4
Brief Cognitive Rating Scale (BCRS)*

<table>
<thead>
<tr>
<th>Axis I: (Circle Highest Score)</th>
<th>Item</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concentration and Calculating Ability</td>
<td>No objective or subjective evidence of deficit in concentration.</td>
</tr>
<tr>
<td>1</td>
<td>Subjective decrement in concentration ability.</td>
</tr>
<tr>
<td>2</td>
<td>Minor objective signs of poor concentration (e.g., on subtraction of serial 7s from 100).</td>
</tr>
<tr>
<td>3</td>
<td>Definite concentration deficit for persons of their background (e.g., marked deficit on serial 7s: frequent deficit in subtraction of serial 4s from 40).</td>
</tr>
<tr>
<td>4</td>
<td>Marked concentration deficit (e.g., giving months backwards or serial 2s from 20).</td>
</tr>
<tr>
<td>5</td>
<td>Forgets the concentration task. Frequently begins to count forward when asked to count backwards from 10 by 1s.</td>
</tr>
<tr>
<td>6</td>
<td>Marked difficulty counting forward to 10 by 1s.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Axis II: Recent Memory</th>
<th>Item</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>No objective or subjective evidence of deficit in recent memory.</td>
</tr>
<tr>
<td>2</td>
<td>Subjective impairment only (e.g., forgetting names more than formerly).</td>
</tr>
<tr>
<td>3</td>
<td>Deficit in recall of specific events evident upon detailed questioning. No deficit in the recall of major recent events.</td>
</tr>
<tr>
<td>4</td>
<td>Cannot recall major events of previous weekend or week. Scanty knowledge (not detailed) of current events, favorite TV shows, etc.</td>
</tr>
<tr>
<td>5</td>
<td>Unsure of weather; may not know current president or current address.</td>
</tr>
<tr>
<td>6</td>
<td>Occasional knowledge of some recent events. Little or no idea of current address, weather, etc.</td>
</tr>
<tr>
<td>7</td>
<td>No knowledge of any recent events.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Axis III: Past Memory</th>
<th>Item</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>No subjective or objective impairment in past memory.</td>
</tr>
<tr>
<td>2</td>
<td>Subjective impairment only. Can recall two or more primary school teachers.</td>
</tr>
<tr>
<td>3</td>
<td>Some gaps in past memory upon detailed questioning. Able to recall at least one childhood teacher and/or one childhood friend:</td>
</tr>
<tr>
<td>4</td>
<td>Clear-cut deficit. The spouse recalls more of the patient's past than the patient. Cannot recall childhood friends and/or teachers but knows the names of most schools attended. Confuses chronology in reciting personal history.</td>
</tr>
<tr>
<td>5</td>
<td>Major past events sometimes not recalled (e.g., names of schools attended).</td>
</tr>
<tr>
<td>6</td>
<td>Some residual memory of past (e.g., may recall country of birth or former occupation).</td>
</tr>
<tr>
<td>7</td>
<td>No memory of past.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Axis IV: Orientation</th>
<th>Item</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>No deficit in memory for time, place, identity of self or others.</td>
</tr>
<tr>
<td>2</td>
<td>Subjective impairment only. Knows time to nearest hour, location.</td>
</tr>
<tr>
<td>3</td>
<td>Any mistake in time—2 hrs; day of week—1 day; date—3 days.</td>
</tr>
<tr>
<td>4</td>
<td>Mistakes in month—10 days or year—one month.</td>
</tr>
<tr>
<td>5</td>
<td>Unsure of month and/or year and/or season; unsure of locale.</td>
</tr>
<tr>
<td>6</td>
<td>No idea of date. Identifies spouse but may not recall name. Knows own name.</td>
</tr>
<tr>
<td>7</td>
<td>Cannot identify spouse. May be unsure of personal identity.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Axis V: Functioning and Self-Care</th>
<th>Item</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>No difficulty, either subjectively or objectively.</td>
</tr>
<tr>
<td>2</td>
<td>Complains of forgetting location of objects. Subjective work difficulties.</td>
</tr>
<tr>
<td>3</td>
<td>Decreased job functioning evident to co-workers. Difficulty in traveling to new locations.</td>
</tr>
<tr>
<td>4</td>
<td>Decreased ability to perform complex tasks (e.g., planning dinner for guests, handling finances, marketing, etc.).</td>
</tr>
<tr>
<td>5</td>
<td>Requires assistance in choosing proper clothing.</td>
</tr>
<tr>
<td>6</td>
<td>Requires assistance in feeding, and/or toileting, and/or bathing, and/or dressing.</td>
</tr>
<tr>
<td>7</td>
<td>Requires constant assistance in all activities of daily life.</td>
</tr>
</tbody>
</table>

*by Barry Reisberg, M.D., Gerri E. Schwartz, Ph.D., Thomas Crook, Ph.D., and Steven H. Ferris, Ph.D.*

queried in detail with respect to his childhood or early school experiences. On these unusual occasions when a mildly or moderately impaired PDD patient is required to recall details from his past, he frequently finds it acceptable to retreat to the rationalization, "It was so long ago, how can I be expected to remember that?" Hence, deficits in past memory, although present, are not as readily manifest, and are not as troubling for the patient or his family. The orientation deficits which are probably manifest at each Global Deterioration Scale stage can be seen in Axis IV of the BCRS. Hence, in the Late Confusional Phase (GDS = 4), the patient is likely to err by 10 or more days in response to queries as to the current date. However, at this stage, the patient most probably can still recall the current year and remains oriented with respect to his or her location.

Functional deficits are particularly notable concomitants of each global stage of deterioration. These deficits are the ones most clearly observed by family members and caretakers of Alzheimer's patients. In the Late Confusional Phase, the characteristic functional deficits are difficulties with handling finances and with marketing. However, these patients not only remain fully capable of putting on their clothing properly, but are also capable of choosing the proper clothing for the season and any special occasions of the moment. Other Clinical Features

In addition to the clinical features described in Tables 1 and 4, other clinically observable changes also accompany the various stages of progressive cognitive decline. The most notable additional clinical features are those related to speech, to psychomotor abilities, and to mood and behavior (Table 5).
Table 5
Brief Cognitive Rating Scale (BCRS)
Language, Motoric, and Mood Concomitants*

<table>
<thead>
<tr>
<th>Axis</th>
<th>Rating</th>
<th>Item</th>
</tr>
</thead>
<tbody>
<tr>
<td>Axis VI:</td>
<td>1</td>
<td>No subjective or objective speech deficit.</td>
</tr>
<tr>
<td>Language</td>
<td>2</td>
<td>Subjective deficits in recalling names of persons and objects.</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>Overt word-finding difficulties which may result in intermittent interruptions of speech or mild stuttering.</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>Decrease of verbalization. Patient becomes more reticent. Alternatively, tendency to ramble.</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>Overt paucity of spontaneous speech. Sentence production abilities remain intact.</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>Inability to speak in sentences. Responses tend to be limited to one or a few words.</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>Verbal abilities are lost. Vocabulary may be limited to one or two words, if any. Patient may repeat words or phrases (verbigeration), or make up new words or phrases (neologisms). Patient’s vocabulary may be limited to grunts or screams.</td>
</tr>
<tr>
<td>Axis VII:</td>
<td>1-2</td>
<td>No subjective or objective motor deficits.</td>
</tr>
<tr>
<td>Motoric</td>
<td>3</td>
<td>Decreased ability in the performance of complex psychomotor tasks such as sailing, or complex constructional tasks.</td>
</tr>
<tr>
<td>functioning</td>
<td>4</td>
<td>Gait becomes slowed. The deficit is noticeable to family members familiar with the patient but not necessarily to clinicians who may not know the patient well. Patient becomes more cautious with respect to movements and activities in general, such as driving an automobile.</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>Slowing of gait and movement is clearly evident, even to strangers. Auto driving ability is compromised or abandoned.</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>Steps become small and movements are markedly slowed. Difficulty with signing name properly may occur.</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>Ability to ambulate is lost. Inability to properly grasp a writing instrument.</td>
</tr>
<tr>
<td>Axis VIII:</td>
<td>1</td>
<td>No subjective or objective changes in mood or behavior.</td>
</tr>
<tr>
<td>Mood and</td>
<td>2</td>
<td>Subjective increase in anxiety or concern with respect to cognitive functioning.</td>
</tr>
<tr>
<td>Behavior</td>
<td>3</td>
<td>Overt anxiety evident to clinician and/or patient’s family.</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>Blunting of emotional responses evident to family.</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>Flattened affect evident to physician. Patient may have crying episodes.</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>Overt agitation and/or formal thinking disorder (e.g., paranoia, hallucinations, delusions).</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>Nonverbal agitation alternating with pathologic passivity.</td>
</tr>
</tbody>
</table>


Changes in Speech and Language

As stated in Table 1, the Forgetfulness Phase is frequently accompanied by subjective difficulty in recalling names of persons and objects. In the Early Confusional Phase more overt word finding difficulties occur and these deficits become evident to spouses and other intimates. Occasionally in this phase, the patient’s verbalizations will be interrupted intermittently as the patient gropes for the proper word. Mild stuttering may also occur on occasion. In the Late Confusional Phase, the language deficit is most frequently manifested in a notable decrease in verbalizations. The patient becomes notably more “quiet” than formerly. The reasons for the Late Confusional Phase patients’ unaccustomed reticence are multiple and include decreased intellectual abilities in general, as well as decreased verbal abilities, specifically. The reticence is also compatible with an affective flattening which occurs at this phase. Conversely, some patients react to this increased word finding deficit in the Confusional Phase with a tendency to ramble or “talk around the point.” This form of adaptation to the deficit may lead to an overall increase in verbalizations, although the precision of speech is compromised.

In the Early Dementia Phase, the earlier reticence becomes an overt “paucity of speech.” Sentence production remains intact; however the patient rarely offers more than single sentence responses to queries. Spontaneous speech is also notably decreased. In the Middle Dementia Phase, the patient is no longer capable of speaking in sentences. Responses tend to be limited to one or, at most, a few words. Patients at this phase who have acquired new languages over the course of their lifetime frequently revert to using words from languages which had been acquired earlier in life.
instance, one man in the Mid-Dementia Phase had been born in Poland, moved to Germany as a child, where he met his wife, and subsequently moved with his wife to the United States, where they resided for the greater portion of their adult lives. This man began speaking to his wife not in their current English tongue, nor in their former mutual language, German, but rather in Polish, which was unintelligible to his wife and others attending the patient.

In the Late Dementia Phase all verbal abilities are lost. Grunting, neologisms, verbalization, echolalia and other major language disturbances frequently occur at this stage. Some patients simply let out infrequent screams. One patient at this stage had a vocabulary consisting entirely of “okay,” which she repeated innumerable times when she recognized a family member, in response to stress or in response to other verbalization-provoking phenomena. Verbieregation is frequently manifested by repetition of the first syllable of a word. At some point in the Late Dementia Phase, most patients eventually lose all verbal abilities.

**Changes in Psychomotor Abilities**

Decreased abilities in the performance of complex psychomotor tasks, such as sailing ability or complex instructional tasks, do not occur until the Early Confusional Phase. Since these kinds of complex motor abilities are not necessarily a part of modern, everyday life, psychomotor deficits may not be noted either by the patient or by the spouse at this phase. In the Late Confusional Phase, motor abilities do overtly decline. Most frequently those who know the patient will note that the patient’s gait has become slowed and that the patient is more “cautious” with respect to movements in general. In the Early Dementia Phase, the slowing of gait and other movements are clearly observable even to a physician unfamiliar with the patient’s previous level of functioning. Although arthritis, mild Parkinsonism, or other clinical causes of impaired movement may sometimes coexist in these aged patients, the Alzheimer’s process alone is sufficient to account for the observed motor changes in the Early Dementia Phase. In the Mid-Dementia Phase, the patient frequently requires assistance with ambulation. Even if assistance is not required, the patient’s steps become very small and movements markedly slowed. Individuals at this phase also frequently have difficulty signing their name properly, even if some assistance is provided in this task. Another psychomotor manifestation at this phase is increased difficulty in handling silverware. The ability to properly utilize a knife or fork is compromised. In the Late Dementia Phase patients lose all ability to walk. They cannot even begin to sign their names and are frequently unable to grasp, in a usable fashion, a pen or pencil placed in their hand. They cannot utilize utensils and either eat with their hands or must be fed.

**Changes in Mood and Behavior**

The cognitive changes are accompanied by changes in mood and behavior which also vary with the overall severity of the illness. The mild subjective symptomatology of the forgetfulness phase is accompanied by an increase in “concern” or anxiety in the patient. This anxiety is voiced by the patient (i.e., it is subjective), however, it is not manifest in a clinically overt manner.

In the Early Confusional Phase the stresses and demands of a lifestyle which the patient is no longer capable of successfully fulfilling frequently result in more overt anxiety manifestations. The latter may be evident to the clinician as well as the patient’s spouse. In the Late Confusional Phase, denial becomes a dominant mechanism of defense, and the patient frequently begins to adaptively withdraw from stresses. The net effect of these denial and withdrawal processes is a blunting of emotional responses which psychiatrists term a “flattening of affect.” The patient becomes less involved in activities—not only intellectually, but also emotionally.

In the Early Dementia Phase this decreased involvement may be accompanied by a mourning process. The patient may suddenly begin to cry for no apparent reason over the course of the day and then just as suddenly stop. Frequently, denial prevents a patient from expressing the reason for their crying episodes. However, in most cases, the patient is probably mourning the loss of his intellect, either consciously or unconsciously. The Mid-Dementia Phase is accompanied by overt agitation. The agitation may result from the constant threat of an environment which the patient can no longer successfully manipulate and which therefore becomes genuinely dangerous. The stresses of the illness, as well as the physiologic changes accompanying the illness, may result in severe psychiatric disturbances at this stage, as well as generalized agitation. Patients may begin “talking to themselves.” They may also experience visual hallucinations, which may be related to their reveries. Frequently patients become paranoid or formally delusional. The paranoia may be the result of adaptive suspicion with respect to a world which is becoming frighteningly unfamiliar. The delusions may serve to provide one explanation for the anger or memory deficits which have befallen the patient.

In the Late Dementia Phase, patients become relatively passive as they lose the ability to speak and to walk. Under these circumstances, agitation is utilized for communication. Excitement or crying out may indicate that the patient is about to have a bowel movement and requires assistance. It might also indicate that the patient has soiled himself. Finally, increased respiration, increased verbalization, or a scream may indicate that the patient sees someone whom he knows well.

**Functional Staging**

Recent work has indicated that functionally, one can distinguish at least 15 distinct ordinal (progressive) stages in the continuum from normal aging to the end stages of Alzheimer’s Disease. These stages are described in Table 4, Axis V, and in Table 6. The recognition of these stages represents an enormous advance in our understanding of Alzheimer’s Disease since they enable clinicians and scientists to accurately quantify, in a readily comprehensible manner, the precise magnitude of impairment in Alzheimer’s Disease much more readily and accurately than previously. It also represents an enormous advance in enabling clinicians to accurately diagnose and differentially diagnose Alzheimer’s Disease.

For example, if a patient with cognitive impairment of gradual onset loses the ability to walk (functional stage 7 c) but the patient is still capable of articulating words, then an etiologic or confounding illness such as CNS neoplastic disease or stroke becomes much more likely to be the origin of the patient’s impairment than Alzheimer’s Disease. Similarly, patients with so-called “depressive pseudodementia” may lose the ability to dress themselves, but still be capable of choosing the proper clothing to wear. Alzheimer’s patients always lose the ability to choose their clothing properly (functional stage 5) before they lose the ability to put on their clothing properly (functional stage 6 a). Hence, the ordinal progression of functional loss in normal aging and SDAT provides a particularly useful tool for both the diagnosis and differential diagnosis of the age-associated cognitive disorders.

**Insight and Denial**

A complex pattern of increased concern, anxiety, and denial of deficit, which is stage specific, accompanies the evolution of progressive cognitive deficits. An understanding of this process is necessary for the proper assessment and clinical differential diagnosis of early age-related memory loss and Alzheimer’s Disease.

“Denial” has been defined as a “defense mechanism, operating unconsciously, used to resolve emotional conflict and allay anxiety by disavowing thoughts, feelings, wishes, needs, or external reality factors that are consciously intolerable?” Denial is generally betrayed by an obvious disparity between the condition of the patient and how he reports it. Such patients often smilingly insist that all is well or that a symptom does not exist! Although denial has been reported as a concomitant of a very broad spectrum of physical and emotional maladies, the extent to which this mechanism operates as a concomitant of cognitive decline in normal aging and in Primary Degenerative Dementia apparently has only recently been systematically studied.

The loss of one’s intellectual and general thinking capacities is a terrible tragedy, too painful for conscious contemplation. As with any devastating illness or loss, the psychological mechanism of defense termed denial operates to prevent fully conscious contemplation of the loss, which would be emotionally overwhelming.

The earliest symptoms of cognitive decline in what we term the Forgetfulness Phase are fully recognized by patients and by those with whom they are in most intimate contact, their spouses. In a
sense, the observational powers of the spouse are validated by the remarkable concordance of both patients and their spouses with respect to the onset and severity of these very subtle early cognitive symptoms. Emotionally, these early symptoms evoke a sense of alarm on the part of both patients and their spouses. Both recognize increased emotional difficulties which noticeably affect their family relationship. Both patients and their spouses become somewhat more irritable as a result of these symptoms. The spouses, in particular, are somewhat ashamed of the patients' forgetfulness: however, neither the patients nor their spouses feel at all helpless at this early stage. Interestingly, at this early stage, patients become not only acutely aware of a cognitive problem in themselves, but also acutely, or perhaps hyperacutely, sensitive to slight cognitive problems in their spouses.

In general, the patients' awareness of their memory deficits tends to peak in the Confusional Phase. Spouses' awareness of memory problems in the patient tends not to differ markedly from the patients' assessments at this phase. Patients and their spouses continue to experience some emotional problems as a result of the patients' memory difficulties. However, increased irritability and shame are transient phenomena which the patient is able to suppress at this phase. A sense of helplessness on the part of both the patient and the spouse also develops for the first time in this phase. Confusional Phase patients and their spouses appear to be capable of adjusting socially to the patients' memory problems and isolating the cognitive symptomatology somewhat in terms of its marital and social manifestations. Denial of specific cognitive problems does occur in the Confusional Phase, however. Specifically, patients, but not their spouses, are unwilling to accept that they might be less capable of carrying out their basic activities of daily living than previously.

In the Dementia Phase, patients develop a profound denial of cognitive and emotional deficit. The denial appears to occur in precisely those areas of cognition and emotional functioning which are most severely affected. Despite the profound denial, even in the Early and Mid-Dementia Phases, patients do appear to display insight with respect to the functioning of their spouses in cognitive and other areas.

Clinically, the denial of cognitive deficit which appears to be such a notable concomitant of Dementia Phase symptomatology manifests itself in various ways. Although they are a minority, some patients find any evaluation of their memory which forces them to begin to confront their deficit too painful an experience for voluntary participation. Some patients refuse to see physicians in general, and physicians or other professionals who will be evaluating their cognitive status in particular. Other patients who are brought in for an evaluation become acutely anxious. They may develop an actual anxiety attack or exhibit conversion or dissociative symptomatology. For example, one woman recently responded to all questions which were put to her by panting and grunting. Other patients simply refuse any evaluation of their memories and leave the office or testing room.

Many other Dementia Phase patients, although they display marked denial symptomatology, do not exhibit the extreme symptoms described above. For example, a typical patient when asked "Who is the President of the United States?" would simply respond with the rationalization, "I don't follow politics very closely." Other rationalizations are also very frequent. A Dementia Phase patient who does not recall the name of the college where he earned his degree might explain, "But that was so many years ago, how can you expect me to remember what school I went to 50 years ago?"

Collectively, these rationalizations and other defense mechanisms buttress the Dementia Phase patients' capacity for denial. The net gain for the patients is the psychological defense which they develop against what would otherwise be very traumatic emotional concomitants of their illness process.

Differential Diagnosis

The prognostic data can be utilized to provide us with a definition of the clinical boundaries between Primary Degenerative Dementia, consistent with Alzheimer's Disease, and age-associated cognitive decline, consistent with normal aging. Clearly, the Forgetfulness Phase is benign and does not fit the definition of a degenerative, slowly progressive condition. Equally clearly, the Late Confusional Phase, with more severe symptomatology, is consistent with a progressive degenerative condition. Early Confusional Phase symptomatology is less prognostically clear-cut, and hence, provides a "borderline" condition midway between "benign senescent forgetfulness" and a degenerative illness consistent with Alzheimer's Disease.

When patients do succumb to Alzheimer's Disease, they generally develop a secondary infection or illness which is the result of their diminished capacity to care for themselves. Pneumonia, secondary to aspiration or exposure, is one of the most frequent immediate causes of death. Infected decubital ulcerations are another frequent cause of mortality. Although it has been said that patients do not die of Alzheimer's Disease directly, this hypothesis is not entirely consistent with clinical experience. Some patients, as progressive brain decay proceeds, become comatose and eventually die in this state. The coma may be preceded by a mild febrile state, however a specific infectious etiology or locus is not always found, even if a complete medical work-up is performed. It is conceivable that diminished hypothalamic function, as well as decreased cortical capacity, are related to this terminal malignant process.

As stated in the introduction to this chapter, the real key to the diagnosis and differential diagnosis of age-associated cognitive decline, consistent with normal aging, and of Alzheimer's Disease from other clinical conditions with which they are commonly confused, is recognition of the characteristic clinical features of the progression of this illness process. These characteristic features have been described briefly in this chapter. Additional salient features in the clinical differential diagnosis of these disorders from conditions with which they are commonly confused can be seen in Table 7.

Conclusion

Alzheimer's Disease, an ancient problem, has been recognized since antiquity. The rudiments of accurate clinical descriptions of the disorder do not appear before the late 18th and early 19th century. Only in the past three years has this syndrome been described in detail. This newfound knowledge represents an enormous advance in our understanding of Alzheimer's Disease. In many ways, the clinical syndrome of Alzheimer's Disease is a very "recent discovery."

<table>
<thead>
<tr>
<th>Table 6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Functional Staging of Severe Alzheimer's Disease*</td>
</tr>
<tr>
<td>GDS 6-7</td>
</tr>
<tr>
<td>6 (a) Difficulty putting on clothing properly</td>
</tr>
<tr>
<td>(b) Unable to bathe without assistance; may develop fear of bathing</td>
</tr>
<tr>
<td>(c) Inability to handle mechanics of toileting</td>
</tr>
<tr>
<td>(d) Urinary incontinence</td>
</tr>
<tr>
<td>(e) Fecal incontinence</td>
</tr>
<tr>
<td>7 (a) Ability to speak limited to one to five words</td>
</tr>
<tr>
<td>(b) All intelligible vocabulary lost</td>
</tr>
<tr>
<td>(c) All motoric abilities lost</td>
</tr>
<tr>
<td>(d) Stuporous</td>
</tr>
<tr>
<td>(e) Comatose</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Onset of Cognitive Impairment</th>
<th>Alzheimer’s Disease</th>
<th>Senescent Forgetfulness (Forgetfulness Phase)</th>
<th>Geriatric Depression</th>
<th>Chronic Schizophrenia</th>
<th>Multi-Infarct Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gradual process extending generally over a period of years if a proper history is obtained.</td>
<td>Gradual process extending over a period of several months to years.</td>
<td>Onset generally sudden and associated with present illness episode; however, a “life-long” history of memory problems is sometimes obtained.</td>
<td></td>
<td>An accurate history of onset is generally not obtained. However, if the patient is seen between florid episodes of the illness process, then the cognitive impairment is generally longstanding, extending for at least several years.</td>
<td>Sudden, “stroke-like” onset.</td>
</tr>
</tbody>
</table>

| Course of Cognitive Impairment | Progression of the process is noted. Patient eventually becomes severely demented with incontinence, loss of ambulatory ability, etc. | No subjective or objective evidence of progression. | If associated with present episode, then the cognitive asymptomaticity will remit: if associated with “chronic depression,” then remains the same. Patients do not become severely demented. | If not associated with an acute episode of the illness, then the cognitive impairment generally continues to worsen over the course of decades. Patients do not become incontinent, do not lose ambulatory ability; speech is, however, sometimes severely compromised. | “Stepwise course” with remissions and exacerbations. |

| Clinical Cognitive Symptomatology | As described in Tables I and II. Deficit proceeds relatively uniformly on concentration, recent memory, past memory, and functioning and orientation axes. | Subjective complaints of cognitive deficit only. No clinically objective evidence of cognitive deterioration is obtained. | Deficits are particularly notable: when present at all, in concentration and in functioning. Despite complaints of “memory problems,” there may be no objective evidence of deficit whatever. Sometimes, these patients, despite excellent recent recall, can remember little with respect to their childhood; this latter deficit is most frequently related to active denial. | Deficits in concentration and functioning are notable; memory for past may be denied. Recent memory is frequently intact. Deficits have been classically described in: concentration, attention, insight, judgement, orientation, and affect. | “Emotional incontinence is frequently noted,” e.g., patient may suddenly begin to cry for no apparent reason. Otherwise, clinical symptomatology is variable. |

| Associated Clinical Symptomatology | As discussed in text and in Tables I and II. | Very mild anxiety and/or depression are only associated symptoms; alternatively, the patient may have no associated clinical symptomatology whatever. | Associated mood disturbances with dysphoria, depression and sadness. Anxiety is frequently associated. “Vegetative symptoms” also frequently occur, these include: sleep and appetite disturbances (insomnia or hyperomnia; anorexia or hyperphagia). Anergia is another frequent symptom. | There is a history of florid psychotic symptomatology with delusions and/or hallucinations, and/or “suspiciousness,” and/or paranoia. | Risk factors for cerebral vascular disease are generally present. May be history of blackouts. Peripheral vascular and cardiovascular disease is frequently present, notably including hypertension. |

Moral and Ethical Dilemmas for the Individual, the Family and Society
by Nancy Neveloff Dubler, LL.B.
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I thank you for the introduction. Lawyers tend to have a poor reputation among health care professionals; I'm grateful for the warm welcome. And hopefully, through my own work, I can further develop a counterpoint to that negative image.

First off, let me introduce myself. I am the lawyer at Montefiore and not for Montefiore Medical Center. This is a distinction which legal counsel for the hospital and I both appreciate. My job is to develop projects in law and medicine—specifically around what I call the rights of underserved populations.

Much of my work over the last eight years has involved working with the right to health care in prisons and jails. As some of you know, there is a constitutional right to care, supported by the eighth amendment. In the last few years my focus has shifted to geriatric care and most especially to the care of Alzheimer's patients.

I came to this area in somewhat the same abstract route that led me to prison health care. I first became interested in prison health care because of its connection with constitutional law. As there is a constitutional right to care in correctional institutions, based on interpretations of the 8th amendment, medicine and law meet not on a plane of malpractice—where in my experience no useful dialogue is possible, but rather around a discussion of appropriate standards of care. Alzheimer's Disease directly relates to the legal concept of personal competence, and that's what first drew my interest to the subject five years ago. The law does not know what it means by competence. Psychiatry is confused and medicine uncertain. But it seemed to me then, as it does now, that when we are caring for and treating patients who are at least, for this moment, on a path of inexorably declining competence, we in the fields outside of medicine need to struggle with medicine to improve, hone and make more sophisticated our understanding of what these concepts are and what the concomitant rights of patients are. These are the concerns of a lawyer who is part of an interdisciplinary health care team at a medical center. How are those concerns different from the concerns of my able colleagues who spoke before? My primary concerns are with concepts of rights, and additionally with concepts of fairness and justice.

Specifically for the purposes of this discussion, for patients of diminishing capacity, how can these concepts be defined and secured? The tools of a lawyer are peculiar and particular. They are not the tools of a legislator or a judge. But they do include a focus on process and procedure. The goal of a lawyer, as I see it in this context, is to try to bring some new sort of clarity to the complex world that involves the allocation of decision-making authority among family, patient and providers. You may properly query, what is my bias in all this interaction? My bias is that without the open engagement of issues and without the difficult grappling with conflicting and competing agendas and perspectives—which are always present in health care—the voice of the least powerful will fail to be heard above the din. And in any case the least powerful tend to be the patients affected with Alzheimer's Disease. If the perception of the law can add anything to the sensitive experience of the caregivers and the scientists who have spoken before me and will address you this afternoon, it is perhaps by the gentle but firm insistence that abstract rights are empty protections without clear procedures to guide and to govern their implementation.

Question: What are these rights? What do I mean by the rights of patients in the context of this devastating disease? And let me point out that I do not mean to infer by discussing the rights of patients that there are not concomitant sets of rights, possessed by families and caregivers. However, in the very few minutes provided to me I must relegate those issues to a different time.

Therefore, I would suggest to you that there are three basic rights. First is the right to know. That is a right clearly possessed by all patients. Obviously for a patient with Alzheimer's Disease, it is a particularly complex right. It is particularly difficult for caregivers to respond to. But there is a right to know. I would argue, furthermore, that there is a right to know as early as possible, because that is when the capabilities are most intact. There is a right to know about diagnosis and prognosis and to be provided, within that context, with the assurance of care and comfort if not cure. I realize that some consider this merely a radical position, and some consider it ludicrous. However, it is my experience and the experience of those lawyers with whom I work that most Alzheimer's patients know, experience, and sense their illness and their decline.

There is often a conspiracy of silence between and among families and providers. I do not think it serves the interests of patients, families or providers. What it does to the patient is ensure that the early confrontation with that disease proceeds more alone and with more solitary fear and trembling than may be necessary.

The right to know is of course a preliminary to that second right which is a right to decide. How long to live or die as a demented patient can be at issue. There are decisions to be made about the disposition of real property and personal property, about assets and long-term estate planning. There are good-byes to be said and relationships to be addressed—all issues which can only be confronted and approached once there has been some information shared.

The law takes rights seriously and rights in the abstract must be provided with protections and process to be assured. I, therefore, come to a third right. First the right to know, second the right to decide and third the right to be provided with a framework for decision-making. This is a right which joins the patient, the family and the provider. Decisions by a person when competent, even if somewhat compromised or disabled and even if unsure, are the best expression of individual will and therefore, in our society, the most deserving of our respect. The problem with a patient afflicted with Alzheimer's, as we all know, is that we're no longer dealing with a clear, concise, comprehensive and strong statement of will. However, we may be dealing with what I've come to call residual will. How do we ferret out this residual of autonomy? We know only by asking early on the key questions to determine personal preference.

The law has yet to adequately consider the peculiar, terrible and awesome sorts of decisions which must be faced by patients and families. There are, with very few exceptions, very few legal opinions that deal with rights in this area. There is almost no legislation. That I think is a task that we can all struggle together to change. From my perspective there are three very clear changes in the legal framework which should arise from the greater focus on and by Alzheimer's patients and families. Number one, we need to define and give power to the sense of abilities, perceptions, and residual will which are attested to by families and exhibited by patients.

We need to know what specific abilities entitle a patient to operate in which sphere. What is their level of competency? When can a patient execute a living will or sign a power of attorney, even if afflicted with Alzheimer's Disease? Secondly, I think we need to develop patterns of practice which are designed to prevent rather than withhold information. Third, we must present research and data to legislators to ask them to help fashion new schemes and statutes to address the particular problems of patients with declining, diminished, or extinguished capacity. We need to develop, for example, durable powers of attorney, that clearly permit third parties to manage property and to control health care decisions. And perhaps we need to develop legislation which permits patients to consent in advance, to later research protocol which will help us to learn more.

Finally, I think we need to be encouraged. In the face of an illness which is devastating to patients, families and caregivers, we need to permit decisions about care to "come out of the closet"—to be the possible role of the law.
Physicians don't yet, for the most part, treat patients for Alzheimer's Disease, but they do treat many Alzheimer's patients for other concurrent diseases. In the course of such treatment, a number of ethical issues emerge: some are unrecognized or ignored by physicians, but more are being confronted, particularly in settings such as hospitals, where the concentration of doctors and other professionals yields a critical mass for debate.

Let me raise four questions which doctors face in treating Alzheimer's Disease patients. First, who should make treatment decisions: whose consent should the doctor seek? I think it's important to recognize that competence—in the sense of a person's understanding of what is proposed and being able to grant or withhold informed consent—is not a simple yes-or-no state, but one which permits many gradations. A diagnosis of Alzheimer's Disease does not in itself make a patient incompetent to agree to or reject medical treatment. Certainly, treatments which are straightforward, carry minimal risk and offer obvious benefits should be discussed with the patient to the extent that he is capable of understanding, even when some degree of memory loss and impaired judgment are present. In more advanced states where comprehension is difficult or impossible, simple courtesy and respect for personhood should lead the physician to inform the patient of ongoing events and ask his permission to treat. If the patient should then refuse, even if others have already consented on his behalf, the doctor should, at the least, think again about the strength of the necessity to treat.

If and when the patient can't give informed consent, who should decide? Most of us would agree that the patient's spouse should do so, with the doctor functioning as advisor, as technical expert, as prognosticator, even as a friend, but not as an independent, paternalistic decision-maker. If there is no spouse, then adult children should be consulted, and if they're not available, then others who have been close to the patient through ties of family or friendship. Rather than following any fixed sequence of responsibility, however, it would be even better if the patient were able, when he or she was still competent, to name a relative or friend as having a durable power of attorney, authorized to make ongoing treatment decisions as the need arises. There is some danger in having treatment decisions made by close relatives: they may insist on overly vigorous therapy out of their own sense of guilt or grief, or they may refuse treatment inappropriately because of their anger and their exhaustion.

This leads us to the second question: to what degree should doctors and relatives consider the quality of the patient's life in making treatment decisions, particularly as those decisions involve potential prolongation of life? It is natural for a healthy person to view the prospect of becoming demented with horror, and to believe therefore that such a life is not worth living. Persons actually in that state, on the other hand, especially if they have no memory of their disease-free past, may experience substantially less distress than do their doctors and relatives. When we invoke quality-of-life issues, we may be projecting an unhappiness that is more ours than the patient's. Even a patient who, early in the course of the disease, gives treatment instructions based on his anticipation of an unacceptable quality of life, really has no way of knowing how he will feel when his disease becomes more advanced. It is more important, I think, to try to determine how much distress and unhappiness the patient is suffering than to consider whether we or the patient would choose voluntarily to face the prospect of such a life.

The third question we must ask is what is the purpose of treatment in each medical encounter? One aim might be to treat the Alzheimer's Disease itself, a goal so far with little success. More likely, we will find that the doctor is aiming to relieve pain or other suffering; to improve or preserve function; or to prolong life. I view the sequence of these three goals as increasingly problematic for the patient with Alzheimer's. Surely all persons are entitled to relief from suffering, and to withhold such treatment would be ethically and humanly unacceptable. Treatment aimed at dysfunction—the improvement, for example, of defective hearing or vision—may be reasonable and even desirable, particularly when cognitive functions are impaired and the ability to cope with physical dysfunction is diminished. On the other hand, I am more than a little troubled by the conception of treatment aimed solely at the prolongation of life, such as therapy for asymptomatic cancer or treatment of serious infection in a patient no longer aware of his environment. I personally find such treatment difficult to justify.

Rather than employ the recent practice of classifying medical treatment as "ordinary" or "extraordinary" on the basis of cost or technical complexity, I prefer to do so on the basis of the intent of the treatment. I would, for example, regard major surgery to relieve intolerable pain from intestinal obstruction as ordinary, and the use of blood transfusion for hemorrhage in an irreversibly comatose patient as extraordinary.

The decision to treat, I think, must also be tempered by the patient's limited ability to understand and to cooperate. There are painful or distressing treatments which we might accept for ourselves because we are convinced of the worth of the benefits we hope to derive from them. The same treatment to a confused and frightened patient deserves careful deliberation if it can be delivered only by tying him down.

Finally, let me mention those questions which physicians are often reluctant to ask, and even more reluctant to answer, namely those which involve costs and the use of limited resources. At the "micro" level, doctors do make such decisions daily when, for example, they decide whether an acutely ill patient with Alzheimer's Disease should be admitted to or excluded from the last bed in the Intensive Care Unit. Limited resource decisions are made less dramatically when busy hospital residents and nurses allocate the time they devote to each of their patients. Though doctors may believe that they do not discriminate among the patients who compete for beds and for their attention, they do so constantly, and there is no question but that they are influenced by the patients' mental state.

At the "macro" level, doctors have traditionally avoided allowing considerations of societal priorities to enter into decisions concerning individual patients: yet as physicians and other professional health workers, we really must start thinking about costs and benefits. What are the nationwide medical costs for the care of Alzheimer's patients in their last year of life? How much support can or should our society give to such patients and their families? Should limits be placed on this support? We face the difficult dilemma of balancing the need for humane treatment and revulsion against the specter of active or passive euthanasia with the near impossibility of developing sufficient resources to satisfy all the needs of our sickest patients. There is an irony in American medicine today: we are spending more and more money and time on those patients least likely to benefit from them. Individual doctors and the families of those patients need guidance from both ethicists and economists in deciding when, if ever, enough is enough.
The Family’s Viewpoint
by Marion Roach
The New York Times
Panelist

My name is Marion Roach. I wrote an article which appeared in the New York Times magazine in January of this year on the subject of my family’s experience with Alzheimer’s Disease. I am one of two daughters of a victim.

Late in 1979 I began to think that my mother was going mad. I called it madness—to myself—at first, because I thought her behavior impossible to understand or explain.

My mother was an independent and willful person. In her life she has been a precious only child, a good student, a beautiful sorority sister, a newspaper reporter, a wife, a mother, a girl scout leader, a visiting nurse volunteer and a teacher at a bilingual school on the lower east side of Manhattan.

In the progression of her disease she has been forgetful, then frightened, depressed, angry, paranoid, hostile and incompetent. She is now completely dependent upon the aid of others. She cannot be left alone. She is repetitive and confused. She is agitated. She cannot read. She cannot drive. She cannot always form complete sentences. She frequently speaks in a rapid gibberish. She cannot bathe properly. She has no short term memory. With the progression of the disease, she will almost assuredly lose control over all of her bodily functions; she will have to be fed, cleaned and dressed.

My mother is 54 years old. She is suffering from senility. She is suffering from the humiliation of having her dignity wrenched from her. She is losing her mind in handfuls.

She is one of two million known people in America who are suffering from the fourth leading killer in this country, and in New York City, where we live, in this age of modern medicine and progressive government, my sister and I can barely get a decent day’s aid, an intelligent suggestion which is within our economic means or an understanding nod from anyone who has not known this disease firsthand.

Alzheimer’s Disease is a brain disorder which causes a progressive and relentless loss of intellectual and physical functioning. At this time there is no cure for Alzheimer’s Disease. Treatment is limited and experimental. We do not know if it is viral or genetic. We do not know if they catch it, or if they pass it along.

We have before us an issue which affects every resident of this country. There is no one who does not or has not known a victim or someone who cares for a victim.

When my mother was first diagnosed as an Alzheimer’s victim, the doctor said, “your mother is not going to die.” We thought these words were being offered in comfort, as reassurance. Our father died five years ago of cancer of the bone marrow. We did not want our mother to suffer too. We have since learned that the doctor’s words were preparing us for extended suffering, with no quick end, no definite release for her—and for us—in sight.

I have come to think of Alzheimer’s Disease as a monster which is trying—plotting daily—to take more than one victim. It doesn’t seem satisfied with the horror it has made of my mother’s stately composure, of her years of education, of her emotional balance and insight. The disease is, as I envision it, trying to take my sister and me too. But we won’t have it.

I have been asked to speak about Ethics and Moral Dilemmas. A year ago I would have argued that I could better speak about the Science of Panic, or How Panic Breeds Ingenuity.

Now, I realize, however, that this subject of Ethics and Moral Dilemmas is appropriate. I realize that my ethics have changed because my morals seemed undereducated and not up to the task.

An Alzheimer’s patient is likely to say and do anything before he or she can do virtually nothing for themselves.

And so, the dilemma begins with the illness.

As a family member, one wonders about compensating for the illness; from answering questions for the victim to limiting their freedom of movement.

In the very beginning I believed that my mother—because she was the mother—had the right to an independent life. My experiences, however, were eroding that belief. The dilemma was resolved when I realized that restricting her movement protected her and pro-
tected others. We took away her car keys and stopped her from going out unattended.

But can you tell me how to live with decision—how to resolve the personal dilemma of locking her telephone? She was harassing the neighbors, dialing the operator literally twenty times an hour to ask what day it was, what time. The dilemma took its toll every time she’d stare at the locked phone and then look at me and ask why we had done that.

Last week my sister phoned me and asked “When is the book coming?” I am writing a book on Alzheimer’s Disease. I was annoyed at the question. I get it from my publisher. “When I finish it,” I replied. This is not how I answer my publisher. “No, no,” said Margaret, “the one which comes in the mail and tells us what to do next, how to cope.”

We try to make light of anything we can. We try to keep a strong sense of humor. I would be interested to know how much is enough, too much.

After the diagnosis, my sister and I wrestled with the decision of whether or not to tell my mother what she has. Some of her closest friends suggested that we do. Others encouraged us not to. My mother had always told me when I was a child that she “never wanted to be a burden” when she got older.

Someone suggested—a close friend—that we tell her what she has so she could kill herself; that if she knew what she had she wouldn’t want to live.

We told my mother what she has. She doesn’t remember. She says she had a stroke. She says, some days, that her memory is bad. She senses her decline but she cannot contribute to her own care.

When we told her, she was already too far into the disease to comprehend its meanings. Should we have known sooner? Should we have told her immediately? I would be interested to know.

Following the diagnosis, we looked everywhere for information. There was no listing in the local phone book. There was no entry in the encyclopedia. The dictionary listed senile as “pertaining to, characteristic of, or proceeding from old age.” The entry for senility reads, “the state of being senile, mental and physical deterioration with old age.”

My mother is not old.

At the time of the diagnosis, and until only two months ago, she had a cross court backhand in tennis that was frightening. She still swims laps, and would swim more often, if many of the people at her local pool hadn’t made her feel terribly uncomfortable by shunning her, because of her disease. I would like to know how many of them deserve my understanding.

Just eight years after completing her Masters degree in education, she had to take a leave and then finally quit her teaching job. Her disability status could not be guaranteed because we were told initially that this disease was not considered a disability, and that therefore we could not be assured disability payments which would be the only way, two years later, to qualify for Medicare.

In the meantime we were advised to transfer her funds to provide for her care, transfer any ownership she had, and take power of attorney so that she should appear destitute. I would like to know if I am lying and, if so, if it’s alright. It did not make sense in the beginning, but with virtually no home care or nursing home benefits available from the federal government, we were facing costs of approximately $30,000 a year, unreimbursable, for her care.

The federal insurance system is geared to underwrite treatable diseases. There is no treatment for Alzheimer’s Disease, only what professionals call management or custodial care. The patients have to be watched and that is not considered an expense for which the family should be reimbursed. Medicare is for the old, Medicaid for the poor. We, the middle income family, are left to fend for ourselves. I would like to know if this is just.

Economics should not be the most important factor in a family’s decision as to whether or not to institutionalize a loved one. I know that.

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As my mother's illness progresses, the type of care she requires becomes more complicated. At first a responsible person with only babysitting skills was necessary. Now, she needs careful policing—to keep her from leaving on the gas burners, to get her to flush the toilet and to bathe. Soon, she will need total care. She will lose all her privacy and we, as daughters, will put her completely in the hands of strangers. I would like to know if this is alright. I need to believe it is.

Perhaps this is hard to comprehend. Perhaps it is difficult to understand why anyone would give up the care of a loved one to a hired person. My sister and I work. It is impossible to spend all day taking care of my mother and still work to support her. But that is not the sole reason for the help. Caring for an Alzheimer's victim is a relentless and sometimes thankless task. They are unable to remember the slightest recent detail, and therefore unable to understand the care being given; eventually unable to recognize the person administering the care. They present constant questions when they are still able to speak and need constant attention to keep them from getting into trouble.

Medicating an Alzheimer's patient presents its own dilemma. It is hard to accept the fact that I am sedating my mother. It took a long time for me to understand that by managing her properly we are preserving her shreds of awareness; that without all her agitation, she is better able to cope with life, and we with her. At first, though, I was guilty of not knowing how much was enough, too much. I sometimes still need to know that medicating her is alright.

Perhaps you are getting my point. Perhaps you just think there is a lot I'd like to know.

There is, for every person touched by this disease, a great deal to learn, a great deal to try and a great deal to accept. Our dilemmas must breed commitment. Otherwise, they are only painful. We must be committed to change; to change the attitude toward diseases of the mind, the attitude toward the elderly.

We must work equally toward acceptance of a description and diagnosis made in life as well as acceptance and understanding of the pathological research so that we can combat this illness with the necessary funding and legislative change. We must have a cohesive network of care.

My mother is daily, falling freely into her gradual demise. It is a terrible thing to watch. Had she been in her eighties, my sister and I might have been guilty of the same thing which has existed through history—of assuming that senility is a natural partner of aging. We might then have learned to live with it without seeking alternative care. My mother is supposed to be in the prime of her life. She is suffering from a disease which is the leading cause of senility regardless of the age of onset. There is nothing natural about it. There is nothing acceptable about it. My dilemmas are reduced to this: Alzheimer's Disease is a horror, and it is here with us, and will be until we attack it in earnest.

Thank you.
The individual with cognitive loss calls into stark relief basic value conflicts and ethical dilemmas. These dilemmas involve the very core of our value foundation and raise questions regarding the meaning and value of life, the rights and responsibilities of families, the distribution of scarce resources, and the tension between the autonomy of the individual and the common good. Dementing illness of any type is a human tragedy, but the insidious nature of Alzheimer's Disease and related disorders raises particularly thorny problems for the patient, the family and care providers.

The Individual
The autonomy of the individual is a basic human value. Bodily integrity, religious freedom, and individual self-determination have each been used to support the concept of personal autonomy, which refers to the individual's right to make decisions which are voluntary and intentional and not the result of coercion, duress or undue influence. Stated quite simply by John Stuart Mill in 1869:

"Neither one person, nor any number of persons, is warranted in saying to another human creature of ripe years, that he shall not do with his life for his own benefit what he chooses to do with it."

In a technical sense, few, if any, individual decisions are truly autonomous. The individual is constrained by the available choices and his own strengths and weaknesses, and is influenced by the wishes of others. For the person with dementia, however, the issue of autonomy is even more complex. Although the ability to make decisions is, by definition, compromised, Alzheimer's patients as a group vary widely in cognitive ability, and individual function may vary from moment to moment. In many instances, however, all decision-making is taken away, with no recognition that for the Alzheimer's patient, competence falls along a continuum rather than forming a dichotomy. The rationale for such an assault on autonomy is usually based on one of two other values: paternalism and the common good.

Paternalism is the "interference with a person's liberty of action, justified by reasons referring exclusively to the welfare, good, happiness, needs, interests or values of the person being coerced" (Dworkin, 1972). Paternalism is frequently practiced with the best of intentions, particularly under circumstances in which the individual for whom decisions are being made is unable to make decisions for himself (Dworkin, 1971). Unfortunately, society often takes a paternalistic approach where there is no evidence indicating that decision-making capability is compromised. Paternalistic behaviors may include a physician providing only partial information to a patient regarding test results, or reporting diagnoses and prognoses to a family member rather than the elder himself, or a family making the decision to place an elder in a nursing home without consulting him regarding his thoughts on the matter.

Non-inclusion of the elder in the decision process carries with it the potential to harm despite our best intentions. One risk is that bad decisions will be made because of incomplete information. Missing information may relate to the wishes of the patient, his fears, expectations, financial situation, circumstances at home or even symptoms of disease. Another potential harm is "learned helplessness": Simply stated, if we treat an individual as if he is helpless, he is likely to become helpless. Research (Avorn, 1982) has demonstrated that if we place an individual in a more restrictive setting than is needed or provide unnecessary supports, the individual's behavior may indeed change to meet the expectations of the environment, with loss of function and life quality in the exchange.

However, there is a growing recognition of the limits of autonomy. Does an individual have the right to choose a course of action which compromises his common good? Circumstances in which the common good supercedes personal autonomy include the quarantine of patients with highly contagious diseases or the confinement of individuals who are considered to be a threat to others. This common good argument is also used to justify the placement of frail elders into nursing homes. The reasoning runs like this. Because resources are so scarce, when it becomes more expensive to maintain the individual at home than in a care facility, he or she should be transferred to the nursing home. In these times of budget austerity, it might well be asked if an elder patient has the right to refuse treatment when such a refusal is likely to result in large and avoidable expenditure of public monies in the long run, or demand care at home when placement in a nursing home is more "cost-effective." The balancing of personal autonomy with other values is particularly difficult when public monies are involved.

The Family
Care of the individual with Alzheimer's Disease raises difficult issues for family members as well. Shifts in dependency relationships are likely to occur as an older person becomes progressively functionally impaired. These shifts change patterns of interaction within the family and call into question long-acclimated styles of decision-making and power relationships. A confusion of values affects the determination of the appropriate level of support to expect from a family for their older members. Contrary to popular opinion, families are not rushing to dump their impaired elder members into nursing homes. It has been estimated that as much as 80% of home care is provided by family members (Brody, 1978; Comptroller General, 1979). And although not reimbursed by Medicaid, this care is not without costs. Studies of informal home care of Alzheimer's patients show that family providers are likely to be suffering a variety of stress-related problems including alcohol and drug abuse, depression, divorce and physical diseases thought to have strong psychosomatic components. Care is often provided by spouses and children until the physical and emotional resources of the family have been all but depleted.

And yet, efforts are under way to increase the level of responsibility of families for the care of their elder members. States now may choose to seek support from families to supplement Medicaid for elders in nursing homes. The political and practical problems in implementing this policy are enormous, but the issue is directly related to the broader question of intergenerational responsibilities (Daniels, 1982). What does one generation owe another? More generally, how do we distribute scarce resources among generations? A full examination of this issue is certainly beyond the scope of this discussion, but this unanswered question shades the formulation of health policy for this country.

The Health Care System
Value considerations determine distribution of resources within the health care system, influence the enactment of laws and enforcement of regulations, and provide the framework for policymaking. The current distribution of health resources is biased in a variety of ways. First, public monies are more likely to be spent for medical/technical services vs. social services; more likely to pay for institutional services in hospitals and nursing homes vs. services which keep elders in their own homes; and are more likely to pay for later, more intrusive interventions vs. earlier interventions which support the elder, his family, and other informal care providers (Fox, 1981).

Public monies for nursing home care are only available to those who have exhausted virtually all of their personal resources (via Medicaid "spend-down"), or who have had the foresight and professional assistance to divest themselves of such resources. Despite state efforts to apply the ethic of equity, public reimbursement for nursing home care for two individuals with identical needs living in the same state may vary by as much as $70 per day.

The egalitarian view would suggest a distribution of resources in which each person receives equal opportunity of access to care. Certain of the voucher proposals currently under discussion in the Department of Health and Human Services uses this as their basic
Others would argue that allocation of resources should be based upon need. But once again we run into difficulties defining need, as well as approaching the technological possibility of almost limitless need for some individuals. The capacity to keep patients alive indefinitely through the application of extremely expensive technology continues to develop. Under a view of distributive justice, resources might be allocated differentially throughout the life span based upon assumptions concerning which interventions are most appropriate at various ages.

Apart from the allocation of resources, a number of value issues arise in the delivery of care for patients with Alzheimer’s Disease, particularly when they become severely disabled and are no longer able to participate in decision-making. For these individuals, surrogates may provide information regarding previously stated preferences, previous behaviors and lifestyle choices. In the absence of stated preferences, therapeutic activism is indicated, including thorough assessment and treatment. Providing appropriate treatment for illness will not only improve the quality of life for the individual, but is imperative in maintaining the highest possible level of function. However, there are circumstances in which forgoing treatment may be the most compassionate and appropriate intervention. There are patients whose quality of life is so compromised that it is no longer worth living.

This is a difficult and tragic issue. There are those who believe that in the absence of stated preference, we must always assume a desire to live. Sanctity of life is a central ethic in the Judeo/Christian value system. It is argued that we should avoid the “slippery slope” of determining for others that some lives are not worth living. I would argue that the footing is no more secure on the side which states that life must be maintained no matter what the costs. Most of us fear maintenance in a dependent, vegetative or actively suffering state more than we fear death itself.

But decisions to withhold treatment and resuscitation must be made with the utmost of care. Decisions which result in non-treatment of impaired elders are made daily in hospitals and nursing homes across the country. Some are based in compassion, caring and full consideration of the ethical issues and value conflicts involved. Others are made as a matter of expedient with little consideration and less discussion.

Compassionate care-taking requires that decisions such as these be made in the bright light of open consideration of the many relevant values and points of view, and involve family members, care-providers, clergy and if possible the elder himself, directly (early in his illness) or through surrogates. Decisions must be made on a case by case basis with clearly stated policy regarding the process of the decision… taking care to avoid blanket decisions involving classes of patients.

Care of the Alzheimer’s patient will always involve difficult decisions and tragic choices. Clarification of assumptions, values and beliefs of each of the participants is an important part of the decision-making process. Decisions will not be easy nor will value conflicts be easily resolved. But if values and ethics are more openly considered, the process of decision-making will be facilitated and the outcomes of that process will be more satisfying. And in the final assessment, we will achieve not only a better quality of life for those that we care for but also a better quality of life for those who provide that care.

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The Eli Goldstein Memorial Humanitarian Award Luncheon honoring Sen. Mark O. Hatfield

Opening Remarks

by Mr. Irving H. Stolz
President
The Hebrew Home for the Aged in Riverdale

For those of you who are familiar with the Hebrew Home for the Aged in Riverdale, I welcome you once again with my heartiest good wishes. And for those of you who are passing through our doors for the first time, allow me to greet you in a spirit of friendship and brotherhood. I can think of no prouder occasion on which to extend my feelings than here, at The Martin Steinberg Memorial Symposium on Alzheimer’s Disease and Related Disorders. The presence of each and every one of you is a direct tribute to Dr. Eli Goldstein, to whom our Humanitarian Award is dedicated this year. A special welcome goes to my good friend, Mr. Milton Gilbert, who has coordinated and propelled this event from a germ of an idea to full fruition. And to Senator Mark Hatfield of Oregon: your participation and your interest in this symposium have been integral. It is vital that our lawmakers and representatives take an interest in the physical well-being of all citizens, including the elderly, infirm and disabled. It is easy to doff a cap to fit the mood of the day, but to champion a cause less known, to fight for the rights of those less able—that takes courage, a characteristic of the conscientious and treasured official.

The cause today, of course, is the study, treatment and cure of Alzheimer’s Disease, its effects, its victims. If I describe Alzheimer’s as an “obscure” disease, I am not belittling its significance, consequences, or its devastation. Instead, I am lamenting the fact that Alzheimer’s Disease research has proceeded so slowly, that progress has proved so difficult, that so many facts have remained unclear, and that so few people have contemplated its seriousness or its nearness to us all.

First described in 1906 by Alois Alzheimer, it has remained somewhat of a mystery to the health professionals and researchers who have studied it since. In fact, only in the last 10 years have major insights been gleaned in the isolation, description and treatment of Alzheimer’s. We know now that there are many types of senility. Alzheimer’s Disease has been described as “the most relentless and devastating” of all these forms.

At the Hebrew Home for the Aged, we are directly concerned with Alzheimer’s Disease and its effect on those of our residents who suffer from it. Alzheimer’s can strike at any age, but it strikes the elderly most often.

Many of our residents are afflicted with Alzheimer’s. It is for those residents—and because we regard Alzheimer’s as an ultimate threat to our society—that we have opted for a position in the vanguard of research on Alzheimer’s Disease. In late 1983 we received New York State authorization to begin the reconstruction of a satellite facility, which will be the first institution in the nation exclusively devoted to research and treatment of Alzheimer’s Disease.

This symposium illustrates our commitment to bringing Alzheimer’s Disease out into the open for public discussion and understanding. Like “cancer,” Alzheimer’s is a disease that has a broad and indiscriminate outreach. Everyone is a potential victim at some time in his life. The Hebrew Home for the Aged will not remain silent on the real and present danger of Alzheimer’s.

We believe that the Home is not a storage space for the elderly, like so many sticks of furniture too good to throw out and not good enough to use and display. We don’t want to see all of our elderly in nursing homes. We want those who can to pursue independently active and profitable lives and are committed to improving patient health to the end. For those who need us, we want to be more than a nursing home, but rather a nurturing home-away-from-home for those unable to care for themselves. This is a philosophy we have pursued for 67 years and will continue to pursue.

Dr. Eli Goldstein, for years the chairman of the Medical Board, inculcated in all of us his belief that the Hebrew Home for the Aged should provide a “total response”—including the best medicine, the best research, the best psychiatric care and social services with tender loving care.

Dr. Goldstein was a man who loved his patients and who loved his work and he never stopped exploring the tenets of that work. We salute him today, knowing that he would have leapt head first into this symposium: speaking, trading ideas and learning with the unquenchable thirst for knowledge that made him an unrivaled physician and a model of a man. His memory lives on in his widow, Mrs. Eli Goldstein, who is here with us today. She should indeed be proud to have shared and to have loved such a charismatic and dedicated individual.

Martin Steinberg was not a physician, yet his concern for the health and welfare of those around him—and society at large—was boundless. He was a philanthropist, and a friend of the Home. His wife, Mrs. Martin Steinberg, is here with us today. She deserves extra special thanks. By providing the essential funding for the Symposium, she has insured that Martin Steinberg will continue to play a leadership role in our present and our future. And now, allow me to introduce Mr. Milton Gilbert, who is the Chairman of the Board of the Hebrew Home. Mr. Gilbert.
Award Presentation
by Milton A. Gilbert
Chairman, Board of Directors
The Hebrew Home for the Aged in Riverdale

Good afternoon. Thank you, Irving, for your very cogent remarks on the little-understood seriousness of Alzheimer’s Disease, and the Home’s commitment to finding the causes and the cure. Alzheimer’s is a ticking bomb timed to go off before we have turned our back on this century. By the year 2000 one out of four Americans will be 65 or older. We cannot afford to have a full quarter of our population vulnerable to a chronic, incurable, although not necessarily terminal, illness. As medicine has offered us new technology and procedures to prolong life, we as gerontologists, as Americans, as human beings, insist on quality of life. Nothing less than a longer, active, profitable, healthy life will do. To prolong life without health is an irresponsible act. We must not go into the 21st century without a responsible commitment to our aging and our future.

You here today have made this commitment or you would not be here. Let me extend my thanks to all of you and reassure you that the Martin Steinberg Inaugural Memorial Symposium is the first of many events to be sponsored by the Home, sharing new research and treatment methodologies and bringing our insistent message to the hundreds of doctors, nurses, researchers, administrators, teachers and others who work in the area of geriatrics.

We are joined today by our very distinguished senator from Oregon, Sen. Mark Hatfield, the Inaugural Recipient of the Eli Goldstein Humanitarian Award. Old age is not a particularly rewarding subject area for a politician, but Senator Hatfield has made aging his issue. In fact, Senator Hatfield has regularly tackled issues that are unpopular. I do not think there is a politician in Washington with his candor, sensitivity or courage. He does not give mere lip service to an issue. He lives the issue, he fights for what he believes and he puts his words into action.

Washington has never been known for its interest in the affairs of the elderly. And Alzheimer’s Disease is hardly a sensational headline-grabbing issue. Yet, for the 500,000 Americans suffering from senile dementia of the Alzheimer’s type, their families and friends, this is an urgent and vital issue. We are not talking about guerrilla coups in Central America, starvation in West Africa or murder in Asia, we are talking about a needless waste of life among our own people and in our own homes.

It is so easy for gerontological issues to be neglected, to fall out of sight among more immediate priorities. Certainly, there are special interest groups in Washington dedicated to representing the concerns of the aged. But their power is empty without a strong political hand guiding them and opening the doors to policymakers and those who appropriate money for research, who have a grip on our lifeline.

Mark Hatfield has that grip and has used it along with Sen. Thomas Eagleton of Missouri. He has sponsored the Hatfield-Eagleton Bill, which would provide more federal funding for the research and treatment of Alzheimer’s Disease. This may not be grandstand politics, but it is sound economy and an investment in our future. Alzheimer’s Disease victims account for a disproportionate share of this country’s long-term health care, a sum that approaches 30 billion dollars. Above all, the Hatfield-Eagleton bill speaks directly to those who have known the terror of the disease, those who have seen it affect their friends and their loved ones, their parents, siblings and spouses.

Allow me now, Senator Hatfield, to congratulate you and to thank you for your efforts. We are pleased and honored to award you the first Eli Goldstein Humanitarian Award. You have brought respect, sincerity and a remarkable degree of energy and commitment to the office of senator. Your contributions to the study and understanding of Alzheimer’s Disease have earned the applause of everyone here. Thank you.
Acceptance Remarks
by Senator Mark O. Hatfield

Thank you very much, Mr. Gilbert. It's indeed a great pleasure for me to be here today. I've been to many homes for the aged over my 33 years in public office, and I am greatly surprised and astonished by the innovation, by the marvelous sense of caring and compassion that is so evident here in Riverdale. By using the words "surprised" and "astonished," I'm reminded of a story about Noah Webster, the great 19th century lexicographer. Seems one time Mr. Webster was in the kitchen making amorous advances towards the maid when Mrs. Webster decided to enter the room. She exclaimed, "Mr. Webster, I am surprised!" And in his precise knowledge of the English language, he retorted, "No, Mrs. Webster. You are astonished; I am surprised." Of course the Hebrew Home is not the Webster's kitchen, but once again, let me register my delight to be among you today.

I'm going to do something that is perhaps a little unique in a politician's career—submit my remarks for the record. For a few moments I'd like to summarize my thoughts and share them with you today.

These are difficult times. I'm not only speaking of the international scene and the political crises we face from one end of the world to the other. I also speak of our own domestic picture, the economic recession and our struggle to recover from that recession. I speak of the growing sense of disconnectedness among our people, and the adversarial relationships that have arisen among us.

One of the most difficult things I face as a politician is to sit as chairman of the Appropriations Committee and see over eight hundred billion dollars of your tax money being allocated for various and sundry programs. What I sense is a great imbalance. I know that many of you are aware of the fact that your government has committed itself to spending one trillion seven hundred billion dollars in the next five years for war armaments. I don't think you have to be a hawk or a dove, a pacifist or a war monger; I'm talking about simple, humanitarian instincts. A cursory view of the nation of which we are a part and its needs would lead one to say: something is out of balance when we have to scrounge to find twenty-two million dollars for research on Alzheimer's Disease and we raised that from the magnificent sum of 3.8 million dollars a few years ago. We can commit ourselves to a hundred million dollars down payment on the resurrection of a chemical weapon that is totally unnecessary for our arsenal, and a hundred million dollar down payment on a four to six billion dollar weapon system, but we can only find twenty-two million dollars for this important research on a disease that is exacting its toll in human suffering, in the wrenching experience that affects both the victims and their families.

In Los Angeles not long ago I had the great pleasure of meeting opera singer Dorothy Kurstin. She told me that her call in life is no longer to sing, but to raise citizen awareness of this dreaded disease, Alzheimer's. She has been personally affected by the disease; her doctor husband diagnosed himself as a victim five years ago. For two years he kept a journal, but for the last three, he has been unable to function at all.

I suppose like many things in life, tragedies can just roll off your back if they don't affect you directly. We hear about so many programs; it is difficult to become involved in each and every one.

I, too, have had personal experience with diseases of the aging. My father, in the prime of his life, was a blacksmith, working for the Southern Pacific Railroad. You never saw a more beautifully built physique in your life. And he was a vital man. Though he didn't have an opportunity for higher education, he managed to memorize Shakespeare and to recite poetry, to maintain a love for literature. He was a renaissance man, vital, dynamic, a wonderful person.

And yet the last three years of his life, he was not my father. Physically, of course, he was, but still, I felt that ambivalence of emotion. He didn't know me, he didn't realize what was happening in the world around him, in the life of the nursing home where he resided. In many ways, I had already said my good-byes. But every time I returned to Oregon, I was drawn in to that nursing home. I felt the duty, and I had an ever-flickering hope that maybe for one second, or for ten seconds, on this visit there might be some kind of return. There never was.

I confess to you that that is why I have felt that our government, our society, should be spending more of its resources to enhance human life, to sustain, to build the quality of life—instead of being so thoroughly committed to developing a higher degree of efficiency in methods and ways to destroy life. It just doesn't make sense. I hate labels, doves and hawks and all that; I'm talking about survival of humanity. I walked through the streets of Hiroshima one month after the bomb had been dropped; the bodies had not been recovered, there was a stench as well as the sight of indiscriminate devastation. And that made an indelible imprint upon my mind that I can never erase. But it also demonstrated to me in a vivid way that here, only one primitive bomb could make that kind of destruction. What would the world be if the United States of America had directed its attention to and unlocked the key to Alzheimer's, or cancer. We say our prestige, our influence in the world, will be enhanced by developing a calibre-force weapon known as the MX missile, the midget man missile. This at a time when two of our twenty-one nuclear submarines could destroy every major Russian city and the Navy wants to build twenty-five more. What degree of overkill do we have to have to be secure?

We are paying a very high price for this pursuit of false security. The Shah of Iran thought his arsenal was his security and he neglected his political, social and economic problems. And they overwhelmed him. And I say to you today that America's vulnerability on the security front is not in the lack of an arsenal, an adequate diversified arsenal; it is in the neglect of our infrastructure made up of health, housing, transportation, utilities, a productive economy and our over-dependence on middle eastern oil. All of these things are our true vulnerability. And the bigger bombs that we build in no way compensate for the failure to address those problems.

If you are not moved by humanitarian concerns, let me point out that the most cost-effective dollar that we can invest of your tax money is in health. It returns thirteen dollars for every dollar we invest at the federal level. There is no other program that can return to the general economy a higher yield on the investment. So if we are money grubbers and are impressed only by economics, we should think of that. And the lowest multiplier in creating new jobs and new wealth in our society is a dollar for an apple. That's the multiplier.

People like you and symposiums like this will make a difference. If you think there is no time and you give up hope then let me just say a few months ago I got thirty thousand letters in two days from just the people of Oregon telling me to repeal the ten percent tax on withholding and on savings.

There is hope. You can determine the course of your government, the balance and the imbalances. And I urge you to not only be content with sharing your own skills, background and experiences here in this great symposium, but to carry your message right through into those areas where these major decisions are made. And don't forget the wonderful words of Hubert Humphrey when he said that ultimately, the moral test of a government is how that government treats those who are in the dawn of life, the children; those who are in the twilight, the elderly; and those who are in the shadows of life, the sick, the needy and the handicapped.
No disease is bearable, but clearly Alzheimer’s Disease is merciless in its destruction of the human mind. What was once regarded as a normal consequence of aging has come to be recognized as a neurological disease that threatens the health and well-being of our entire society. Alzheimer’s Disease affects 1.5–2 million people in this country. It claims the lives of 120,000 each year. The suffering endured by its victims is immeasurable, as is the emotional strain placed on families and loved ones. The cost to society in terms of medical expenses alone is conservatively estimated to be $12 billion annually by NIH.

As bad as all that sounds, consider the prospects for the future, when so many more of our citizens will be in the high-risk elderly age bracket. By the year 2030, it is estimated that more than 65 million people will be age 65 or older. From a humanitarian or economic standpoint—it is imperative that we act now to put a stop to this horrible illness. The victim is completely stripped of all mental and emotional faculties and becomes a prisoner within the human body but unable to carry out the simplest human activity. Our best hope lies in research aimed at uncovering just what causes Alzheimer’s Disease. We certainly know more about the disease than we did 10 years ago, but not yet enough to find a cure or treatment. A major step forward was the recognition that Alzheimer’s Disease is a neurological disorder—not a result of the normal consequences of aging.

We in Congress are doing what we can to help in this effort. The 98th Congress has devoted a substantial amount of its time and attention to finding out what medical science is doing to unravel the mysteries surrounding Alzheimer’s Disease and examining how the disease affects its victims and its families. The Senate Appropriations Committee has held hearings on Alzheimer’s Disease. We have heard very moving testimony, both from the medical experts and from family members. The Committee directed the National Institutes of Health to provide a comprehensive report. We asked to be informed on research progress (state of the science) and what efforts were under way to coordinate the work being done at NIH and other government agencies, such as the Veterans Administration. I like to think that our involvement set off a chain reaction that will bring us much closer to finding an answer to this dreadful problem.

Shortly after we received the report on Alzheimer’s Disease, HHS Secretary Heckler announced her plans to create a task force to coordinate government research activities and to develop a comprehensive plan for attacking the problem.

Furthermore, other congressional committees have turned their attention to this matter. In May, the Senate Labor and Human Resources Committee held extensive hearings on the research aspects of the disease. Senator Hatch and his Committee have proposed legislation that is intended to bolster the level of research being conducted and to increase the level of Congressional oversight of government-wide efforts in this area. Similar action has been recommended by our colleagues in the House (Committee on Energy and the Environment). In July, Claude Pepper and others on the House Aging Committee begin to examine some of the problems associated with providing long-term care for Alzheimer’s victims. The Senate Aging Committee is also looking into this issue. Finally, several Members in Congress have expressed concern, which I share, over the fact that Medicare does not cover this disease because the care that is given is regarded as custodial in nature.

Since 1976, the amount of government funds spent in this area has grown from $3.8 million to $22 million. The Appropriations Committee has recommended that this high level of funding be continued.

Major Department of Health and Human Services research activities are in NIMH, Alcohol, Drug Abuse and Mental Health (ADAMHA), NIA, and National Institute of Neurological and Communicative Disorders and Stroke (NINCDS). Related research is also done by National Institute of Allergy and Infectious Diseases (NIAID). The 1983 estimate for research by these four is $22.34 million.

One major source of assistance (other than financial) to Alzheimer’s Disease patient’s families is the Alzheimer’s Disease and Related Disorders Association, which was formed in 1979 and now has over 60 chapters throughout the country. A number of witnesses at Congressional hearings have noted the enormous psychological and social support they have received through this organization. ADRDA also provides educational and informational materials, and funds some small grants. There is great need for more research on the needs of families and on how to help families cope with Alzheimer’s Disease, which imposes an enormous emotional and financial burden on them.

Even though there is no treatment for Alzheimer’s Disease, there are two drugs which are being looked at and show some interesting early results. Press reports of their potential as treatments have unfortunately been exaggerated. The drugs, still in early research protocols, are naloxone and physostigmine.

There is a great deal yet to do, as I have indicated. The problem is not going to disappear unless we have a strong sustained commitment on the part of every facet of the community…government and private sectors alike. It might well be a protracted battle. But let us keep in mind the words of Hubert Humphrey who said that: “The moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight, the elderly; and those who are in the shadows of life, the sick, the needy and the handicapped.”
Caring for the Alzheimer's Disease Patient—A Communal Response

The Role of the Family
by Rose Dobrof, D.S.W.
Director, Brookdale Center on Aging
Hunter College Panelist

There is a particular appropriateness to this occasion which I must make mention of before getting to the subject of my paper. This audience is surely aware of the position the Hebrew Home occupies in the field of long term care: it serves as an exemplary model in the United States and internationally. This symposium on Alzheimer's Disease and Related Disorders; the recent acquisition of the facility which will serve as a treatment and research center on Alzheimer's; and the linkage of the Home and the Albert Einstein College of Medicine all demonstrate the leadership the Home is presently taking in the struggle against the blight of Alzheimer's Disease.

The role is not a new one for the Home; however, today's event is part of a historical continuity, linked to the Home's aspirations for the future, to be sure, but connected also to its past accomplishments. It is this heritage of accomplishments that make this occasion so exquisitely appropriate, and the record of today is not complete if it does not include citation of the past. It is now more than two decades ago that the late Alvin Goldfarb, a pioneer in geriatric psychiatry, first began calling the attention of his colleagues, public officials, and others to the increasing numbers of mentally-impaired older people who were being cared for in the Homes for the Aged and nursing homes in our state.

Dr. Goldfarb saw this as an inevitable and not inappropriate development: his concern, however, was for the quality of care that was being provided in the Homes for the Aged and nursing homes. A series of studies he did provided the factual basis for his concern: he found that staff of these homes often did not recognize the existence of mental impairment among the old people in their care; and that even when they did, they had little knowledge about treatment methodologies, environmental design, staff-patient ratio, etc.

Alvin knew that it was the bench researchers who would ultimately find the p.s.h.s to prevention of mental impairment, but in the meantime, though he thought of himself as a researcher, he knew that the payoff of the work of the researchers would count for little in the lives of old people, already impaired, and their families and the professionals and other staff who tried to help them. His essential humanism required that he concentrate on the here and now; that he respond to the needs of those who came to him for help. He had come to know the excellence of this Home under the leadership of its then new executive director, Ruben Reingold; and its Board of Directors, including its current president, Irving H. Stolz, and it became the focus of some of his most substantial work. The staff training program he developed; the fine-tuning of his assessment instruments; his writings on the nature of the therapeutic relationship; his attention to the families of the mentally impaired and to the stress they experience—all of these were elements of the work he did here. The work reflected the particularly creative collaboration between the staff and Dr. Goldfarb, and it was important in establishing the Home as a model of the proper linkage between research, education, and clinical practice. It is this historical continuity—this connection between the work of the past, the accomplishments of the present, and the aspirations for the future—which makes today so appropriate an occasion and which should be for the Board and staff of the Home both a source of pride and strength and a standard against which to measure the deeds of today and the goals for tomorrow.

And now to our work. I should like to suggest three themes for your consideration: first, that the American family continues to be a bulwark of strength for its aged members; second, that Alzheimer's Disease takes its toll not only in the life of the victim but also in the lives of family members, and renders the family itself and the individuals within it particularly vulnerable to physical illnesses, economic impoverishment and social and psychological distress; and third, that for the sake of the family as well as the old person, there must be a partnership between family and service system.

Now for the first theme, that having to do with the capacity of the American family to care for its aged members. Thankfully, when speak-
victim is, or the victim’s status in the family.

Eli Savitsky wrote in 1972 that:

“Family members more easily understand and accept physical illness than mental impairment or other psychological disorders. They see it more as a not unexpected fact of life and feel less bewildered as to its cause and course than they do about mental illness with its uncertain origin and unfamiliar, frequently frightening manifestation.”

In relation to this point, I commend to you the two recent books by Joel Veroff and his associates—The Inner American and Mental Health in America, 1957 to 1976 (New York: Basic Books, 1981). Veroff had been a member of the team of social scientists who in the late 1950’s studied the attitudes of Americans toward mental health issues, and in 1960 published their findings in the seminal Americans View Their Mental Health (New York: Basic Books, 1960). They concluded then that:

“People tend to externalize their problems, to locate them in ‘concrete’ material things…, to see them as reactions to external events…(There is a)…tendency for people in the general population to phrase their problems in non-psychological terms….” (p. 49)

In 1976 they found Americans more likely now than they had been in the ’50s to define psychological or relationship problems in those terms rather than in external and concrete terms. They found also that Americans today are more likely to seek help when psychological or relationship problems cause them distress. The researchers found American adults of today less likely than in the 1950s to accept such problems as their lot in life, to be endured without hope, instead of confronted and solved.

Despite these shifts in the years between 1957 and 1976, there remain in the United States attitudes and beliefs which make it difficult for some families to accept as a disease something whose presence is announced in behavioral terms, and in behavior which so frequently assaults the very souls of the spouses and children.

The philosopher wrote: Cogito, ergo sum; I think, therefore I am; and I suspect at bottom many Americans, even those who do not know these words and even many in this room, believe in the truth of this assertion. What defines our humanness and separates us from all other living beings on this earth, we believe, is that we think; we plan; we remember; we calculate; we build theories; we accumulate knowledge. Cogito, ergo sum; I think, therefore I am; and when I no longer can think, when my intelligence is gone, then my personhood, that which I am, is gone.

This, I think, is what the wife means when she says the husband I knew is gone, and this necessity to respond to, care for, look after a human being now robbed of that which defined him as a person, this I think is at the core of the pain families experience—it is this which makes them so vulnerable and which can tarnish even the most faithful and loving relationships.

One more dimension of the pain families experience—and this leads to my final point about the necessity for partnerships between families and service agencies and professionals. Alas, some of the pain is iatrogenic in nature—it is caused by the pathology in our health and social service systems, by the lack of responsiveness of large systems to individual need, by the holes in the service system, by the complexity of its rules and regulations. One of my colleagues, presently doing research on Information and Referral Services, says that when the families of Alzheimer's victims call Information and Referral Services for help, the primary characteristic of these families is their desperation. And the desperation comes not just from the recognition of the increasing impairment of the Alzheimer's victim—it is the desperation of families carrying a burden far beyond their capability and without help from the community in which they live. One 72-year-old husband, a man who had a proud record of service to his community, now is facing the awful reality of the disease's toll on his afflicted wife. He is frightened about how he is going to manage. His wife's physician couldn't give him any information about programs or benefits; he doesn't know where to turn for help; he isn't sure what he needs or what he's eligible for. No one seemed ready with both a listening ear and accurate, up-to-date information. So he's been carrying the burden by himself. "I worked hard in and for this community for 40 years, and so did my wife. And now it's like it's all wasted. Don't we have a right to make a claim on the community for help now that we need it?"

This man's sense of desperation and abandon is, I am saying, is iatrogenic in origin: it is caused by, and reflective of, the pathology of our fragmented, incomplete, and hard-to-reach system. It is, therefore, not an inevitable, intrinsic element of the disease, but an altogether preventable dimension of pain.

All of the research on family caregivers, including that of Brody, Shana, Sussman, Litvak and Curland, among others, demonstrates both the willingness of families to perform caregiving tasks and the need of families for help from agencies and institutions on which they can rely and from professionals who understand and value the efforts of families to do what is right. In all of the model projects—the CSS Natural Supports program here, Florence Salford's work and that of Alida Silverman in Michigan—wherever there have been projects aimed at providing supports and services for caregiving families, the evidence has been clear that when services are provided to families, families do not respond by abdicating their responsibilities to the agencies. Rather, the provision of services—the partnership between family and agency, the sharing of the responsibility—enhances the capacity of the family to carry its share and shores up its ability to sustain itself and its members, even in the face of the continued decline of the Alzheimer's patient. Moreover, even if institutional care becomes the appropriate arrangement, the necessity for the partnership between Home and family continues. The mentally-impaired old people in this Home today who have the benefit of the care and services of the Home and also the concern and love of their family will have more than will the old person without family who, to paraphrase the playwright, must always depend on the kindness of strangers.

And when the death of the mentally-impaired mother or father comes, the children who have been able to be partners to the Home and continue to carry responsibility—if only to visit or to bring small necessities or to make sure all is well—these children will at least have the comfort of knowing that they did what was right; they did the best they could.

The family who must carry this responsibility alone, without help and without understanding, is a family at risk, and a society which continues to permit families to carry this burden without providing the help that they need is equally at risk. I hope that in our deliberations today and when we return to our appointed tasks tomorrow we do not lose sight of our responsibility to be good partners to the families who come to us for help.
The Role of the Institution
by Helene D. Grossman, M.S.
Associate Executive Director
The Hebrew Home for the Aged in Riverdale
Panelist

When I first arrived at the Hebrew Home in 1976, many individuals had a primary diagnosis of OBS—organic brain syndrome, but that was, and remains, a catch-all category with little meaning. Soon after that, we began to see a few new patients being admitted with a primary diagnosis of Alzheimer's Disease. These individuals were under the care of physicians who were either medically sophisticated or had sophisticated office addresses. This trend, though, was also short lived. Within a few brief years, even if the patient had Alzheimer's Disease, the diagnosis did not appear on the intake report. Families were afraid to tell us the diagnosis, for fear that the institution would not accept the patient. Some of these fears stemmed from policy issues related to concerns about Medicare reimbursement for an Alzheimer's patient. Other fears were based on the families' misconceptions about the disease process.

Alzheimer's Disease has become more fashionable again. The President proclaimed Alzheimer's Recognition Week. The National Institute of Mental Health is funding research into the causes and cures, and Alzheimer's Disease has caught the imagination of the media. We at the Hebrew Home are once again beginning to see more patients with an intake diagnosis of Alzheimer's Disease. Whether or not all of these new patients are, in fact, suffering from Alzheimer's Disease is still questionable. In fact, the diagnosis of Alzheimer's Disease may still be more a function of the referring physician than the patients' illness. Some of the patients being admitted to the Hebrew Home with this diagnosis have had complete diagnostic workups, others have not. While the institutional role is not one of diagnosis, it is the role of the institution to accurately differentiate patients according to their levels of need. It therefore follows that the institution too must stress the importance of accuracy in differential diagnosis.

Research has taught us to recognize that there are a variety of different dementias, and that senility is not a normal consequence of advancing age. We are even careful now to diagnose Alzheimer's Disease as S.D.A.T.—senile dementia of the Alzheimer's type (DMA-III 1981). This suggests that there is not one type of Alzheimer's Disease but a variety of subtypes. They may all result in similar symptoms, but may have somewhat different causes and courses. Inevitably, we will find that the various sub-types have different forms of therapeutic intervention. Presently being debated is the policy issue of institutional maintenance or active therapeutic intervention as the more appropriate mode of treatment for the Alzheimer's patient. As an institution, what role do we now take? Do we assume that SDAT is a universal illness, with one on-going treatment or intervention modality, and if so, what is the best type?

Over the years, long term care facilities have been caring for individuals with behavior indicative of dementia. The care, and the types of patients, however, have been slowly changing. There are now more older adults surviving to advanced age. Along with increasing age comes an increasing incidence of Alzheimer's Disease.

A related issue is this age factor. Long term care facilities tend to admit individuals over the age of 65. Alzheimer's Disease can, and often does, occur in individuals in their 50s. We are not yet clear on the differences, if any, between Alzheimer's patients in their 50s, and those in their late 60s or older. We tend to believe that younger individuals with Alzheimer's Disease are more ambulatory and feet of foot, and hence, more difficult to care for. As a result, long term care facilities have generally shied away from accepting individuals of this kind. This approach may turn out to be a misconception but, here too, we still do not know enough about SDAT to respond in an educated manner.

With emphasis on providing more support to older adults in the community (GAO, 1982), those requiring care in a facility, will more likely be individuals who are difficult to manage outside of an institution. Institutions will have to respond to these individuals with a more structured and supportive environment. One example might include a physical activity and active exercise program for those patients who wander or have other physical needs of expression (Snyder, et. al., 1978).

The importance of individualizing care and learning to know who each individual person was, through psychosocial, cultural and spiritual histories, and then reviving whatever interest once existed through a variety of interventions, is recognized and emphasized.

The literature suggests that reality orientation programs are only moderately effective over the long term. The fact that they can be effective at all, indicates that different individuals have different needs, even different forms of the disease. Here too, we stress the importance of differential diagnosis, which will lead to a clear understanding of the best intervention strategy. To respond to this variety of need, the institution must be flexible in its support, and research-oriented in its approach.

We now know that patients with Alzheimer's types of dementia respond well to supportive environments and a variety of different sensory stimuli. We place large calendars on the units and teach our staff to remind patients the time of day, where they are, and even who they are. We use bright colors on the units and our recreation workers and therapists have the patients work their hands, arms, eyes and brain as much as possible. Some patients respond to this stimulation, others do not. Why this is so is one issue that can be explored in a long term facility. We struggle as well with such additional issues as restraints, incontinence and retraining, and the effects of multiple simultaneous drug therapies. Institutions, by virtue of their structure, can perform critical analysis of the impact, effects and costs of alternate programming with different categories of patients, and can provide a wealth of important information on both an applied and basic level.

Reality orientation, sensory stimulation and physical activity programs are all part of the services offered to patients in long term care facilities. Most of these programs are also offered to other patients in the facility. An interesting issue is raised by this. Often, demented patients exhibit behavior that other patients find annoying. As part of a study recently completed at the Hebrew Home, patients and staff were asked about some of their feelings regarding their unit of placement. In general, 80% of the staff interviewed said that it would be easier to perform their job, and patients would be more comfortable, if the patients were placed according to their type and level of care needs. Patients who were interviewed responded in the same way. They too reported that they would prefer to be on units that had other individuals with the same illness and level of care need (Salamon, 1983). By addressing this as an issue we begin to see that different patients have different levels of orientation and need for care. It is in institutions that these research issues can best be addressed.

It must be recognized, as well, that the staff of a long term care facility, particularly the hands-on staff, can be exhausted, frustrated and at times even frightened by the psychological aspects of Alzheimer's and the concomitant changes in personality and behavior. Staff education, on-going assessment of morale, peer and professional support as well as caring and nurturing to continue to do their jobs well are also viewed as an integral role of the institution!

There are other issues related to the role of the long term care facility in caring for patients with Alzheimer's Disease. The long term care facility is usually viewed by the family as the last option for care (Vladeck, 1980). There are programs, however, that suggest that facilities can provide an important service to individuals with Alzheimer's Disease in the community. Day care programs and facilities which provide respite services are some of the ways that this can be performed. Others include providing support services for relatives who are caring for a family member at home who is suffering from Alzheimer's disease. Just providing a place for family members to meet is a useful intervention. The institution will no longer be foreign, or negative to the family. Family members will become more aware of the role of the institution and more open to the services pro-
vided there. The staff of the institution can work with the family, introducing them to the range of options available. When institutionalization becomes necessary, the family will be more comfortable with the transition and more aware of the course of the illness.

**Research/Evaluation**

Many aspects of Alzheimer's disease remain... in Winston Churchill's phrase about Russia... "A riddle wrapped in a mystery inside an enigma." Long term care facilities can fill leadership roles in the area of research and particularly evaluation regarding the variety of needs different patients present with, the assessment of those needs, successful programming interventions and constructive approaches to working with the family. If the institution is open to these possibilities it can provide a full range of services plus contribute to knowledge in a number of important ways.

The Hebrew Home for the Aged in Riverdale has developed an exciting set of plans towards this end which will be addressed by our Executive Vice President, Jacob Reingold, in the next session.

1. Generation/Beginners article.

**References**


The Community as a Resource
by Janet S. Sainer
Commissioner
New York City Department for the Aging
Panelist

Although there are no exact figures on the number of persons who suffer from Alzheimer's Disease and related disorders, recent reports in Science estimate that from five to ten percent of those over 65 or as many as 2 million Americans are afflicted. Worse, as we conquer or ameliorate other illnesses, thereby extending the lives of individuals and increasing the number of elderly, the incidence of Alzheimer's Disease rises. It is projected that the prevalence of these illnesses will more than triple in the next 50 years.

Up to now those who are afflicted by Alzheimer's Disease and those who care for them have tended to close themselves off, to cope silently with little help, except from those in the institutional field. Until very recently Alzheimer's Disease has been viewed as an institutional rather than a community-based problem.

However, by the most conservative estimates, at least a million Alzheimer's patients are maintained at home. In New York City there are probably upwards of 50,000 persons over 65 living in the community who are afflicted with Alzheimer's or similar disorders.

We are well aware that a diagnosis of Alzheimer's Disease changes the life of the entire family for as long as the patient lives. Recent studies indicate that most families maintain their relatives at home for four to eight years. Families are caught in the dilemma of increasing demands and decreasing resources. Progressive deterioration and unpredictability of symptoms force the patient and the family to adjust continually to new problems and higher levels of impairment.

Clearly, until we achieve a major breakthrough in research to prevent the onset of Alzheimer's Disease and other related disorders, an urgent need exists to develop programs and services to assist families who can care for their stricken members and humane services for those who have no families. Moreover, we must be sure that quality services are available, accessible and appropriate; that there is widespread public education about the enormity and complexity of this problem, as well as knowledge of programs that can alleviate the physical, financial and emotional strain placed upon patients and their caregivers.

One of the major resources for caregivers is the family support groups which are springing up across the country, supported by local agencies, major hospitals and chapters of Alzheimer's Disease and Related Disorders Association (ADRSA). These groups strive to keep the morale, well-being and treatment skills of care providers; they are also alerting the community to a serious social and health problem. ADRDA is a nationwide organization with over 80 chapters and is dedicated to fighting Alzheimer's Disease and informing the public through newsletters, educational forums and family support groups. Moreover, they serve as a resource for families seeking guidance as to where to turn for help.

Since as many as 30-40% of people with symptoms of dementia have a correctible disorder, an essential first step is receiving an accurate diagnosis.

In New York City, in addition to competent private practitioners, there are four renowned Alzheimer Diagnostic Centers: Milhauser Labs at New York University Medical Center, Albert Einstein College of Medicine, Bronx V.A. Medical Center and Mt. Sinai Geriatric Clinic. In addition to providing diagnostic workups, they offer a broad variety of services to patients and their families and can make referrals to home care agencies, social services and financial counselors, and provide family support groups.

Once a diagnosis is made the caregiver is faced with the task of arranging for care and supervision of the person and property in order to maintain the patient at home as long as possible. Assuredly the proper administration of home care for an Alzheimer's patient is an enormous task. Presently the city's Human Resources Administration provides three types of publicly supported, home care assistance for those who meet the income eligibility criteria: Housekeepers: Duties include housekeeping, laundry, shopping, escort and meal preparation; Homemakers/Home Attendants: Duties include the above plus limited personal care, grooming and feeding; Home Health Aides: In addition to homemaker responsibilities, health related tasks such as overseeing medication, changing dressings and bathing assistance are provided.

For those who are just above Medicaid Eligibility, the Department for the Aging provides in-home services on a limited basis, as well as escort services, friends visiting and telephone reassurance—all aimed at assisting the elderly in the community. In addition, the Department is responsible for administering the total Home Delivered Meals Program in New York City, which currently provides meals five days a week to 6,000 homebound elderly.

Despite what may appear to many to be very limited services, it must be noted that New York City as the largest home care program in the nation, serving 38,000 homebound individuals. In order to be eligible for this program, the client must be Medicaid eligible and capable of directing and supervising the home attendant or have family available to provide the supervision.

The Medicaid income eligibility in New York State is now $4,000 a year for a single person and $6,400 for a couple. Assets can only include $2,700 for one person and $4,200 for a couple. Plus $1,500 per person for a burial fund.

At this time only about 17% of New York City's elderly are Medicaid eligible. The large majority are not. However, lack of Medicaid eligibility does not necessarily ensure one's ability to pay for needed services and care. Most recent income data for the city's elderly indicate that half of those 65 and over have incomes falling between $4,000 and $10,000. Families and individuals requiring full time help may have to pay between $250-$400 a week. Certainly not many elderly or their families can support such costs.

Unfortunately, our current system not only overburdens adult children who assume responsibility for their disabled relatives, but also can perversely affect the care giver.

If the community is to be a true resource, then a continuum of care from in-home services to institutional care must be provided. I believe that Medicare must be expanded to include long term care services, and not just acute care. In that way in-home services for the chronically disabled, such as Alzheimer's patients, would be financed under Medicare.

If Medicare is not expanded then society will be paying for increased lengths of stay in hospitals or sending patients to nursing homes when such care is not needed.

The current staggering costs of long term illness also raise serious legal questions. Most people think that estate planning implies planning for the distribution and management of an estate at death. In the case of the Alzheimer's victim, the difficulties as well as urgent necessities for planning for the living but incapacable person are dramatically illustrated. Early in the onset of the illness it is important to ensure that any funds in the name of the victim will be best used for his or her care and that the remaining family members be provided for.

There are several legal resources open to families of individuals with dementia. The Hunter-Brookdale Institute on Law and Rights for Older Persons can provide advice on areas such as obtaining power of attorney, conservatorship or representative payee. Families can also turn to the Older Americans Act Legal Services Programs, sponsored by the Department for the Aging, which offer free legal assistance to senior citizens in four boroughs. In addition, the Department's Central Information and Referral Unit can offer advice on services and entitlements, find the proper source of assistance in the community and ensure that those who are eligible for benefits have access to them. Social workers at senior citizen centers and social service organizations can assist the family in the formal processes for whatever benefits and reimbursement might be available.

Other public and voluntary agencies can offer services which can be helpful. To reiterate, home care services can be obtained from both the Human Resources Administration and the Department for the Aging; the Department of Mental Health, Mental Retardation and Alcoholism Services sponsors geriatric mental health clinics. Some of the New York State psychiatric facilities operate mobile
Locating a nursing home which will accept an Alzheimer's victim can be a difficult task. Lists of institutions, how to apply, rights of patients, etc. can be obtained from the Friends and Relatives of the Institutionalized Aged (FTRA), the Long Term Care Nursing Home Unit of the Department for the Aging, or the Association of Homes for the Aged.

As we experience the "aging of the aged" and view the current and projected increase in the number of those over 85 years, the shortage of nursing home beds in New York State will become a more pressing issue. Institutions are an integral part of our community and if we aspire to be a just society then we must ensure that all our institutions are open to the most needy and disabled members of our population. The availability of nursing home beds must reflect the relevant demographic changes and the projected incidence of Alzheimer's Disease. It is possible that the creation of increased institutional resources may be more cost effective than the present expenditure for hospital back-up. Institutional resources should be architecturally appropriate and be staffed by persons specifically trained to meet the unique care needs of dementia patients.

New York City is an urban community, and like other urban areas throughout the country, has seen significant changes in its elderly population over the past ten years: it has grown older and it has become increasingly live-alone. The 75-84 year cohort rose 15 percent from 1970, while those 85 and over increased by 37 percent. In addition, the number of elderly living alone increased by 13.4 percent in the past decade. Clearly, more and more of our aged are alone and more often—some are the very old, the very poor and usually female. Moreover, the lives of urban elderly are different from those of their counterparts elsewhere. They are apartment dwellers and many live in communities which have undergone enormous change in the past ten years. Their private doctors are growing older and are not being replaced by new physicians. Thus, there is often no doctor who knows them personally and who can recognize the subtle behavior changes that herald the onset of a deteriorating condition. The neighbors of the elderly who live alone are frequently casual acquaintances and younger people who also may not be aware of changes in the older person until some overt act, such as turning on and forgetting the gas or letting a tub overflow, occurs which threatens not only the older person but his or her neighbors. Our department is all too familiar with calls from landlords, housing project managers and the police who have identified these potential patients and are seeking assistance on their behalf.

Families cannot shoulder the responsibility of caring for an Alzheimer's patient alone—this requires a societal commitment for care. As a community we need to expand our attempts to meet the very immediate needs of Alzheimer's patients and those who care for them. Perhaps by providing the vital day-to-day support needed we can lessen the tragic impact of this disease.

It is a truism that "the elderly of today cannot afford to wait for a better tomorrow." The challenge of Alzheimer's Disease is before us and it is a challenge that we can no longer ignore. Those of us present today share a common concern and now we must work together for a common goal: to ensure that our concerns are translated into action, to ensure that in the future the phenomenon of a "36 hour day" will no longer be applicable in the discussion of Alzheimer's Disease.
Implications for the Future—Public and Private Initiatives
by Raymond Vickers, M.D.
Associate Commissioner
Chief of Geriatric Services
New York State Office of Mental Health
Chairperson

Before I have the pleasure of introducing my illustrious co-panel members. I would like to say something about where we are now so that the challenges on which their initiatives should be based are a little more clear to you. Listening to a series of programs as we have done today, it would be easy to think that we have done nothing about these challenges. But I want to say to you that what is being done in this country and this state is a very great deal. However, almost everything that can be said positively about our efforts has a "but" attached to it. And that's what I plan to point out.

No other country in the world spends so much on public medical care programs as the U.S.A.: but there is no system of public benefits that has so many barriers to benefits for mental illness. No other country spends such a high percentage of its national product on research: but no other country spends such a small proportion on medical research compared with the proportion spend on armaments research and development. No other country has a longer history (and this may be a surprise to you) of the adoption of the concept of geriatrics, a word which was coined in this country: but the A.M.A. has withheld the naming of the specialty of geriatrics for those practitioners who specialize in that area to this day. No other state than New York has more institutional beds (mental and nursing home) for the aged: but in no other state do they cost more to occupy. No other state has a higher percentage or number of its population resident in mental hospitals (forty-four percent of those residents are over the age of 65) many with Alzheimer's Disease: but in no other state do we hear a more clamoruous demand to open more mental hospital beds to the elderly, especially those suffering from Alzheimer's Disease. Currently there are about a hundred thousand HRF and SNF beds: but 65 percent of those are believed to be occupied by people with Alzheimer's Disease and related disorders.

This was the first state to enact the state legislation to authorize the Medicaid amendments to the Social Security Act, and except for one other state, it has more benefits under Medicaid: but continues to exclude persons with Alzheimer's Disease from some of the benefits such as eligibility for the C.A.S.A. channelling program. It was the first state to have a long-term home health care nursing program: but has failed to expand it to all areas of the state. New York is probably the first state to have over a hundred thousand sufferers of Alzheimer's Disease within its borders: but has no epidemiological data to record them.

I've been spending a very interesting time recently trying to find out what it must be like to be in the world of Alzheimer's sufferers. For instance, I often hear people say things like "father is now a stranger to us," but father says, "everyone is a stranger to me." And that must be for father a much bigger tragedy, because it involves everyone in his life. These people are strangers in a familiar land and if you want to try to think what that's like just recall the last time you committed the error of walking into the wrong room. Nearly everybody's done this at one time or another. And as you looked around and saw everything looking unexpectedly strange and somewhat unfamiliar, someone may have noticed you and looked you aghast and somewhat threatened. That is something of the reception that the Alzheimer's person suffers continuously. A permanently unfamiliar world is the world of the Alzheimer's victim. And so as you go home you might have a little fantasy and pretend to yourself that you don't know where you are, and you don't know anyone you meet. This may remind you of some past occasions in your life when you've had those same feelings. In that way perhaps you can understand more meaningfully those who are feeling that way at every moment.
Federal Responses to Alzheimer’s Disease
by John M. Corman
Executive Director
The Gerontological Society of America
Panelist

I. The Need to Think in Multiples
For the past five or six hours you have heard from an impressive array of experts on the state of knowledge about Alzheimer’s Disease and related disorders. The presentations have run the gamut from research into causes, to problems of diagnosis, to difficulties of securing quality and affordable care, to moral and ethical problems raised by the disease, to the need for family support. I believe I could make a persuasive case that five hours of such presentations is about as much, if not more, than most of us can usefully absorb, and that this next 75 minutes might better be spent individually mulling over some of the sobering data offered us. However, unable to secure in advance the agreement of the chairman and other members of the panel to offer a period of silent meditation, I have prepared some broad thoughts on what necessarily must be a broad theme—implications of what we’ve heard for initiatives by the federal government. In doing so, I proceed on the assumption that, given the earlier presentations, there is no need to document here the awful human and financial impacts on individuals and families if the number of Alzheimer’s sufferers increases as projected, or the ethical and moral dilemmas the disease creates for patient, family, caregiver, and lawmaker.

My purpose, then, will not be to justify the need for federal initiatives or to lay out a detailed program which the federal government ought to launch. Rather, I will offer examples of some choices and some factors which may affect those choices which ought to be considered in fashioning a federal response to Alzheimer’s Disease, and will suggest some candidates for immediate consideration. If my remarks turn out helpful, they will do so not because they break new ground, but because they will indicate the need for a political framework in devising, promoting, securing and implementing a federal response to Alzheimer’s.

No matter how sure we are of the moral or economic righteousness of any cause, politics will and ought to determine the shape of federal policies relating to Alzheimer’s Disease. Clearly, the use of the verbs “will” and “ought to” suggests that politics, in the context of these remarks, is viewed at worst as a necessary evil and at best as the way society makes decisions in conflicts created by competing but legitimate claims on limited resources.

Two recent events brought home the difficult choices involved in just deciding how to spend federal biomedical research dollars:

* At a House Appropriations Subcommittee hearing, the group preceding the Gerontological Society was an organization formed on behalf of sufferers of and parents of sufferers of epidermolysis bullosa, a skin disease which afflicts young people. The condition, for example, can make the skin of the throat so sore the sufferer cannot eat. The group of testifiers, which included children with the disease whose parents of determination should be an example for us all, were asking much like Alzheimer’s family support groups, if anyone were listening to their cries for help, and for money to fund research on preventing or treating the disease.

* An ad hoc organization formed to advocate increased federal funds for biomedical research listed heart disease, cancer, diabetes, arthritis and water-on-the-brain, as well as Alzheimer’s, as deserving of continued and expanded research.

And, of course, the federal budget for biomedical research must compete in a broader arena, just as do the non-biomedical programs designed to deal with issues created by the increase in Alzheimer’s Disease. So as we seek to design and have implemented federal responses to Alzheimer’s Disease, we must think in multiples, about the political milieu in which we work, the range of concerns which deserve consideration if not action, relationships of these concerns to other aging and national issues, and the effects new knowledge will have tomorrow on whatever programs may be started today. Rest assured I am not about to explore all the options and nuances included in each of those broad areas, but I hope to offer enough examples to remind us, if that is necessary, that, with apologies to the poet John Donne, no issue “is an island.”

Before proceeding, however, I would like to offer a caveat. As we have heard, relatively little is known about Alzheimer’s Disease. “There may be as many as 100 conditions which mimic the symptoms of Alzheimer’s Disease,” and indeed, Alzheimer’s may have more than one cause and may turn out to be more than one disease. Therefore, in terms of research, we should not anticipate discovery of a single treatment; and in terms of care, we should be concerned with all conditions resulting from mental impairment, whether or not the cause turns out to be Alzheimer’s. Progressive, irreversible mental impairment, regardless of cause, warrants sympathetic care and creates identical problems for caregivers. Therefore, just as physicians are urged to be cautious in diagnosing the disease, we all ought to be careful not to create false impressions when discussing the disease. Consequently, in this paper “Alzheimer’s Disease” is used generically to encompass both general symptoms which may appear to be Alzheimer’s and specific conditions of the brain discovered by autopsy, which is the only certain way to diagnose the disease.

II. The Range of Concerns
The range of federal concerns or activities prompted by the increase in the number of Alzheimer’s sufferers can be said, for purposes of this discussion, to fall into three categories: biomedical/clinical, care, and family support. In each category, there is a need for research, education, and, in some cases, ongoing service delivery programs.

For example, under biomedical/clinical, we do not know the cause of Alzheimer’s and the diagnosis is difficult, costly, and certain only after death. Those two facts alone suggest the need for a broad-based biomedical/clinical research program able to pursue multiple leads in the search for treatment and/or prevention, and affordable procedures for accurately diagnosing the disease. As research develops knowledge about the disease, it is important to translate and transmit that knowledge to appropriate practitioners. And, depending on how the art of diagnosing the disease progresses, it may make sense to establish an ongoing program to assist practitioners in diagnosing Alzheimer’s.

Under care, we need to know more about how caregivers (whether family members or professionals) should act to lengthen the time persons with Alzheimer’s can function, the comparative costs of different kinds of care, what kinds of institutions are best equipped to handle Alzheimer’s patients at what stages of the disease, and how many of what kinds of facilities to build at what cost to whom to care for the increasing number of Alzheimer’s patients. Depending on the results of such investigations, helpful results need to be translated and transmitted to caregivers and to decision-makers who will have to decide whether, for example, an effort similar to the Hill-Burton hospital construction program is needed.

Under family assistance, in addition to the need for knowledge relating to the delivery of care mentioned above, we need research to tell us more about the financial, physical and mental strain Alzheimer’s Disease puts on families, and what kinds of assistance, at what costs, can help alleviate those adverse impacts. Again, depending on the answers, the information must reach counselors, professional caregivers, community leaders, and family members, as well as those who will design and implement programs to provide relief.

It would be easy to expand this list, but even this brief, cursory review indicates that Alzheimer’s, like aging, requires a broad, interdisciplinary response.

III. Political Milieu
However one feels about $200 billion federal deficits, the economic policies of President Reagan, or restructuring federal-state-local responsibilities, I think we can agree that the nation is in a process of sorting out priorities, a process made more difficult by a realization of limited resources. Legitimate claims on those resources abound, and, added together, far exceed the resources available—or at least, the resources our society presently is willing to make available.
How that priority-sorting process works out will determine the political milieu in which the claims created by Alzheimer's Disease will be weighed and honored or rejected.

On the question of the proper role of the federal government in our society, proposals to provide federal assistance to families of Alzheimer's Disease run counter to the view that families and/or the voluntary sector should assume such burdens. It may be instructive that the chairman of the Senate Agriculture Committee was quoted this past week as saying that Congress was not meeting their responsibilities in combating hunger, which suggests a preference for soup kitchens over federal food stamps or financial assistance.

On the question of federal spending priorities, proposals for major new expenditures on Alzheimer's Disease-related programs become part of the "guns or butter" debate, with the recent actions of the Soviets being used to support the former. One can argue, with justification, that for many families seeking to pay the costs of caring for an Alzheimer's patient, the choice is not butter or no butter, but financial independence or poverty. Whether that argument can be heard amid demands for MX missiles, nerve gas, jobs programs and education loans remains to be seen.

On the question of domestic spending priorities, efforts to use federal health insurance programs to provide assistance for the costs of caring for an Alzheimer's patient run counter to the federal government's desire to contain its Medicaid and Medicare costs. Similarly, assistance through tax credits/deductions could be of concern to those worried about the size of the national debt.

In setting research priorities, tensions between funding basic and applied research increase as costs increase and budgets tighten, with those approving funds tending to favor the latter which promises to provide the visible results sooner. In the instance of Alzheimer's, a strong case exists for basic research in the searches for prevention, treatment, and diagnosis, and for applied research to improve diagnosis, care, and family support mechanisms.

It would be easy to expand this list, but even this brief, cursory overview indicates the impact the political milieu will have on the selection of federal responses to Alzheimer's-like diseases.

IV. The Impact of New Knowledge

It wasn't so long ago that "senility" was considered a normal condition of growing old. Now we understand senility is not "a normal part of growing old; in fact, it is not even a disease."3 "Senility," it turns out, is a collection of symptoms caused by a number of different diseases, including Alzheimer's. As a result of this discovery, we are now embarked on searches that was once thought to be "unavoidable results of aging. I can think of no better way to describe the impact of new knowledge on directions of research, service delivery and family assistance policies. Clearly new knowledge affects the policy options as well as the political milieu. The recognition that diseases cause mental impairment among the elderly, for example, both defined a need for research and helped create a political milieu supportive of such research. Of course, new knowledge continues to—or should continue to—affect policy options until an issue is solved or, for whatever reason, disappears from the national agenda. In the instance of Alzheimer's, for example, discovery of prevention or treatment could alter projected needs for financial assistance and 24-hour care. Such discoveries could create a need for research on how to remove the cause, if environmental, or how to make the "prevention," or treatment widely accessible. If either were expensive, the case for financial assistance could switch from care to treatment. The policymaker needs to keep abreast of research lest new knowledge makes current policy options obsolete. It is not rare to find that in the time taken to devise and implement a public policy the problem has changed if not disappeared.

Interestingly enough, sensitivity to the impact new knowledge can have on policy options brings me back to the discussion of the range of concerns raised by Alzheimer's. In the quest for "answers," do we put our research resources into basic and/or applied research in biomedical, clinical medicine or service delivery investigations? Should research be directed at specific problems or diseases; and/or at general topics, such as aging; and/or at targets of opportunity created by new discoveries? Who decides and how? Each area of investigation is important, and discoveries in each area could affect public policies in the future; each approach to research is valid, and discoveries resulting from each can affect public policies in the future. The Congressional Office of Technology Assessment feels the answers to such questions are important enough to warrant a major investigation, scheduled to be completed early next year.

It would be easy to expand the list of potential impacts of new knowledge on federal Alzheimer-related policies, or to expand the list of choices facing research policymakers, but even this cursory review indicates the need for flexibility in devising federal initiatives in this area.

V. Some: Conclusions

Thus far, I have posed questions and offered no answers. However, by joining those questions with my opening assumption that previous presenters have documented the extent of adverse economic and personal impacts expected if the number of Alzheimer's sufferers increases as projected, it is possible to offer some concrete recommendations for federal responses to be pursued promptly.

Alzheimer's has been described as a disease which starts out as the patient's and ends up the family's. Because it does, the disease requires a multi-faceted response, involving development of family care and financial support mechanisms as well as biomedical and clinical research. In devising that response, attention should be paid to what is not known as well as to what is known.

We do not know its cause or how to prevent or treat the disease. The projected growth in the number of persons expected to have Alzheimer's and in the costs of caring for persons with the disease, and concern for stress placed on the families of Alzheimer's victims, justify federal support for research seeking the causes of Alzheimer's and ways to prevent or treat the disease.

Because we do not know how to diagnose the disease accurately and because it has been estimated that up to 20 percent of persons believed to have Alzheimer's may have different and, in some cases, treatable disorders, the federal government should support programs to develop and promote "excellence in diagnosis and delivery of clinical services" for persons believed to have the disease.

We do know that families, despite major life-style changes, continue to provide a major portion of care for the mentally impaired elderly, including Alzheimer's sufferers, that the mental and financial burdens of providing this care cause serious strains if not destroy the stability of many of these families, and that existing federal health insurance programs do not help these families meet the expense of providing home care or of placing Alzheimer's patients in institutions when home care is no longer possible. Based on that knowledge, the federal government should encourage development of family-focused services, including day care, and should help, personnel, and services for the patient and respite service for caregivers. Further, federal health insurance programs should be adjusted to help pay the costs of home care and institutionalization of Alzheimer's patients. The costs of not providing such assistance were summed up by Elaine Brody, Director of the Department of Human Services at the Philadelphia Geriatric Center:

"If social policy does not move to mitigate these strains to the fullest possible extent by affording help to the families of Alzheimer's patients and other impaired older people, the ultimate costs will increase. The hidden costs now becoming visible—costs in terms of family strain and mental or physical breakdown—hold the potential for increasing the economic costs to the health and mental health systems. Both the social costs and the economic costs will be transmitted down through the generations."4

And finally, we know that federal responses to the challenge of Alzheimer's ultimately will be shaped by the political milieu and new knowledge. Those of us who believe Alzheimer's Disease and related disorders warrant a major federal response carry the burden of thinking in multiples as we promote our interest. Support for federal Alzheimer's initiatives will be affected by broad national priorities, as well as by priorities within aging. A single-purpose approach can create unnecessary competition for limited resources, or unjustly exclude persons needing assistance. We should work, then, for a broadly shared understanding:

...
That the study of aging is not the study of the elderly alone, but of living, as important to each of us as learning how to eliminate hunger or to educate minds.

That the study of Alzheimer's Disease and related disorders, which affects people of all ages, may unlock secrets about the aging brain from early in life through old age; and

That in promoting particular "Alzheimer's" policies today, there is the need for policymakers and advocates alike to be sensitive to potential impacts of new knowledge, and to how those policies relate to other aging and national priorities and concerns.


A Partnership
by Eleanor C. Friedenberg, R.N., M.S.
Deputy Director, Division of Prevention and Special Mental Health
National Institute of Mental Health
Panelist

All of today's speakers have identified and addressed the multiple dimensions of Alzheimer's Disease (AD)—medical, social, legal, and ethical. This panel addresses the implications for the future—in terms of initiatives called for by both the public and the private sectors. As we listened to today's speakers, there was a sense of being overwhelmed by the magnitude of the problem, and the experience of a sense of fear of the unknown—what is this disease—am I a candidate?

I experienced today almost a sense of split personality—I listened as a potential AD patient; as the family member (granddaughter) of an AD patient; as a nurse who has cared for AD patients; as a member of an agency staff at the National level involved in planning, program development, policy formulation, and research and training grant fund disbursements; and finally, as a private citizen in a local and State community. All of the various "Me's" need to get together in a partnership if any progress is to be made on the various dimensions of this disease. If there is any one message I would wish to call to the attention of this audience, it is the essentialness of the shared responsibility we have from the various perspectives we all represent. Without this shared responsibility on a planned and coordinated basis, the implication for the future is simply "Wheelspinning." Let me give a few examples of what I mean. On the National level, a key element in policy, planning and financing is the Federal government—but, who/what is the Federal government? All of us act as citizens in the Federal government through our vote for congressional representation (legislative branch) and President (executive branch), and through our communication, as individuals and as members of advocacy/constituency groups, of our desires and positions on policy and legislation. To be effective for our purposes, there must be a partnership of the legislative branch, which writes the laws and appropriates the money, and the executive branch, which implements the laws and disburses the funds. It is all too easy for each to blame the other for failure to address certain areas. Present laws do not allow for costs of care for AD patients to be covered under certain benefit or entitlement programs—changing this situation requires a public/private initiative at all levels and a partnership of two branches of the Federal government in enacting and implementing new legislation. The importance of this issue at the Federal executive branch level is evidenced by the DHHS Secretary's Task Force on Alzheimer's Disease—membership is comprised of high level agency administrators, and the executive secretariat is the NIMH Center for Studies of the Mental Health of the Aging. This certainly supports the thesis we have heard today about the interactive organic/health and behavior/psychosocial elements of AD, with a major concern being the psychological impact on patient and family.

At the State and local level, the partnership is essential between the various service agencies—health and welfare most specifically—and requires a sharing of resources. This interagency collaboration has always been difficult to orchestrate, even in the best of economic times, let alone at a time of continuing fiscal constraints. Private groups and organizations, the networking of concerned private citizens, play an important role in monitoring or being a sort of nagging conscience to the public sector. The public sector has the difficult task of balancing the competing demands from the many private advocacy groups. From a research perspective—about which we have heard some exciting developments today—there is another public/private initiative and partnership which demands increasing effort. We are actually participating in that partnership today; public and private sector representatives have gathered to share information, learn from research findings which are funded from multiple sources (public and private), discuss ways of utilizing this research in many different settings, and honor a great public servant on behalf of a great private institution.

Another example of private initiative is the extensive research being funded by pharmaceutical companies in developing an effective drug in the treatment of AD. Granted, the company which succeeds in making a breakthrough stands to gain substantially financially, but this is a high risk venture for the private sector that will be of significant benefit to the public sector. In two weeks, NIMH is supporting the first national conference on research issues regarding the role of nursing homes in the care of the mentally disabled. The conference is being held in a private facility—The Hebrew Home of Greater Washington.

At the risk of digressing from the main theme of this panel, as I thought about the essential nature of the public and private sector "Partnership," I was reminded of another parameter of partnership which has been a favorite subject of mine for many years and about which we have heard a little today. My esteemed colleague, Rose Dobrow, and I have had many conversations about inter/multi-disciplinary collaborations—or partnership, particularly nursing and social work. I am struck today with the diversity of professional disciplines represented in this assembly—physicians, psychologists, sociologists, social workers, nurses, health care technicians, clergy, planners, administrators, managers—I'm sure I've overlooked a group and I apologize. The point is, it takes many different talents and fields of expertise for a comprehensive and effective program of research, prevention and service. If any single discipline were to attempt to "own" the problems of Alzheimer's, it would be impossible to solve the problem.

Implications for the Future?—Challenging, exciting. The problems are not insurmountable, but they require the concerned efforts of us all as citizens and professionals in the public and private sectors.
Meeting Tomorrow's Challenge
by Jacob Reingold, M.S.
Executive Vice President
The Hebrew Home for the Aged in Riverdale
Panelist

Alzheimer’s Disease has emerged as a critical although not necessarily terminal illness that yearly afflicts half a million Americans. Senile dementia of the Alzheimer’s type is a disease of catastrophic proportions. Now regarded as the major type of old age senility, it is a surprisingly common, although little known and understood, disorder that affects the cells of the brain. While experts formerly believed that Alzheimer’s Disease occurred only in persons under age 65, this disorder is now recognized as the most common cause of severe intellectual impairment in older individuals. Whether the classic form of Alzheimer’s Disease, which was first described in middle-aged adults, is identical in cause, mechanism, and course to senile dementia of the Alzheimer’s type is a matter of controversy.

The major debilitating symptoms of Alzheimer’s disease include serious forgetfulness, particularly about recent events, and confusion. At first, the individual experiences only minor and almost imperceptible symptoms that are often attributed to emotional upsets or other physical illnesses. Gradually, however, the person becomes more forgetful, to the consternation of anxious relatives. The person may neglect to turn off the oven, may misplace things, may forget whether he has performed a task or not, may take longer to complete a chore that was previously routine, or may repeat already answered questions. As the disease progresses, memory loss, personality changes, mood and behavior imbalances are likely to appear. Judgment, concentration, orientation, writing, reading, speech, motor behavior and naming of objects may also be affected. Even when a loving and caring family is available for support, the Alzheimer’s victim is most likely to spend his or her last days in a nursing home or long-term care institution. At this time, there is no cure for Alzheimer’s Disease and its causes are inadequately understood.

In working toward the creation of the Hebrew Home Alzheimer’s Center, The Hebrew Home for the Aged in Riverdale is responding to a critical national and local need by developing a model for the comprehensive institutional care of the Alzheimer’s victim. Using this 200-bed skilled nursing facility as a base, present Holland Care services will be expanded to provide teaching and research opportunities for the individual still living in the community, and family support programs.

Currently, placement in nursing homes in New York State is a function of patients and family as well as the predictor scores obtained on the NYS-JMS-1 profile. Pre-admission workups for individuals seeking admission to the Hebrew Home for the Aged in Riverdale’s main campus also include a physical examination and a brief mental status evaluation.

For those applicants to the Hebrew Home Alzheimer’s Center presenting symptomatology of organic or functional mental impairment, the critical processes of differential diagnoses will be employed. This will include a detailed history, a comprehensive physical examination, mental status and psychiatric evaluation and appropriate ancillary examinations. The latter category might also include: computed tomographic scan; electroencephalogram; complete blood count; metabolic screen; or DDRIL. The goal of such specified diagnostic workups is to provide data for placement within a specialized long-term care setting, to develop an appropriate plan of care with realistic patient expectations and to provide meaningful information and counselling for the families.

The skilled nursing facility will provide care to any individual aged 55 and over with a primary diagnosis of mental impairment, either organic or functional. Specific units within the facility will be designed to address the progressive nature of the dementia syndromes. The facility will include a 10–15 bed locked, skilled nursing facility unit for the physically active and potentially abusive Alzheimer’s patient. The units will be equipped with a gymnasium to encourage positive physical activity and counter-balance aggressive and abusive behavior. The facility will also include a 40 bed unit for the moderately mentally impaired with few physical infirmities. This unit will be designed as a therapeutic community, building upon the existing resources of each individual. Additionally, there will be a 10 bed respite unit for individuals with related diagnoses who will stay for average periods of 15 days, to provide a respite for their families.

The Alzheimer’s facility will be designed to be environmentally and programmatically supportive. The use of chemical and physical restraints will be viewed as non-advantageous alternatives. Among supportive features planned for the facility are: color-coded rooms matched to the individual’s ID bracelet; remotivation, reality orientation and resocialization classes and programs; physical activity as therapy, including a gymnasium; special and color-coded furniture; a quiet room; a psychiatrist as medical director; and psychiatric nursing staff supported by mental health technicians.

Given the unique nature of the Alzheimer’s facility, prior to its opening a research program will be developed to evaluate staffing; the impact of various program options; the longevity morbidity; use of external hospital or specialty care required by the population; quality of life for patient and families; staff turnover and the cost of the various units compared to traditional skilled nursing facilities and State hospitals. Research with the Albert Einstein College of Medicine will provide complementary basic science information.

There is little doubt that the redesign of the Hebrew Home Alzheimer’s Center will meet a significant community need. The ideal accessible location of this facility enhances its value as a community resource. Program plans for the facility to maximize community value might include adult day care for the mentally impaired population; an evaluation service for individuals currently residing in the community who are exhibiting symptoms of dementia in order to provide guidance and recommendations to their families; and an out-patient department.

The Hebrew Home Alzheimer’s Center facility provides an unusual opportunity to our community to develop a model for the care of the Alzheimer’s patient. Extension of our program through research and training opportunities provides potential for a significant contribution to the larger field of gerontology. This is an opportunity which the Hebrew Home for the Aged in Riverdale is eager to pursue; a challenge we are ready and willing to meet.
Criterion For Admission To A Specialized SNF Unit

To be admitted to this unit patients will meet the following criteria:

I. Cognitive:

Patient will have moderate to severe cognitive decline as indicated by one or more of the following:

1. Decreased knowledge of current and recent events - disorientation to time (day of week, season, etc.) or place.
2. Exhibits deficit in memory of one's personal history (e.g. age, year married, etc.).
3. Concentration deficit elicited on serial subtractions (backwards from 40 by 4).
4. Inability to perform, or follow through on complex tasks for functional reasons (dressing self, etc.).

AND/OR

II. Behavioral: (Observed and documented by staff)

1. Wandering into others rooms, being disruptive or intrusive, or,
2. Antisocial behavior - spitting, yelling, banging, fighting, undressing, or,
3. Injurious behavior to self or others.

AND

III. Physical

1. Physicians diagnosis of an Organic Mental Disorder, i.e.,
   A. Primary degenerative dementia (DSM III 290.xx)
   B. Multi-infarct dementia (DSM III 290.4X)
   C. Alzheimer's Disease or SDAT, or

2. A diagnosis of a major psychosis with behavior as described in II, i.e.,
   A. Schizophrenic disorder (DSM III 295.xx) or,
   B. Paranoid disorder (DSM III 297.xx) or,
   C. Bipolar disorder (with psychotic features) (DSM III 296.xx)

IV. DMS-1 Measurement

1. Patient must have a DMS-1 score of at least 180. (Scores are generally well over 300).
2. Total points for the mental status section will range from 85 to 210.

NOTE: Given the above behavioral/cognitive function, the patients considered for transfer will have a resultant need for greater and/or specialized assistance, support and care.
1. **DIAGNOSIS:**

A. Organic Mental Disorder (Primary degenerative dementia, Multi-infarct dementia, SDAT)
   - Yes [ ] No [x]

B. Major Psychosis (Schizophrenia, Paranoia, Bipolar disorders with psychotic features)
   - Yes [x] No [ ]

Any Comment ____________________________

2. **BEHAVIORAL** (Must have been observed and documented) (Dates-Frequency)
   - Nurses S.W.

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<td>A. Wandering</td>
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<td>B. Distructive or Intrusive</td>
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<td>C. Anti-social: spitting, yelling, fighting, undressing</td>
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3. **COGNITIVE** (Not necessary if "yes" to both #1 and #2; not necessary if "no" to both #1 and #2)

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<td>A. Disoriented to time</td>
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<td>C. Deficit in memory of personal history (e.g. age, year married)</td>
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<td>D. Serial subtractions (backwards from 40 x 4, document last correct in number in notes section)</td>
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<td>E. Inability to follow through on complex tasks for functional reasons (holding a cup, dressing)</td>
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4. This patient is [x] is not [ ] recommended for admission/placement on a specialized unit.

Additional Comment ____________________________

5. Total DMS-1 Score ________________ Points in Mental Status ________________

________________________   __________________________
Date       Signature & Department of Person(s)

Completing Form